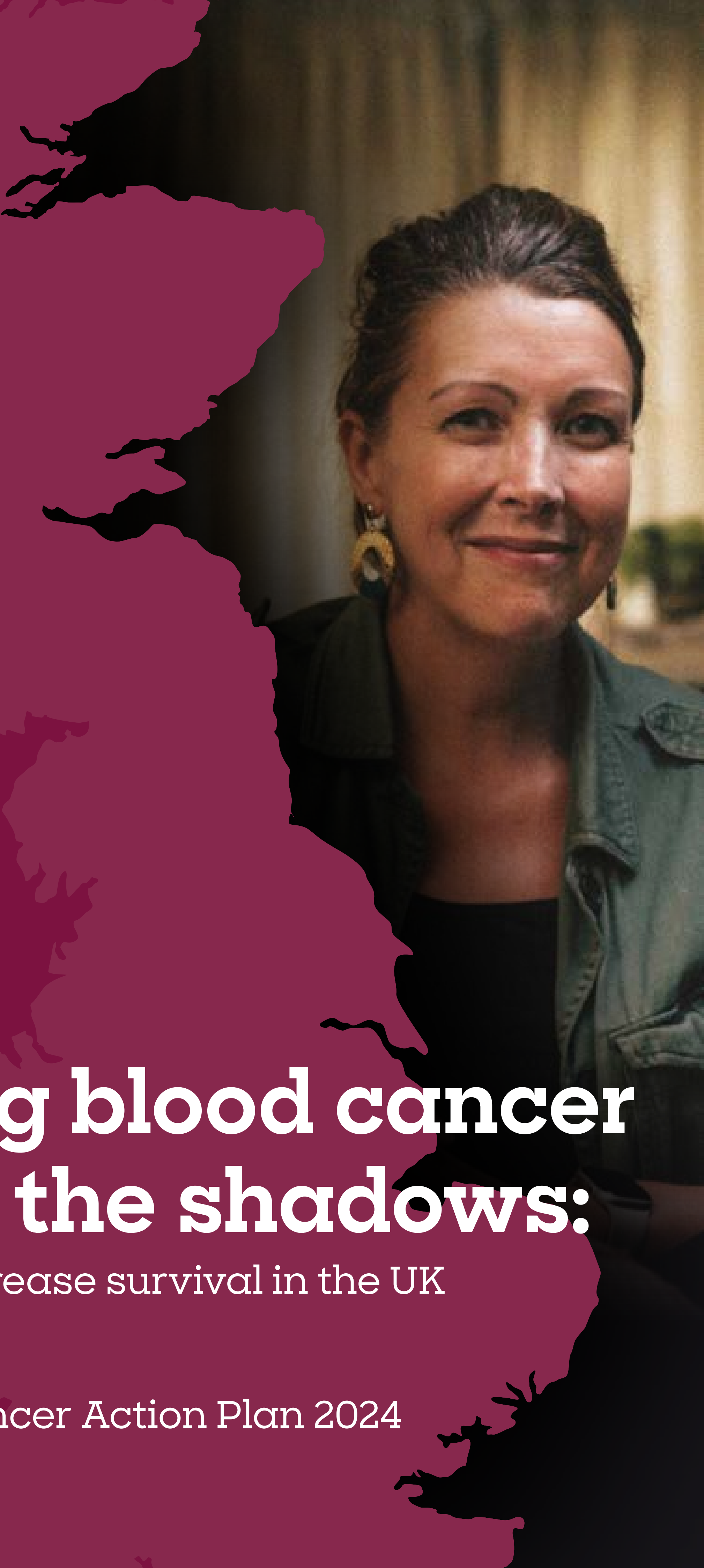
Blood
cancer
UK



REPORT

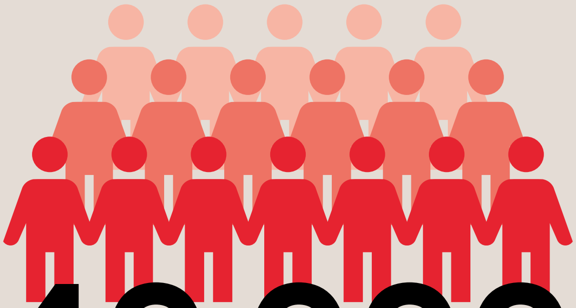
Taking blood cancer out of the shadows:

A plan to increase survival in the UK

UK Blood Cancer Action Plan 2024

What is blood cancer?

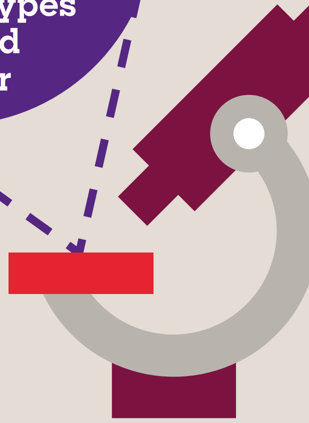
Blood cancer
is the UK's
3rd biggest
cancer killer



40,000
people in the UK
are diagnosed every year

Around
280,000
people in the UK
are currently living
with or in remission
from blood cancer

There
are over
100
different types
of blood
cancer



Every year,
more than **15,000**
people die of blood cancer

The most
common blood
cancers are a
type of **leukaemia**,
lymphoma
or **myeloma**

Blood
cancer is the
5th
most common
cancer in
the UK

The 5 most common types of blood cancer are:

Acute myeloid leukaemia (AML)

Diffuse large B-cell lymphoma (DLBCL)

Chronic myeloproliferative neoplasms (MPN)

Chronic lymphocytic leukaemia (CLL)

Myeloma

Blood cancers are traditionally sub-divided into three groups of leukaemia, lymphoma and myeloma, but they all have different symptoms, treatments and prognoses.

Contents

Acknowledgements

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We would also like to thank all members of the Blood Cancer Action Plan taskforce, its working groups, focus groups, community representatives, and all other healthcare professionals, researchers, experts, and every person affected by blood cancer who helped shape this report.

Because of you, we will beat blood cancer.

Because too many people are dying of blood cancer

Foreword

Investment in blood cancer research by Blood Cancer UK and others has been transformational over the past 60 years in ensuring more people are living longer. Innovative treatments are being developed which, if made available in the UK, could revolutionise blood cancer care further. However, the stark reality is that **too many people are still dying from blood cancer**, and **the UK is now falling behind similar countries when it comes to research, outcomes and survival.** As a blood cancer community, we wanted to understand why this is happening and the experiences and priorities of people living with blood cancer and the people working in the NHS who provide their care and treatment.

This Action Plan sets out the complex challenges that stand in the way of the improvement needed. It is well established that diagnosing blood cancer can be difficult, but survival rates are impacted by a series of other complex and interconnected challenges too. Workforce gaps,[1,2,3] health inequalities[4,5], funding uncertainties[6], limited access to clinical trials[7,8,9] and inconsistencies in national data[10] are just some of the critical issues preventing progress.

It is grounded in newly available data and the lived experiences of people affected by blood cancer, healthcare professionals and researchers.

After considering the evidence, we have proposed **realistic but ambitious recommendations for the new Westminster Government, those in Edinburgh, Cardiff and Belfast and everyone involved in blood cancer care in the UK.** Some of the recommendations will need further insight and research, whilst others could be implemented now. There will inevitably be costs associated with some, but others will require a change of thinking or process. However, they will improve the outcomes for people living with blood cancer and those who will be diagnosed in the future.

Blood Cancer Action Plan taskforce co-chairs:

Helen Rowntree,
Chief Executive of Blood Cancer UK

Professor Adele Fielding
Professor of Haematology, University of York
Clinical Director of the Centre for Blood Research and Head of Experimental Medicine and Biomedicine, Hull York Medical School

A message from the blood cancer community

We are a group of people affected by blood cancer who have helped co-produce this report.

We speak to you not as statistics but as the human face of blood cancer in the UK. As members of the Action Plan taskforce, we've had the opportunity to share our unique experiences and challenges in our cancer journeys to help identify areas for improvement in blood cancer care.

We represent the 280,000-strong community of people in this country living with or in remission from blood cancer. Some of us are in the thick of treatment; others are monitored closely for the return of symptoms, and some of us struggle every day to live full lives due to the effects of the illness. We bring our lived experience of the impact of a blood cancer diagnosis on day-to-day living, the gruelling challenges of treatment, and the vital role of the healthcare professionals who supported us.

Our journeys are unique and deeply personal, yet we are united by one goal: for everyone diagnosed in the UK, now and in the future, to have the best possible care and treatment.

For too long, we've been held back by a lack of understanding of blood cancer, even amongst healthcare professionals, along with a host of other issues that impact care, meaning too many people are dying from blood cancer. That's why we have used our voices to share our experiences and help shape the recommendations within this report.

We are proud of the report we have co-produced. If these recommendations are implemented, there is no reason why the UK couldn't be at the forefront of blood cancer care and treatment globally, giving hope for a better future for people affected by this disease. But this will only be achieved through the combined efforts and determination of many people. We hope this report, and our experiences, will convince you to become one of those people.

We implore decision-makers and policy-makers to act on the recommendations of the Blood Cancer Action Plan, ensuring that where someone lives or their background doesn't determine their chance of survival. This is your chance to make a difference, because people with blood cancer deserve better.

Community representatives David, Sue, Jacquie, George, Alastair and Scott

Our approach

We needed to understand the experiences and priorities of those who deliver treatment and care for blood cancer, those who have experienced that treatment and care, and those who are driving progress and improvement through laboratory, clinical and data research.

To achieve this, we brought together a taskforce with representation from across the four nations of the UK, from different healthcare settings and with experience in treating or being treated for chronic and acute blood cancer. Meeting regularly between April 2023 and May 2024, the Action Plan taskforce examined and challenged evidence, provided direction and insight and agreed recommendations for governments, the NHS, charities, the pharmaceutical industry and others.

By acting on the recommendations in this report, we can revolutionise blood cancer care in the UK. By defining a new standard for blood cancer care, we can create a future where people living with the disease can have complete confidence that they have the best possible chance of survival simply because they live here. This report is the roadmap to making that future a reality.

Because beating blood cancer is why we're here

Action Plan recommendations

Building a robust clinical and diagnostic workforce fit for the future

Future NHS workforce plans must meaningfully include:

- Modelling to determine the number and skill sets of healthcare professionals needed across all aspects of blood cancer care, including diagnosis, and the development of national standards for staffing and facilities (for the NHS, British Society for Haematology (BSH) and Blood Cancer UK).
- An increase in the number of blood cancer Clinical Nurse Specialists (CNSs) and a programme of continuous support for service CNSs, including the development of a new blood cancer support role, with a CNS-informed job description (for the NHS).
- Action to reverse the decline in clinical academics dedicated to blood cancer research by addressing the lack of suitable posts and retention challenges. Provide dedicated support and protected time for clinical academics and researchers within the NHS to drive research (for universities and organisations that fund clinical academic posts).

Improving referral and diagnosis

- Address the barriers that prevent people from some groups, such as those from ethnic minorities or deprived backgrounds or those living in geographically remote locations, from receiving a timely diagnosis of blood cancer (for the NHS).
- Strengthen safety netting practices in primary care and ensure the Non-Specific Symptom (NSS) pathway for unsuspected cancers is available across the whole population (for the NHS).
- Implement targeted monitoring programmes for people at higher risk of developing blood cancer (for the NHS).
- Fully implement and maintain the NICE guidelines among existing Specialist Integrated Haematological Malignancy Diagnostic Service (SIHMDS) teams, establish similar diagnostic models in the devolved nations, and proactively identify and address gaps or changes to services to diagnose blood cancer across the UK (for the NHS).

Reducing barriers that prevent access to care

- Undertake further research into the practical barriers that prevent people with blood cancer from accessing care and propose solutions (for Blood Cancer UK).
- Empower patients with self-monitoring knowledge, awareness of their blood cancer team and resources to encourage patient advocacy, including sign-posting and referral into charity support services (for the NHS).
- Identify and make recommendations to address critical gaps in information sharing and delivery that impact the treatment and care of people with blood cancer (for Blood Cancer UK).

Increasing access to trials

- Offer comprehensive and targeted support for both investigator-led and commercially sponsored clinical trials through streamlined regulatory processes, funding and access to research networks (for universities, the NHS, government departments and agencies in the UK nations that fund clinical research such as UK Research and Innovation (UKRI) and National Institute for Health and Care Research (NIHR), BSH and blood cancer charities).
- Develop strategies to increase participation in clinical trials, particularly among underrepresented groups, addressing the cultural, financial and communication barriers that prevent involvement (for clinical trial leads and funders).

Increasing access to drugs and treatments

- The UK drug and treatment approval bodies must streamline approval processes, and they and the pharmaceutical industry should focus on ensuring patients in the UK have access to cutting-edge blood cancer treatments. This depends on both sides being more flexible (for the Blood Cancer Alliance, the NHS and the pharmaceutical industry).
- Assess how often, where, and why drugs approved for use on the NHS are not routinely prescribed, and then make proposals to ensure everyone has access to the treatment recommended by their medical team (for Blood Cancer UK).
- Define the minimum standard of care that supports clinical excellence and equity of access to approved treatments in all settings, including remote locations and treatment closer to home (for the NHS, blood cancer charities, societies including BSH, royal colleges and the pharmaceutical industry).

Driving improvement through our national data

- National blood cancer data collected, analysed and reported by national cancer registries should be consistent and comparable between UK nations. It should include treatment, diagnostic and demographic data and provide meaningful statistics based on cell morphology and behaviour (for UK national cancer registries).
- Blood cancer should be routinely included as a distinct category alongside solid tumours when reporting on key metrics such as prevalence, healthcare utilisation and other appropriate benchmarks (for the NHS).

When we say NHS, we mean commissioning bodies and health service providers including:

- NHS England, including Health Education England and NHS Digital, Integrated Care Boards in England, Primary Care, NHS Trusts and Foundation Trusts, and NHS Cancer Alliances.
- NHS Scotland Regional NHS Boards, Special NHS Boards, including Public Health Scotland, NHS Education for Scotland, and NHS National Services Scotland, including the Scottish Cancer Network.
- NHS Wales, Health Boards and Trusts, Health Education and Improvement Wales, Public Health Wales, Digital Health and Care Wales, and Wales Cancer Network (part of the NHS Executive for Wales).
- Health and Social Care Northern Ireland, Local Commissioning Groups, Integrated Care Partnerships (ICPs), Health and Social Care Trusts, Public Health Agency for Northern Ireland and the Northern Ireland Cancer Network.

A wake-up call for blood cancer survival in the UK

What does the latest data tell us?

Thanks to research breakthroughs and the subsequent development of new treatments, the outlook for some blood cancers has dramatically improved in recent years. Five-year survival for chronic myeloid leukaemia (CML), chronic lymphocytic leukaemia (CLL) and follicular lymphoma is now over 85%.[11]

However, for other blood cancers, such as acute myeloid leukaemia (AML) and myeloma, **five-year survival is less than 50%.** People with myeloma, for example, live on average 12 years less than the rest of the population. For non-Hodgkin lymphoma, it is an average of nearly 14 years less for each person. Hodgkin lymphoma is less common but has a significant impact, with people with this condition losing an average of 19 years of life.[12]

Disparities in care further complicate the landscape, with access to vital treatment and specialists unevenly distributed across the country. Even more shockingly, our new data has uncovered that socioeconomic status also impacts the chances of survival from blood cancer.

Survival in the UK compared with other high-income countries

Analysis of international data from population-based cancer registries in over 60 countries in the CONCORD programme indicates that **five-year survival for people with blood cancer in the UK lags behind similar nations**. For blood cancers of lymphoid origin, UK survival was 64.9%, well below the highest-performing countries achieving over 70%. For blood cancers of myeloid origin, five-year survival of 48.7% placed the UK in the third bracket behind nations achieving 50-54% and 55-60% survival.[13]

Within these broad groupings, survival from each blood cancer subtype can vary widely. So, to examine what may be driving poorer survival in the UK, we commissioned more detailed analyses of international data from population-based cancer registries by blood cancer subtype, gender and age.

It was clear from these analyses that **for every blood cancer subtype, survival in the UK falls short of that seen in some nations with similar wealth and health systems.** For some blood cancers, the lag can be seen as early as one year after diagnosis. With blood cancer being more prevalent in older adults, it is deeply concerning to see that adults aged over 65 have poorer survival in the UK than in other countries.

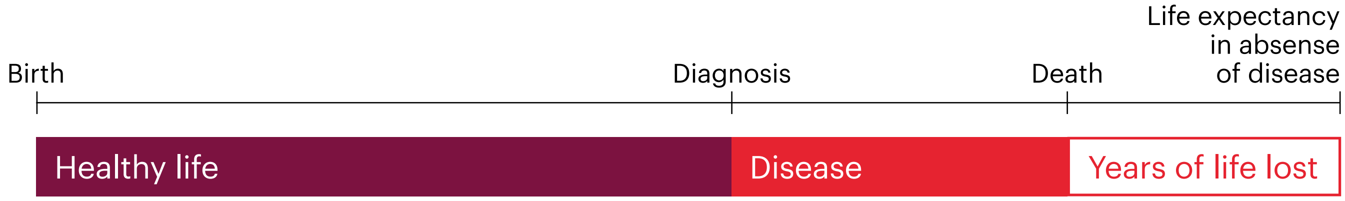
The drivers of better survival in high-performing countries urgently need to be understood and implemented for people currently affected by blood cancer in the UK.

Survival in the UK across the four devolved nations

As well as benchmarking the UK's blood cancer survival against international counterparts, we wanted to explore the impact and drivers of these disparities within and across the UK. We used data collected by cancer registries in each

Over one million potential years of life are lost to people in the UK diagnosed with blood cancer over a 10-year period.

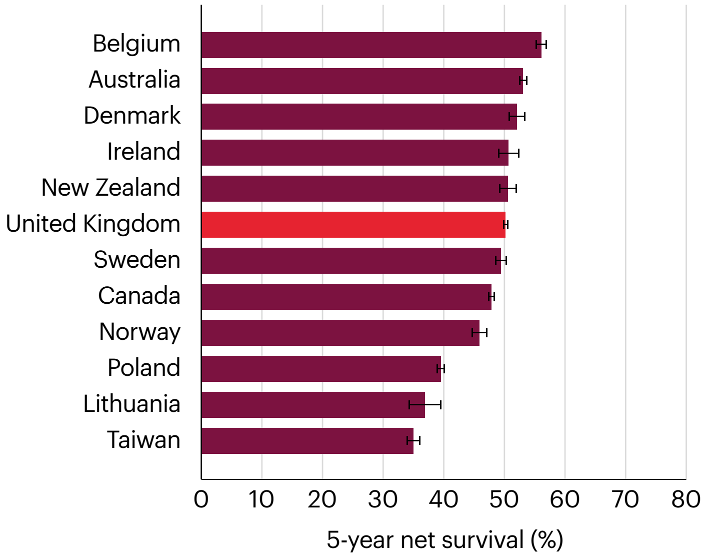
A sum of the number of remaining years of life expectancy among people who died of a certain cause.
Unlike mortality rates, gives greater weight to deaths at young ages.



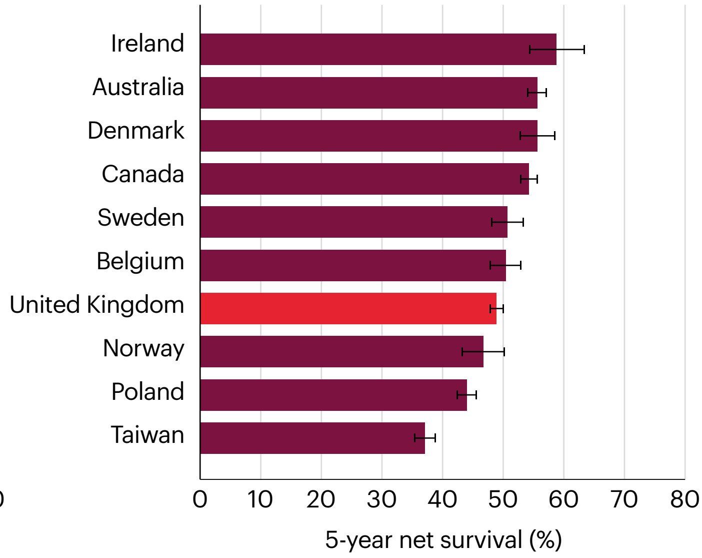
Remaining life expectancy from national life tables produced by the Office of National Statistics.
Life tables account for age, sex and calendar time. In England, they are adjusted for deprivation.

International survival

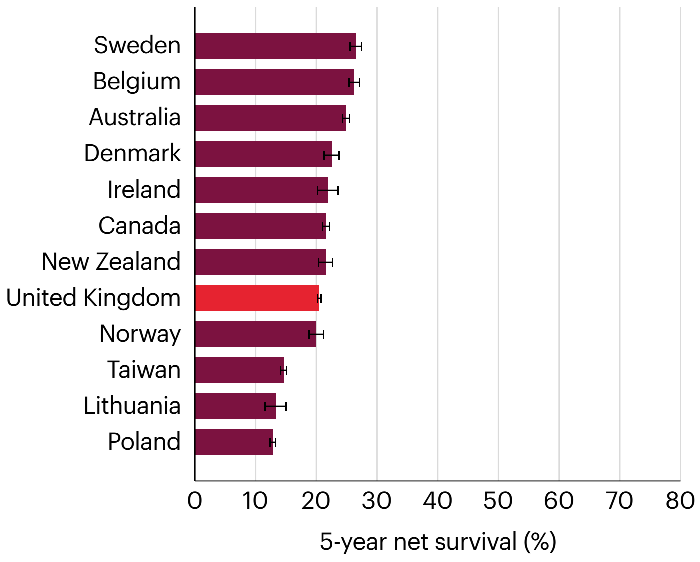
Plasma cell neoplasms



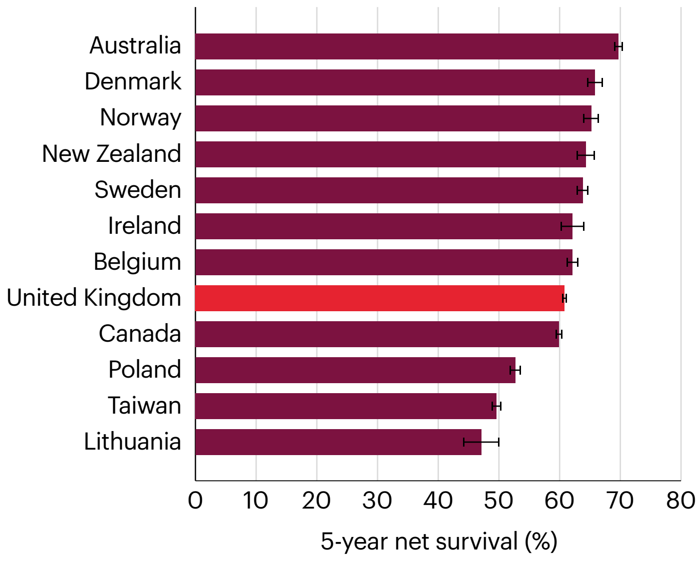
Lymphoblastic lymphoma/acute (precursor cell) lymphatic leukaemia



Acute myeloid leukaemia



Diffuse B cell lymphoma



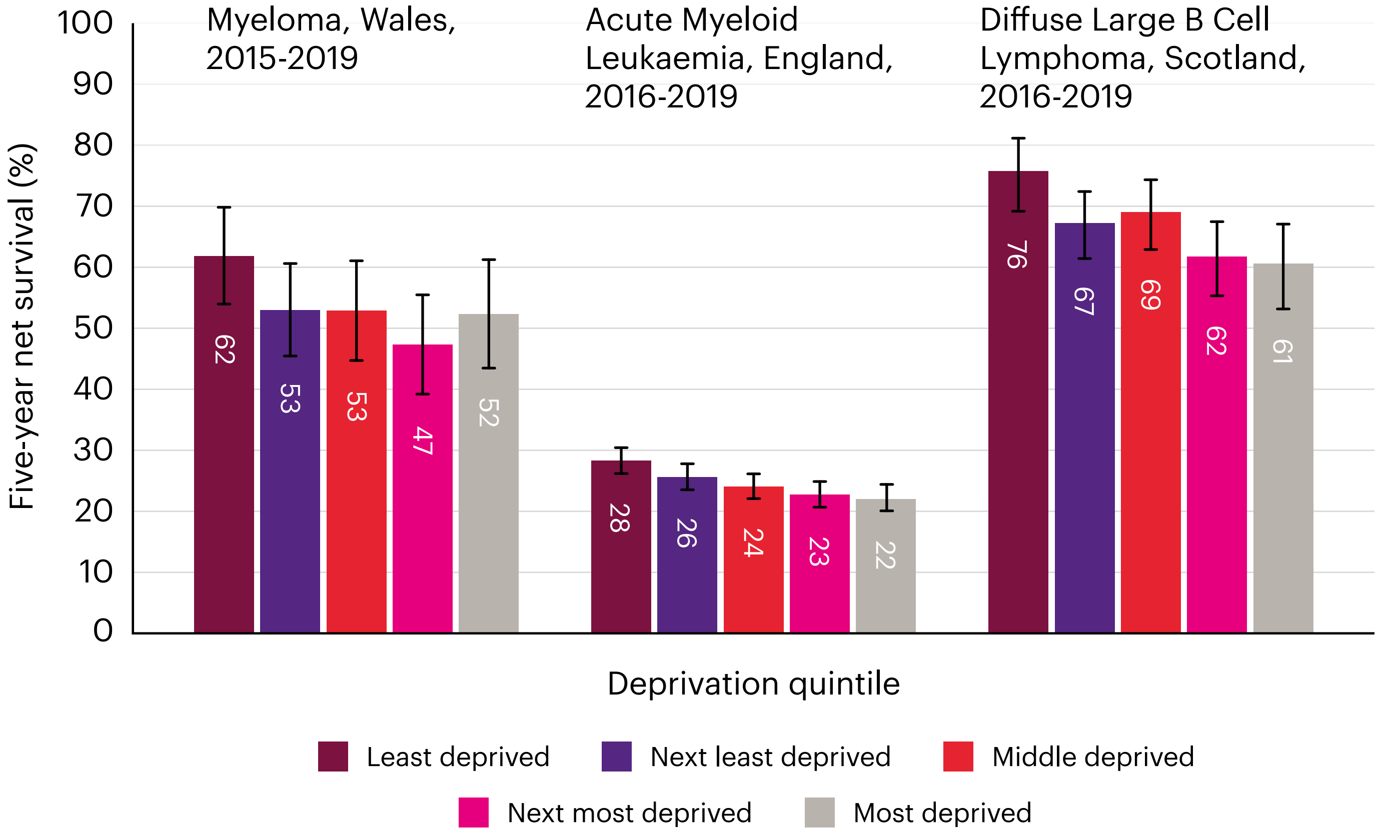
CONCORD
Global surveillance of cancer survival

Patients diagnosed during 2010-2014 from national (100% coverage) population-based cancer registries, and followed up to 31 Dec 2014. Error bars indicate 95% CI. CONCORD Central Analytic Team, © Cancer Survival Group, London School of Hygiene and Topical Medicine, 2024 of the four nations and assessed different cancer subtype groups where case numbers allowed (given the considerable differences in populations served by each registry).

The data shows that **over one million potential years of life are lost** to people in the UK diagnosed with blood cancer over a 10-year period; more than a third of these are among people under the age of 65. While over half of the potential years of life lost were caused by AML, Diffuse large B cell lymphoma (DLBCL) and myeloma, the challenges of obtaining a timely diagnosis and the limited treatment options for rarer subtypes should not be overlooked.

The data suggests that for some blood cancers, socioeconomic status impacts survival. For example, in Scotland, the five-year survival for DLBCL is approximately 15 percentage points higher among people living in the least deprived neighbourhoods compared to those in the most deprived, even after accounting for known differences in life expectancy. Other examples of socioeconomic disparities in five-year net survival were not reported at the subtype level for Northern Ireland due to small numbers.

If all persons diagnosed with blood cancer in England had the five-year survival rates of those in the least deprived quintile, an estimated 650 excess deaths per year could be avoided.



(Withrow et al. University of Oxford) Methods and data sources are available on page 61.

Because too many people are diagnosed too late

From limited hope to survival: A case study in the life-changing impact of treatment breakthroughs

Jacquie, in remission from DLBCL

CASE STUDY:

Jacquie, in remission from DLBCL

Jacquie describes the impact of receiving successive gruelling chemotherapy treatments for relapsed DLBCL, eventually achieving long-term remission after having CAR-T cell therapy.

"Because it may have been in my central nervous system, I was given some very difficult treatments followed by radiotherapy throughout 2019. I felt well until April 2021, but after three weeks [with swollen lymph nodes], my clinical nurse specialist said, 'I think you need to come in.'"

Jacquie was prescribed another chemotherapy treatment for relapsed DLBCL.

"It was a challenging time; I needed three blood transfusions and three platelet infusions. I had neutropenic sepsis. And all my hair loss came back again, not just your hair, your eyebrows, your eyelashes and the whole thing.

My next PET scan showed it was not really having an impact, so I had another treatment which my body really did not like. After almost two years of chemotherapy, I was told by a doctor that I was frail. I was a 58-year-old woman, I didn't want to be frail. They gave me three months off treatment which was a tricky period for me – feeling that I've got a really aggressive cancer that's getting bigger."

Once stronger, Jacquie was eventually referred to the hospital's CAR-T team and received the therapy in February 2022. This was more than nine months after she learnt about the treatment's potential, but being required to endure another standard treatment and a relapse before it was an option to her.

"I felt very tired and unable to do a lot, but the only thing that was being impacted by my triumphant little T cells was the pesky [cancerous] B cells. I had no lymphoma in my PET scan at 28 days. My consultant could not wait to tell me."

> **"My body needed this treatment and I feel very privileged and grateful to be in that position."**

Workforce

Building a robust clinical and diagnostic workforce fit for the future

Because people with blood cancer need a sufficient and supported workforce to receive a timely diagnosis and the best standard of care.

Overstretched and understaffed

Critical staff shortages and increasingly complex treatments have left people delivering NHS blood cancer care under major pressure. At the same time, a dwindling pipeline of clinical academics threatens the future of blood cancer research in the UK.

- In the next decade, 55% of permanent haematology consultants across the UK will reach the age of 60 with a shortfall in trainees to replace them; in Wales, this figure rises to 74%.[14]
- Clinical haematology staff sickness rates are higher than the NHS average and three times higher than the average UK worker,[1] and only 3% of NHS histopathology departments have enough staff to meet clinical demand.[15]
- In rural locations, workforce challenges are even more acute, dramatically impacting blood cancer patient care. For example, the withdrawal of in-person consultant haematology services from one location in Scotland has forced those needing specialist treatment to make a 200-mile round trip to Glasgow.[2]
- Over one-third (35%) of the UK's clinical academics are over 55,[3] and a stark decline in senior clinical academics specialising in pathology means there are less than half the number in post in 2022 compared to 2004.[3]

Alongside the quantitative data above, we were alarmed by the stark message given to us by healthcare professionals in focus groups to inform this Action Plan. **We firmly believe that the current blood cancer workforce is doing an exceptional job in unacceptable circumstances.** This view reflects the position of the new Labour Government and its Department of Health and Social Care, who immediately announced that "the policy of this department is that the NHS is broken".[16] The blood cancer workforce must be meaningfully included in the Government's 10-year plan to radically reform the NHS.[17]

Staff shortages raise concerns about patient safety and impact access to new medicines, while also deepening the reliance on costly locum consultants. Soon-to-retire blood cancer consultants and nurses shared with us their feelings of guilt about retiring, worrying they're not leaving services in safe hands.

> I am at a certain age where it's difficult to work full time and I want to cut down my hours; I'm feeling it. But I can't do that.
>
> **Consultant Haematologist**

Concern over the wide variation of patient-to-nurse ratios across haematology in the UK is growing.[1] We believe the BSH should set guidelines and tests for safe staffing levels in acute blood cancer wards to allow better monitoring and to understand and address the full extent of blood cancer workforce shortages.

> I'm worried we are going to be running off locums permanently. They get a much higher pay packet, and don't have to do the on-calls... which is sad.
>
> **Consultant Haematologist**

Increasingly complex treatments for people with complex needs

New treatments, such as CAR-T cell therapy, are helping people with blood cancer to live longer. Yet, they can also be more demanding to deliver, often requiring multiple treatment episodes over a longer duration, stretching the workforce further. Increasingly complex and longer treatments mean that it is no longer cost-effective or safe to fund blood cancer services based on the incidence of the condition alone.

> There's a limit to how much you can do just through efficiency... you get to the point where the only way you can move things on is to improve capacity.
>
> **Consultant Haematologist at a teaching hospital**

Championing rewarding haematology careers

At District General Hospitals (DGHs), which often serve more rural or suburban populations, attracting and retaining staff is a significant challenge. Careers at district general hospitals can be perceived as having fewer opportunities to specialise and participate in research. Yet healthcare professionals working in these settings play an essential role in delivering care closer to home, expanding access to clinical trials and securing joined-up care through a local, close-knit team.

At James Cook University Hospital in Middlesbrough and the Northern Region Haematology Group, a proactive investment in building a team culture has improved staff morale, retention, and patient care.

Reimagining the blood cancer workforce

Without an existing research infrastructure, it is more challenging for DGHs to set up clinical trial sites to deliver new, lifesaving treatments. Research funders, including Blood Cancer UK, should foster more research and clinical trial opportunities that hospitals can more readily participate in, bringing new treatments to more people and attracting new members of the workforce to blood cancer and the area.

The NHS needs to find smarter ways to handle more blood cancer patients while reducing strain on its staff, ultimately leading to better patient outcomes.

Other proposals include pharmacist-led clinics or identifying how Physician Associates can support care.
The blood cancer workforce, via BSH, should contribute to ongoing discussions about the role of Physician Associates in enhancing blood cancer care pathways.

All proposals would rely on addressing staff shortages among other professions, including pharmacists, and supporting people with blood cancer to understand changes to their treating team.

> We had [a pharmacist-led clinic], but it was taken away. It was a pharmacy-assisted MPN clinic where 95% of patients are on repeat medication. He would pre-make up the prescriptions, prescribe and go through the drugs in detail.
>
> **Consultant Haematologist**

CASE STUDY:

Dr Raymond Dang – Consultant Haematologist at the James Cook University Hospital, Middlesbrough

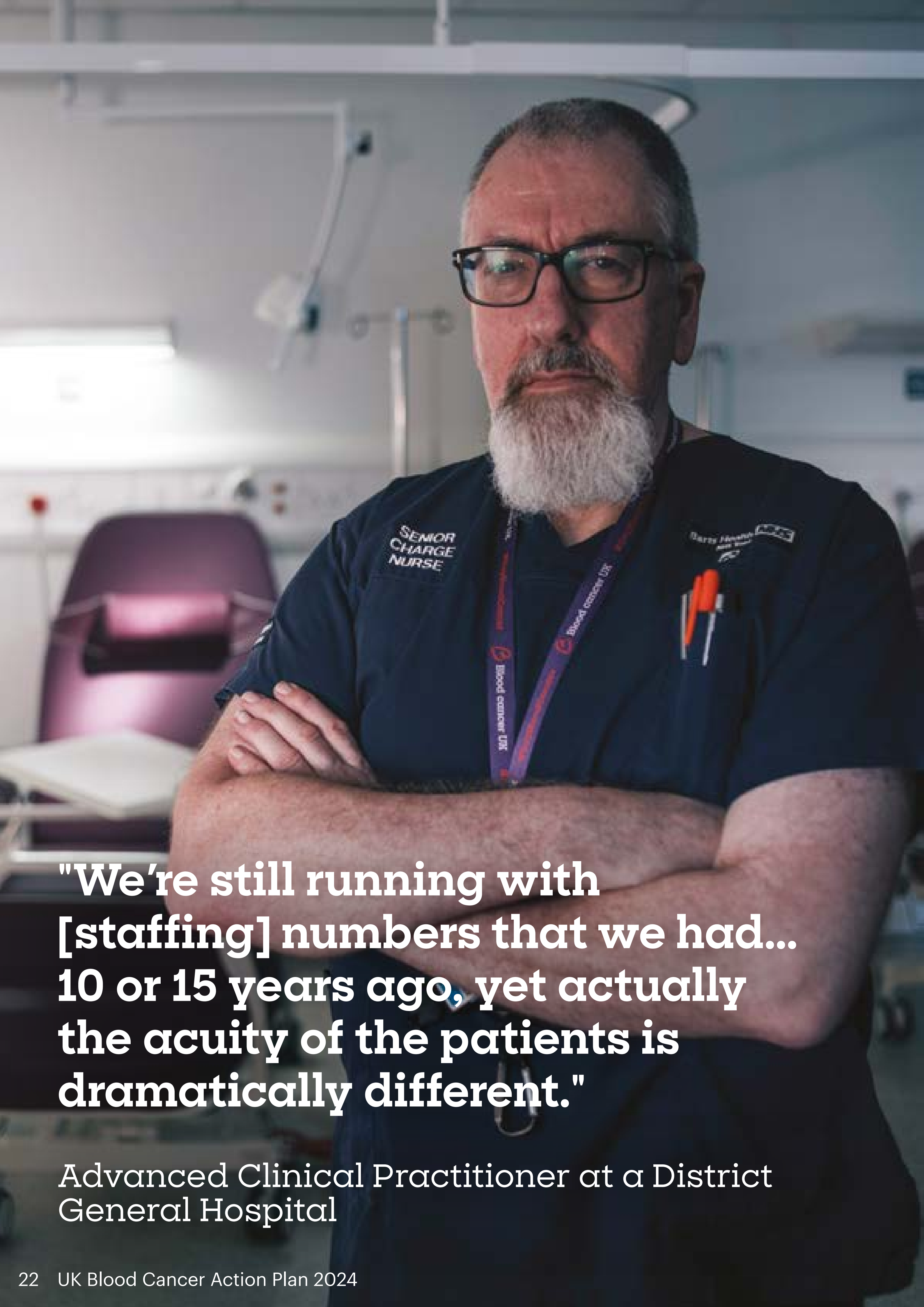
"We have disease-specific clinics, each area staffed by more than one consultant to provide a concentration of specialist interest and expertise. Consultants in each team support and cover one another when someone is away or unavailable. This refers to times of unexpected absences as much as planned annual or study leave. We are very proud that we get on extremely well as a team on a personal level, which I believe is the cornerstone of a well-functioning team. And I believe patient care benefits from this.

This attitude of mutual care cascades down to the middle-grade doctors and other trust/staff grades. I believe the sense of value and belonging is vitally important. **Our trainees are made to feel they are part of a family and not just here to do a job.**

When possible, informal teaching is offered, and in the case of blood and bone marrow morphology, sessions occur weekly. Most of our trust-grade doctors are in transit to move on to specialist haematology training. Most choose, when possible, to remain in the Northern Region due to the quality of training and positive culture of haematology.

Our nurses also embrace a similar culture of harmony, and they work seamlessly with the medical staff."

Leaders of clinical teams should be supported and have non-clinical time allocated to further develop multidisciplinary teams that commit to each other and provide the highest standard of blood cancer care.



"We're still running with [staffing] numbers that we had… 10 or 15 years ago, yet actually the acuity of the patients is dramatically different."

Advanced Clinical Practitioner at a District General Hospital

Lack of hospital space

A close-knit, co-located team can quickly consult with each other when needed. However, new innovative treatments like CAR-T create complex care needs that challenge the layout of existing blood cancer departments. People with blood cancer are highly vulnerable to infection and need single rooms. However, critical space shortage means patients often have to stay on different wards, such as frailty wards, leaving them with non-specialist care and straining relationships with their medical team.

Cancer patients not given a named CNS have the lowest survival rate.[18]

Source: Alessy SA, Davies E, Rawlinson J, et al

Clinical Nurse Specialists: The cornerstone of care

Blood cancer CNSs are vitally important. They connect to all professionals involved in every aspect of care, as well as community, palliative and shared care relationships.

People with blood cancer told us that CNSs provide a practical response, discuss symptoms and side effects and are an intermediary between them and their consultant. More than anything, CNSs provide information and support when making decisions about their care and treatment and this reflects the fact they have often spent their whole careers doing so.

> I don't leave the ward feeling certain that everything's going to go alright overnight.
>
> **Consultant Haematologist at a teaching hospital**

Despite the clear advantages, the CNS role does not benefit all those it should. Our 2024 survey found that 31% of respondents do not know who their CNS is, and 22% do not know how to contact their CNS. This is despite the 2019 NHS Long Term Plan committing to all cancer patients having access to the expertise and support of a CNS or other support worker by 2021.[19]

Healthcare professionals from across the blood cancer workforce have told us that nursing levels have not adjusted to the higher level of care (acuity) needed by patients on the ward and in outpatient chemotherapy. Furthermore, the measures of CNS activity do not reflect the hundreds of interactions they have with patients every day.

We do not need blood cancer CNSs to work harder, faster, and more – we need more blood cancer CNSs. UK and devolved governments must include funding to increase the number of blood cancer CNSs in future budgets, and health and care boards should reevaluate how nursing outputs can be more effectively measured.

> My CNS has been my point of contact from day one; she has stayed with me for continuity, I see her every month. She has been through everything for me, she has been there for emotional support as well as practical support.
>
> **Person living with blood cancer in Shropshire**

Creating space to learn

Increasing CNS numbers alone won't address retention, wellbeing or career development. Our focus groups highlighted conferences as a valuable learning opportunity, but a lack of funding and time prevented CNSs from attending these. CNSs were also keen to see more opportunities for mutual learning and sharing practices. Charities, including Blood Cancer UK, should try to fill this gap through online community groups, webinars and the development of new resources.

> It's a lot of admin time and we're not really doing the specialist tasks that we should be reserved for.
>
> **Blood Cancer Clinical Nurse Specialist at a DGH**

To enable CNSs to focus on blood cancer care, some administrative tasks, such as chasing blood tests, should be allocated to other colleagues. We also heard of different CNSs' support roles, such as Patient Navigators and Pathway Coordinators, but we also heard CNS frustration with overseeing delegated tasks.

The Scottish Government has funded 12 Single Point of Contact (SPOC) pilot projects designed to provide person-centred support to help patients navigate the cancer pathway, and positively impact the cancer workforce by freeing up staff capacity.[20] This is a welcome development, and we look forward to seeing the outcomes of a national evaluation.

We want to see the development of a new quality administrative blood cancer support role, with a blood cancer CNS-informed job description. Managers, trusts and health and care boards should invest time and funds to develop and pilot such a role, before giving feedback on their experience and scaling up if successful.

> I can't take half a day a week for learning, that leaves a huge hole and the rest of the team struggling.
>
> **Blood Cancer Clinical Nurse Specialist**

Addressing the decline in clinical academics

Clinical academics within the NHS are key to ensuring scientific discoveries are brought into clinical practice to benefit patients. Their careers balance clinical, research and teaching roles. In senior leadership positions, they drive improvements in their hospital trusts through cutting-edge research at the forefront of cancer treatment, securing funding and investment and embedding community involvement.

However, over one-third (35%) of the UK's clinical academics are over 55[3] with fewer in the pipeline to replace those retiring in the next decade. There has also been a stark decline in senior clinical academics specialising in pathology, with less than half the number in post in 2022 compared to 2004.[3] The lack of suitable senior roles results in a loss of nurtured PhD-qualified research talent. With a knock-on effect on trainees deciding against specialising in haematology at all.

Lack of protected time and support from middle and senior managers hinders clinical trial research in the NHS[11] and

> **"80% of the time allocated for our ward meeting today in fact was spent discussing whether we could admit them or not. What an inefficient way to run a service, purely because of a shortage of beds."**
>
> Consultant Haematologist

> **"My CNS helped me navigate the worst case scenarios."**
>
> Person living with chronic blood cancer in Manchester

compounds the challenges of high staff turnover, inadequate recruitment and a lack of specialist pharmacists. Income from industry-funded research needs to be invested back into research staff and infrastructure, breaking the vicious cycle that is hindering progress in healthcare.

With a supported and secure career structure and allocated time for research in their schedules, clinical academics could conduct more research that leads to scientific discoveries, bring new treatments into routine clinical practice and nurture the next generation of blood cancer clinicians and researchers.

Delays in diagnosing blood cancer

Most consultant haematologists combine clinical work with vital diagnostic activity in the laboratory, which informs treatments and drives innovation. As such, declining numbers of haematology trainees will also severely impact the future diagnostics workforce;[1] this is compounded by a loss of pathologists, radiographers, radiologists, GPs, and genomic scientists.

Since 2015, the overall number of GPs (including GP trainees) has seen little growth, while the number of GP partners has also declined significantly during this time.[21] Without targeted action and investment, the number of histopathologists is forecast to reduce from an existing shortfall by an additional 2% by 2029.[22]

Only 3% of NHS histopathology departments have enough staff to meet clinical demand.[14]

Source: The Royal College of Pathologists

Increased demand and persistent staff vacancies have increased the complexity and work burden for the pathology workforce.[14] These shortages have unsurprisingly increased the dependence on service providers outside of the NHS. An independent review of diagnostic services for NHS England has recommended a major drive to expand the pathology workforce.[20] For patients with blood cancer, the accompanying shortfall of 4,000 diagnostic radiographers and 2,000 radiologists further risks post-referral diagnostic delays.

Expansion of the specialist genomics workforce is becoming increasingly critical for blood cancer diagnosis and treatment.[23] While artificial intelligence (AI), machine learning and deep learning can aid the cancer screening process with data analysis, imaging, risk assessment and stratification, even when implemented, they will only support clinicians through the diagnostic process rather than replace them altogether.[24]

With enough haematopathologists, histopathologists, radiologists and genomics scientists, we can prevent further delays after referral from primary care.

Recommendations on the NHS blood cancer workforce

Action needed:

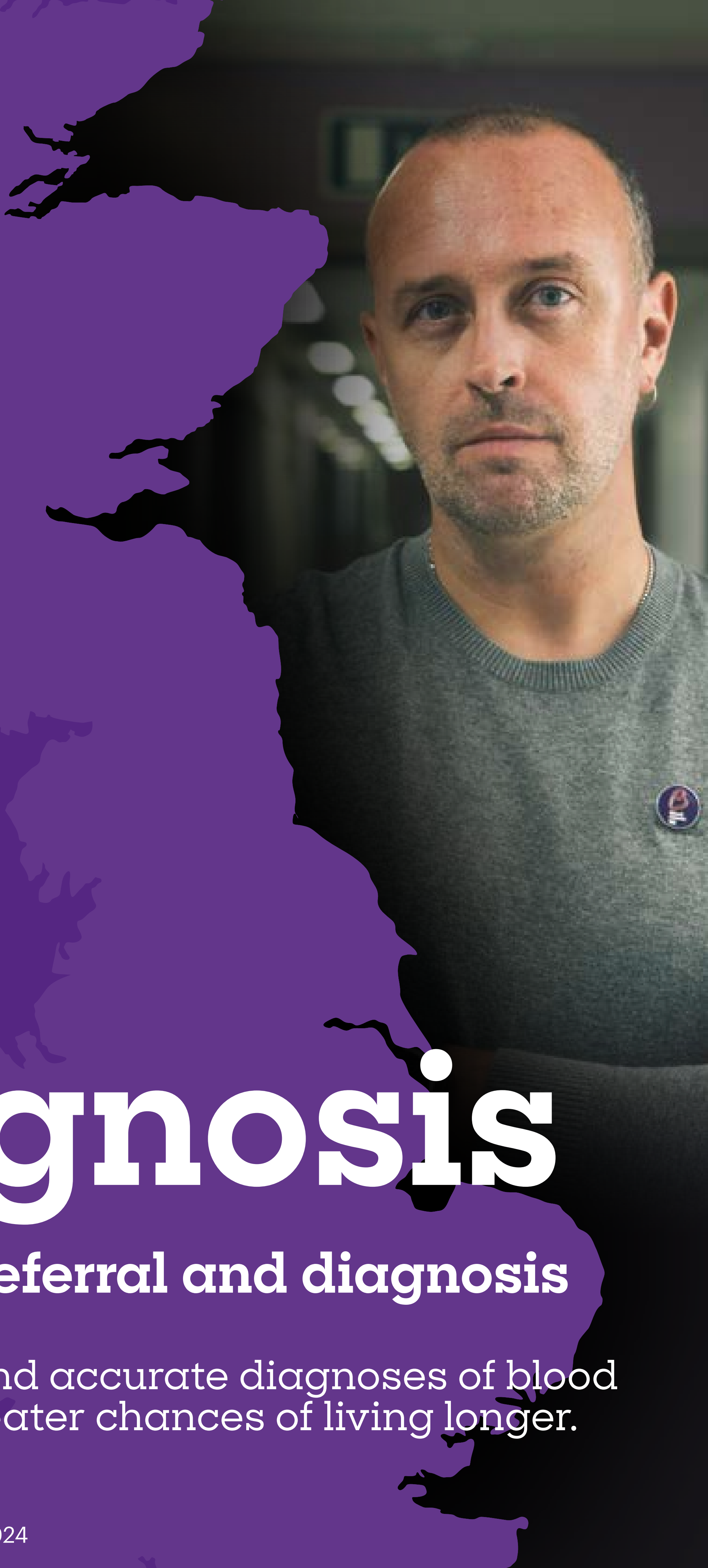
Modelling to determine the number and skillsets of healthcare professionals needed across all aspects of blood cancer care including diagnosis; and the development of national standards for staffing and facilities (for the NHS, BSH and Blood Cancer UK).

An increase in the number of blood cancer clinical nurse specialists and a programme of continuous support for service CNSs, including the development of a new blood cancer support role, with a CNS-informed job description (for the NHS).

Action to reverse the decline in clinical academics dedicated to blood cancer research by addressing the lack of suitable posts and retention challenges. Provide dedicated support and protected time for clinical academics and clinical researchers within the NHS to drive research (for universities and organisations which fund clinical academic posts).

Outcome:

This will ensure the safe and effective delivery of approved blood cancer treatments and care across the UK.



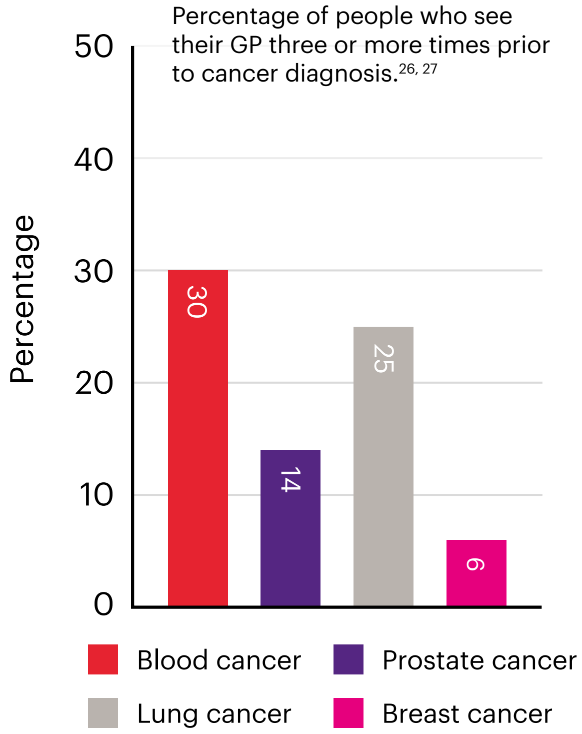
Diagnosis

Improving referral and diagnosis

Because swift and accurate diagnoses of blood cancer bring greater chances of living longer.

More than 1/4 of all new blood cancer diagnoses present as an emergency.[22]

Source: **NHS**



Blood cancer is a disease with a myriad of symptoms — some evident, some more difficult to recognise both for individuals themselves and GPs. While timely detection of blood cancer is crucial for successful treatment, vague symptoms like fatigue, weight loss, or frequent infections mimic those of other illnesses and can make diagnosis challenging for GPs.

As a result, too many blood cancer diagnoses are subject to lengthy delays that limit treatment options and results in people dying sooner than they would have if diagnosed earlier. New research paints a concerning picture of delayed diagnosis of blood cancers. This crisis is evident in the alarming rate of emergency presentations — 27% of new blood cancer cases are diagnosed via emergency routes[25] compared with just 3% in breast cancer and 7% in prostate cancer.[28] Although some of these emergency diagnoses would have been extremely difficult to diagnose beforehand, for others, opportunities had been missed.

Delayed diagnosis can have devastating consequences for people with blood cancer, including:

- **Fewer treatment options:** Emergency diagnoses, often a consequence of delays, limit the treatments available to patients.
- **Poorer quality of life:** Patients with delayed diagnoses experience a more significant impact on their daily lives, as demonstrated by a recent Myeloma UK study.[79]
- **Potential for reduced life expectancy:** Early intervention is crucial for blood cancer, and delays can have serious consequences.

Empowering GPs with safety-netting techniques can dramatically improve early detection of blood cancer. These techniques, like scheduled follow-ups, targeted testing and clear guidelines for seeking urgent care, ensure potential red flags aren't missed. Investing in GP training and providing accessible information can help catch blood cancers earlier, when treatment is most effective — a proactive approach that translates to better outcomes and potentially saves lives.

GPs may suspect that their patient could have a cancer, but their symptoms don't fit a single urgent cancer referral pathway, such as for breast or colorectal cancer. These patients, which include those with blood cancer, often experience severe diagnostic delays. The NHS has developed a non-specific symptom (NSS) pathway which is intended to include people who do not fit clearly into a single 'urgent cancer' referral pathway but who are nonetheless at risk of being diagnosed with cancer. 'Non-specific' symptoms include unexplained weight loss, fatigue, abdominal pain or nausea, and/or a GP ‘gut feeling’ about cancer.

The average time to diagnose or rule out cancer through Rapid Diagnostic Centres in Scotland was just 16 days; 13.5% of patients diagnosed with cancer through this route had a type of blood cancer.[6]

Source: University of Strathclyde

Evaluation of this programme in England showed that blood cancer was one of the four most likely cancers to be diagnosed through the NSS pathway,[29] accounting for approximately 20% of all cancers diagnosed this way.

While this pathway drives innovation in diagnostic practice, there is unequal access to these services across the UK. In Northern Ireland, the rollout of services has lagged behind the rest of the UK, while in Scotland, a sustainable recurring funding stream has yet to be agreed, creating uncertainty regarding the future of these services[6].

In England, the Faster Diagnosis Standard (FDS) aims to diagnose or rule out cancer within a maximum of 28 days from referral.[30] In contrast, Scotland, Wales and Northern Ireland assess performance against a 62-day standard between referral and treatment.[31] Regional variations identified in a 2022 evaluation in England must be addressed.[29] Timed diagnostic pathways, which support improvement efforts to shorten diagnostic pathways, are yet to be developed for any subtype of blood cancer.[32]

Research has shown that the NSS pathway is most effective when it has an effective multidisciplinary team, input from both generalist and specialist clinicians, and the use of patient navigators[33]. **We urge continued funding, effective access to haematology expertise at Rapid Diagnostic Centres, and continued action on equity of access to improve patient outcomes.**

> It was not clear what the cancer might be, or indeed at that stage if it actually was cancer. The referral to the NSS pathway then happened, and a nurse from the hospital got in touch — she was absolutely brilliant, explaining what was happening and why. She advised me about each result and next step and initiated action very promptly. Information was provided by her in a very digestible way, the whole process felt proactive and engaged.
>
> **Person living with blood cancer diagnosed through the NSS pathway**

Closing the gap on blood cancer diagnosis

Data reveals significant ethnic disparities in blood cancer diagnosis that are alarming. People from an ethnic minority background are four times more likely to experience delays in referral for a blood cancer diagnosis[4] and are less likely to meet the threshold for the 28-day Faster Diagnostic Standard.[22]

While this data sheds light on a crucial aspect of the problem, there is now an urgent need for better availability of complete ethnicity data to better understand and address where variations exist, considering intersectionality across levels of deprivation, race/ethnicity, gender, disabilities, sexual orientation.[34]

Stark disparities exist by ethnicity in blood cancer diagnosis, with 45% of blood cancer respondents from ethnic minority communities reporting that they have had to visit their GP three or more times before referral for testing.[35] Awareness of blood cancer and awareness of symptoms among these groups is also low. In a survey, 77% of people from black ethnic groups had not heard of myeloma, even though ethnicity is a risk factor[36] and therefore should have an accelerated diagnostic pathway.

Increasing accessibility to information is an important step towards levelling inequalities and empowering people affected by blood cancer. Providing information in different languages or tailored to raise awareness and support a specific community, like Blood Cancer UK's information for the African Caribbean community,[37] is a simple but effective step towards this ambition.

Applying the learnings from other successful inequality initiatives to blood cancer diagnosis could significantly contribute to closing the gap in health inequalities. Targeting high-risk populations, such as people in areas with the highest deprivation rates, has proved successful for other cancers, for example, the Targeted Lung Health Checks Programme.[38]

A £22 million government investment in Genomics England to tackle health inequalities in genomic medicine could positively impact diagnosis rates for blood cancer. This includes tailored sequencing of 15,000 to 25,000 participants from diverse backgrounds by 2025, as well as extensive community engagement work with marginalised groups.[39]

Efficient monitoring saves lives

Blood cancer monitoring is crucial for both high-risk individuals and those diagnosed without needing immediate treatment. For example, people with monoclonal gammopathy of unknown significance (MGUS) carry an increased risk of myeloma or non-Hodgkin lymphoma. People who have had chemotherapy for breast cancer have an increased risk of developing myelodysplastic syndrome (MDS) and AML. Early detection of changes through monitoring is critical for improving survival. However, this needs to be standardised, take place in the most appropriate setting and developed with input from GPs, hospitals, and patients.

The successful MGUS Tracker in Torbay Hospital exemplifies this. Patients with intermediate or high-risk MGUS receive timely requests for blood tests, which they can have through their GP. Test results are reviewed by an advanced clinical practitioner who can immediately discuss any concerns with the consultant-led team and arrange a clinic review if needed.

Funding research is essential in the mission to beat all types of blood cancer. That's why Blood Cancer UK has funded an ambitious project to establish a specialised clinical network. Patients at high risk of developing myeloid blood cancers will undergo an in-person visit, followed by remote or virtual follow-up visits.[40]

Stolen chances: The real impact of delayed diagnosis

Referral services aim to avoid unnecessary hospital visits, but **a clear pathway for identifying potential blood cancer cases needs to be established within the NHS, particularly when a patient is referred *out* of another specialty.** Patients with myeloma who were initially assessed by another specialty had a median time to diagnosis that was double that of those diagnosed by direct referral from their GP or via acute services.[35]

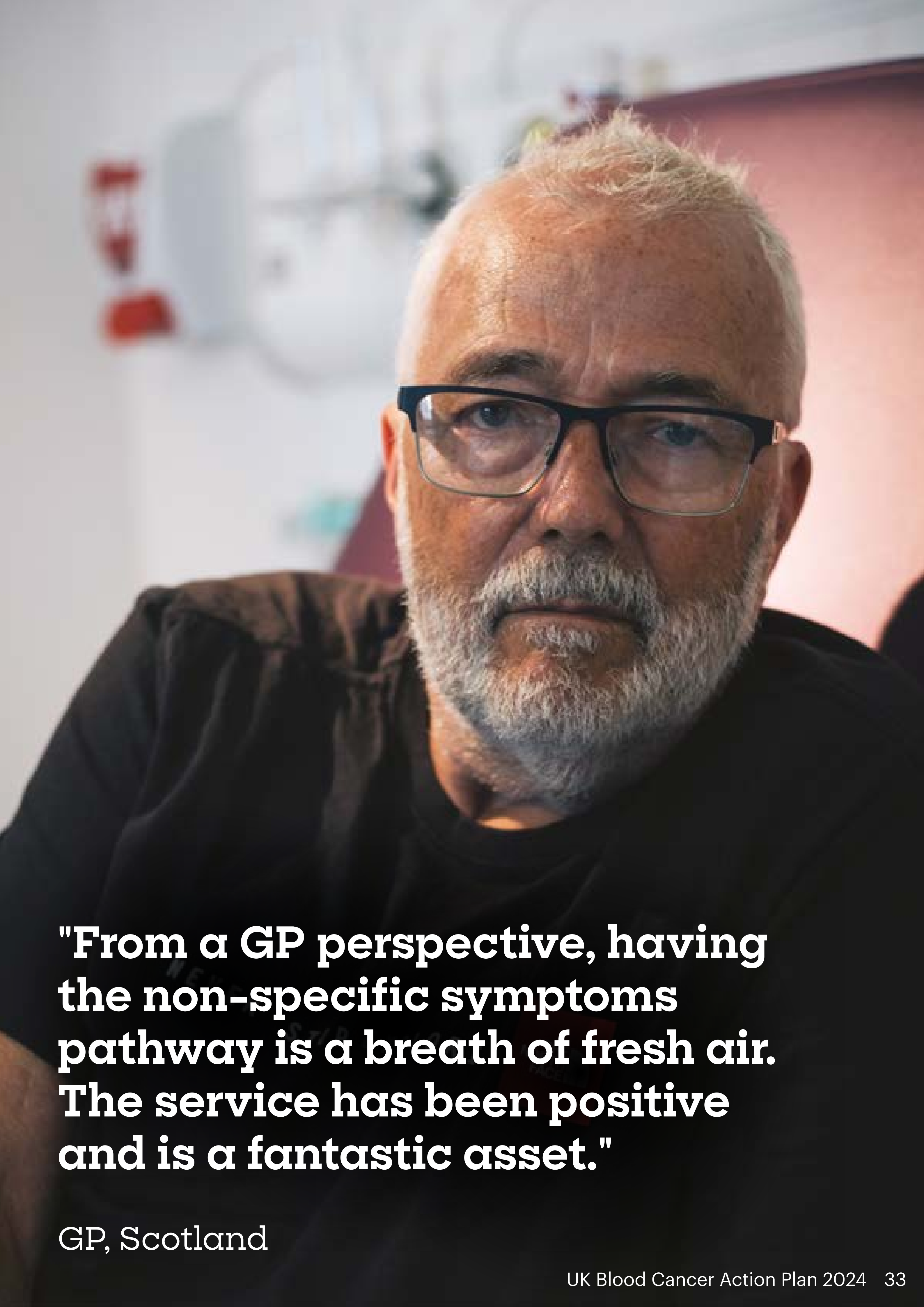
> On the 18th of September 2019, at 1pm I was told I had myeloma and would need a bone marrow biopsy at 2pm. Three weeks later, I was on chemotherapy. It was all going so fast; appointments were being made, plans were being adjusted.
>
> Getting to this diagnosis had taken three years of me going to my local GP with what I now know are obvious symptoms, which could have led to me being diagnosed quicker.
>
> I had an ear infection for two years. I couldn't get rid of a simple verruca for four years. I've a historic back problem, but pointed to my kidneys and said to my GP, 'I feel my kidneys are struggling.' I was dismissed. A simple blood test told us my kidneys were failing. And after visiting kidney specialists, my bloods got to the right department, and I was immediately placed on treatment.
>
> **Person living with myeloma**

A broken blueprint

Blood cancer diagnosis is complex and involves specialised laboratory tests. Different experts work together as a Specialist Integrated Haematology Malignancies Diagnostic Service (SIHMDS) to build a picture of a patient's blood cancer to be discussed by a multidisciplinary team (MDT).

NICE guidelines (NG47) define how SIHMDS should operate but there is variation in how well these have been implemented. Responses to an anonymous survey showed that not all SIHMDS in England could issue a collated report containing all test results and disease management information, and not all reports were reviewed by the MDT. These differences indicate unequal access and quality of blood cancer diagnostic services - a reality that impacts patient care.[42]

These tests are increasingly crucial for an accurate diagnosis and selection of the most effective treatment. Tests may look at a single gene or the whole DNA content of cancer cells (genome). However, some genetic and genomic tests are now performed through a network of NHS **Genomic Laboratory Hubs**.[43] In Scotland, instead of SIHMDS, genetic testing services for people with blood cancer are delivered through four regional laboratories via the Scottish Strategic Network for Genomic Medicine SSNGM.[78] Though efficient, the wider rollout of this 'networked model' and removal of these tests from the successful SIHMDS model is concerning, and a review of the impact of these changes on the timely provision of essential test results is needed.



"From a GP perspective, having the non-specific symptoms pathway is a breath of fresh air. The service has been positive and is a fantastic asset."

GP, Scotland

CASE STUDY:

Dr Renata Walewska, University Hospital Dorset

Patients presenting with enlarged lymph nodes may signify underlying conditions from autoimmune disorders to cancers; only a third will have lymphoma. However, without an efficient referral route from primary care or another specialty, they may experience long diagnostic delays. The Lymph Node Pathway Project at the University Hospitals Dorset provides an efficient nurse-led service with consultant supervision to image, review and biopsy potentially cancerous lymph nodes. This reduced the time to diagnosis in secondary care from 31 to 17 days, and in primary care from 66 to 26 days. With a CNS on the team, patients received dedicated support throughout the diagnosis.

> Patients who are at the beginning of their cancer journey receive support and efficient streamlined investigations, rather than endure a ping pong referral from one specialty to another until someone establishes diagnosis.
>
> **Dr Renata Walewska, University Hospital Dorset**

Recommendations on improving diagnosis of blood cancer

Action needed:

Address the barriers that prevent people from some groups, such as those from ethnic minorities or deprived backgrounds or those living in geographically remote locations, from receiving a timely diagnosis of blood cancer (for the NHS).

Strengthen safety netting practices in primary care and ensure the non-specific symptoms pathway for suspected cancers is available across the whole population (for the NHS).

Implement targeted monitoring programmes for people at higher risk of developing blood cancer (for the NHS).

Fully implement and maintain the NICE guidelines among existing specialist diagnostic service (SIHMDS) teams, establish similar diagnostic models in the devolved nations, and proactively identify and address gaps or changes to services to diagnose blood cancer across the UK (for the NHS).

Outcome:

Prompt referrals and monitoring lead to earlier detection of blood cancers, significantly improving patient outcomes.

Care

Reducing barriers that prevent access to care

Because all people with blood cancer should be able to access the care they need, and all clinical teams should have access to all the relevant and up-to-date information.

Unequal access: Understanding the obstacles to optimal blood cancer care

Funding challenges, communication failures, disjointed data systems and deprivation are just some of the reasons people living with blood cancer are not receiving the best care possible.

A 2024 study from Wales found that social deprivation impacts survival in people with CLL. Suggested contributing factors included increased fear of cancer, the need to take time off work, inequalities in accessing healthcare, comorbidities, patient compliance and medical staff awareness of deprivation and bias.[5]

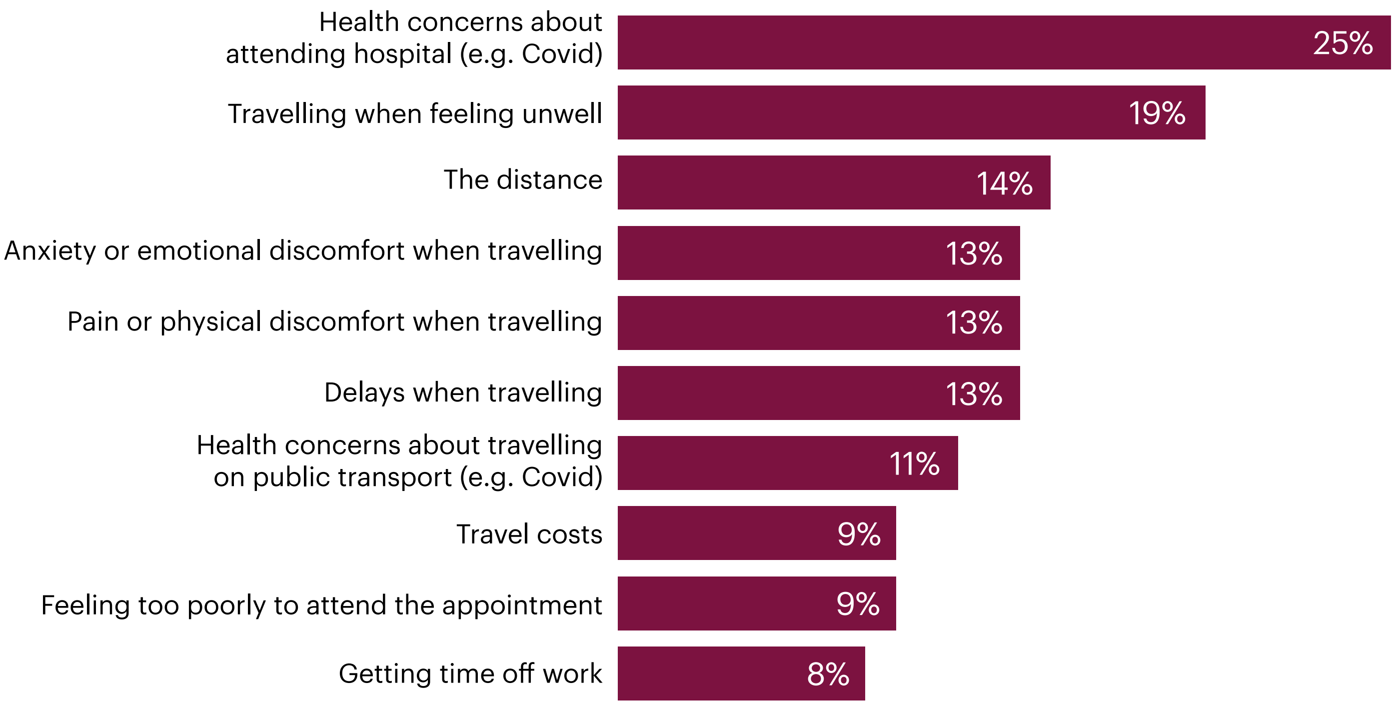
In our 2024 survey of adults in the UK diagnosed with blood cancer in the last five years, 60% of respondents selected at least one challenge that they had experienced when attending appointments in person.[44]

While generalist support is often delivered locally, the increased centralisation of specialist services means that people with blood cancer in rural areas are often faced with significant travel distances for specialised care.

Our survey also uncovered that certain groups were more challenged by some factors than others. While 27% described pain or discomfort when travelling, this is more a concern for women (29%) than men (22%). Fear of hospitals is only prominent for under 45s, a group which is also made up of more acute than chronic patients compared to other groups. In Scotland, 23% of people with blood cancer described distance as an issue, compared with 14% of the total sample. People with an income below £30,000 (lower than the national average) were more likely to report experiencing anxiety or emotional discomfort when travelling (19% vs. 10%). Those under the age of 55 showed more concerns over the cost of attending appointments and challenges getting time off work.

This echoes what we have heard in focus groups with people with blood cancer and can be compounded by caring responsibilities. One example was the introduction of a centralised

Challenges when attending blood cancer appointments



Blood Cancer Action Plan survey, 2024

booking system, which was less able to accommodate an individual's childcare needs when booking chemotherapy appointments.

Virtual appointments, by phone or video call, can help patients attend appointments. Of the 72% of our survey respondents who have experienced virtual appointments, 71% have done so by telephone and only 6% by video call. The unreliability of Wi-Fi connectivity within hospitals may contribute to more reliance on telephone calls. Impressions of virtual appointments are also mixed. People in Scotland were over 3 times more likely to have experienced video calls but were also more likely to say that it is hard to listen/understand/take things in and have experienced connectivity problems.

> I don't like telephone appointments much; they make me feel uncomfortable. I find it harder to explain how I'm doing and I'm more inclined to gloss over my symptoms. I find video calls better; it helps to see a face and feel like there's a connection.
>
> **Person living with blood cancer**

Health and care boards and trusts, and haematology department managers serving rural communities, should understand the physical and digital limitations that impact attendance so patients can be present, heard and seen during appointments. They must also ensure that the introduction of technological solutions does not worsen digital exclusion.

People with blood cancer are highly vulnerable to infection. Our insight suggests that patients' fear of being exposed to seasonal viruses, including COVID-19, is a barrier to attending in-person appointments. Infection prevention and control teams across hospitals must consider how people with blood cancer can safely and confidently access all spaces within a hospital.

With limited time within appointments, it is important that patients are empowered to raise concerns and ask questions.

> There was confusion around the long-term side effects impacting testosterone levels, and there was almost a lack of engagement with it, when it was really, massively affecting my life.
>
> **Person living with blood cancer in London**

Initiatives like Blood Cancer UK's Service Transformation Project will help with these many challenges. The project will transform access to services from diagnosis, starting with co-designing a mechanism whereby healthcare professionals can quickly and easily refer their patients to Blood Cancer UK, who, in turn, will proactively contact and guide patients through available services. **Further actions are needed, such as letters and appointments presented in lay language and time with a CNS to discuss information.**

Worryingly, appointments are often postponed due to the monitoring blood tests to be discussed being cancelled or delayed. This seems to be a particular problem for older and frailer people with chronic blood cancer having home blood tests. CNSs describe feeling that administrative

"I've got two children, and I haven't got anyone around who can help, so I'm stuck without a little bit of support to maybe shift those chemotherapy appointments slightly."

Person living with blood cancer in Hampshire

"It's hard because you want to empower the patient and support them in their Watch and Wait pathway but they're not having their bloods done."

Haematology Advanced Clinical Practitioner at a DGH services consider these low priority, and with services so stretched, tests can be cancelled, overriding clinical decisions.

To improve monitoring of blood cancer, health and care boards and trusts should prioritise timely monitoring of blood tests and educate staff on their crucial role in identifying changes.

What do we mean by data?

People with blood cancer must navigate a complex healthcare system. They may have additional conditions which are managed through their GP or local hospital. Every contact with the NHS is recorded electronically.

The primary purpose for collecting data is to deliver care. Over the last two decades, local solutions for managing and protecting this information have created a patchwork of disconnected IT systems, presenting challenges for people with blood cancer and the team caring for them.

Disconnected data: The impact of disjointed systems on care for people with blood cancer

All people with blood cancer should be readily able to access the care they need. However, the fundamental complexity of blood cancer impacts many aspects of diagnosis, care and the development and delivery of treatments. To make the best clinical decision for each patient, clinicians must be able to see all the information they need at the time of the consultation and in whichever setting that takes place.

Without this, patients risk potentially damaging delays or revisions in their treatment plans, the burden of having to repeat tests and the frustration of repeating information that should be available. Unfortunately, due to data challenges and system failures, this is not the case - resulting in a huge waste of healthcare professionals' time, unanswered questions for people with blood cancer and delays in care. As everything is recorded electronically, it is often surprising to patients that this information is not readily available.[45]

> When I got to the clinic this morning, I had to open about six different programmes.
>
> **Consultant Haematologist at a teaching hospital**

The safe use of routinely collected data can tell us a lot about how treatments are working for blood cancer, help get treatments approved for use on the NHS, and identify areas for improvement in access.

Unfortunately, the current processes for collecting, curating and accessing national data hinder research. A government-commissioned review in 2022 acknowledged 'research with substantial patient benefit being blocked by the complexities, duplications, delays and contradictions of multiple legal, regulatory, professional and ethical restrictions.'[46]

Each of the four nations has set out a vision of secure access to the right information about patient care by the right person at the right time, and to ensure the safe use of this information at a population level to improve health services and drive research.

The complexity of blood cancer treatment inevitably results in a mixture of local and specialist centre care. It is essential that information is seamlessly shared between local and specialist centres, which may be within a different region or under a different health and care board or trust.

We hear of digital inefficiencies creating delays in the delivery of urgent blood test results, directly impacting treatment and

Progress in action

Examples of digital success in the devolved nations include the HaemBase Cymru data solution in Wales, proving blood cancer data integration is possible. This project captures and integrates outpatient data for myeloma patients, making it instantly accessible to the entire clinical team through the Welsh Clinical Portal.[47]

care. Healthcare professionals are being put in impossible situations, having to weigh up if it's safer to wait for a test result to be transferred digitally at a glacial pace or to note the result down manually over the phone, risking multiple opportunities for human error.

Similarly, patients, particularly those on active monitoring (also known as watch and wait) who do not need treatment straight away, have expressed their frustrations that blood tests can't be taken locally and transferred to treating teams. Such disjointed data and information between neighbouring health and care boards means that, too often, results get lost or are so delayed that appointments are postponed.

The lives of people with blood cancer do not neatly fit into the boundaries set by health and care boards and trusts or within one UK nation. For example, in bordering towns like Hereford, people with blood cancer are referred to specialists in Cardiff or Birmingham. Those with comorbidities rely on rapid communication between different departments. This often fails, with treatments being delayed because a letter from one consultant to another can take weeks to arrive. **Health and care boards and trusts across the UK, the NHS and UK and devolved governments must work collaboratively to find a solution for fast and effective health data and information sharing.** We are encouraged that in its Manifesto, the new Labour Government commits to developing an NHS innovation and adoption strategy in England in response to the data and life sciences challenges in the NHS.[48]

It is also true that many local information sharing tools and the national GP Connect platform in England are already in place. However, awareness of these tools and how they connect across shared care records is low among blood cancer teams. **Haematology departments should ask their care board or trust what is available and request for training to be provided for blood cancer healthcare professionals to get the most out of existing systems.**

> It's a 34-mile round trip to get to the hospital. If I depended on public transport, it would take me all day, practically. I don't know why they cannot use more local resources to take the bloods and then take it from there.
>
> **Person living with chronic blood cancer in Angus**

Ensuring clinical, patient and public involvement in the design and rollout of new digital systems is vital. Too often we've heard from healthcare professionals that the rollout of digital systems hasn't been clinician-led, resulting in a system that then doesn't work for them. **When introducing new data, information, and IT tools, health and care boards and trusts must ensure that blood cancer clinicians are involved in shaping their setup and launch.**

Better care through better knowledge

In the NHS, multi-disciplinary teams (MDTs) bring together a group of health professionals, including haematologists, nurses, pharmacists, radiologists and psychologists, who combine their expertise to provide coordinated care. Through this collaborative approach, MDTs tailor treatment plans to each patient's needs and deliver continuity of care.

Despite this, 55% of people affected by blood cancer told us that the role of the MDT was not clear to them at the start of their care journey, with one in four saying the role still isn't clear. Pharmacists contribute hugely to the delivery of blood cancer treatment, yet when we asked people with blood cancer how they would feel about pharmacists taking a more significant role in their care, we were met with feelings of worry, frustration and sometimes fear.

> I think my biggest worry is when we mention a pharmacist, I automatically think of the pharmacist at a supermarket where I pick other medication up and this really terrifies me - having to have conversations with strangers who don't have the full understanding of blood cancer.
>
> **Person living with blood cancer in Shropshire**

MDTs should be a well-understood enabler of better care and outcomes. **Clinical system leaders in the NHS should oversee a transformation of the understanding of the blood cancer MDT, creating peer-to-peer learning opportunities for all the healthcare professionals within it.**

Increasing awareness of the many skilled healthcare professionals involved in the delivery of blood cancer care will ease the introduction of new ways of delivering care such as pharmacist-led clinics.

Broader awareness and clearer communication are required beyond people already affected by blood cancer. Nurses told us that a common reason for people not attending two-week-wait referrals to haematology is not understanding the urgency of the appointment. Our focus groups described receiving referral letters to haematology and not knowing what haematology is.

> I got a phone call out of the blue whilst having lunch to say, 'a haematologist is going to be calling you shortly.' And then got told 10 minutes later, just before I was about to pick my child up from school, that I probably had incurable blood cancer, which was quite shocking.
>
> **Person living with blood cancer in South East England**

People with chronic and rare blood cancers have told us that GPs are often open about how little they know about their type of blood cancer but show a willingness to learn. Resources exist to enable GPs to support them, such as an information guide created by Maidstone and Tunbridge Wells NHS Trust, which aids in GP referrals and further investigation of people with stage A CLL.[49]

Focus group participants with chronic blood cancer repeatedly told us that they struggled to understand 'what bad looks like' while on active monitoring (watch and wait) and needed to contact their CNS to understand symptoms or side effects. We would like to see resources and information be shared to guide people with chronic blood cancer and their GPs through self-monitoring.

Recommendations to ensure high quality care and treatment

Action needed:

Undertake further research into the practical barriers that prevent people with blood cancer from accessing care and propose solutions. (for Blood Cancer UK).

Empower patients with self-monitoring knowledge, awareness of their blood cancer team and resources to encourage patient advocacy, including signposting and referral into charity support services (for the NHS).

Identify and make recommendations to address critical gaps in information sharing and delivery that impact the treatment and care of people with blood cancer (Blood Cancer UK).

Outcome:

More people with blood cancer can access the high-quality clinical care, support and information needed to live well with blood cancer and its treatments.

Trials and Treatment

Increasing access to trials and treatments

Because every person with blood cancer has the right to receive drugs and treatment that have been approved for use on the NHS and recommended by their medical team.

1,500 more blood cancer survivors in England each year as a result of treatment advancements.[50]

Source: Blood Cancer UK

Barriers to breakthroughs

Radiotherapy and surgery are rarely used in the treatment of blood cancer which means that anti-cancer treatments, such as chemotherapy, stem cell transplant and immunotherapies are often the main option. Acceptance into a clinical trial can sometimes offer vital access to new drugs. While clinical trials can offer promising treatment options for blood cancer patients, significant hurdles exist; from limited availability and eligibility criteria to practical, financial and social barriers that prevent participation.

Recruitment to blood cancer trials fell by 78% in 2020/2021[7] and post-pandemic recovery has been challenged by delays and a chronically understaffed workforce. Healthcare professionals feel that trials are not a priority for NHS trusts and emphasise that it is now considerably more challenging to deliver investigator-led trials and to accept commercial trial opportunities.[11]

Late-stage commercial trials provide new drugs to the largest number of patients, yet the UK has fallen from 4th to 10th place in global rankings for these.[8] Evidence received from the pharmaceutical industry confirmed that they need confidence that UK hospitals can deliver the trial and successfully recruit patients.

To increase opportunities for patients and re-establish the UK's position as a science superpower, action on the recommendations outlined in the subsequent independent review by Lord O'Shaughnessy is needed.[51,52] **Reinvestment of commercial trial income in clinical research is needed to rebuild and expand the UK blood cancer trial infrastructure.**

Low awareness of trials is inhibiting access

People with blood cancer have told us that there is variable awareness of trials amongst their clinical teams. In the absence of a searchable, well-curated public database of open trials, patient organisations have stepped into the gap, for example, **Blood Cancer UK's Clinical Trial Support Service**.[53]

Discussion of trial opportunities should be an integral part of patient consultations. However, National Cancer Patient Experience Surveys indicate that only 38% of respondents with blood cancer in England and 26% in Wales had discussed research opportunities.[26,54] Without prompt discussion, trial opportunities may be lost due to the progression of disease, stealing opportunities from the patients who need them most.

Hope deferred: The practical, financial and social challenges blocking access to clinical trials

Healthcare professionals highlighted that trial participants are more likely to have a network of family and friends supporting their appointments. They also observed barriers presented by socio-economic factors and geography.[9]

> I have to keep reminding myself that if I hadn't had my CAR-T [therapy], I don't think I'd be here.
>
> **Person in remission from DLBCL after receiving CAR-T therapy**

In a survey commissioned by the Blood Cancer Alliance, less than a third (32%) of those from ethnic minority communities reported being offered the opportunity to participate in a clinical trial.[4] Similarly, black patients were shown to be significantly underrepresented in early-phase clinical trials in myeloma.[55] While late diagnosis or comorbidities may contribute to unequal access to trials, consideration should also be given to English language proficiency, as well as prejudices, biases, and stereotypes. **Providing accessible patient information, improving the diversity of patient and public input and nvolvement in clinical research is urgently required to tackle health inequalities.[56]**

To develop a deep understanding of the practical, cultural and socio-economic barriers to clinical trial awareness and access, Blood Cancer UK has initiated an 18-month programme of work with a local community particularly affected by blood cancer. This initiative will address inequalities identified through this programme by co-designing and piloting local awareness campaigns or services to increase clinical trial participation. As well as providing practical tools to support increased awareness and access, projects like this one must consider long-term scalability models for future successful initiatives.

UK approvals lag behind European counterparts

The **NHS spends around £20 billion**[57] every year on prescribed medicines and treatments in England. Yet, bureaucratic approval processes, funding limitations and geographic disparities mean that access to treatments is still a central issue for many people receiving care from the NHS.

Concerns about whether people in the UK are accessing the most effective and innovative treatments are particularly important for people with blood cancer because radiotherapy and surgery are unlikely to be options. Therefore, drug approval decisions can have life-or-death consequences.

There has been significant progress, with the approval of around 20 new drugs between 2010 and 2016 for use by the NHS. Further positive recommendations by SMC and NICE, including through the Cancer Drugs Fund in England, have since increased treatment options. Since July 2016, 76 treatments of 257 available through the Cancer Drugs Fund were for blood cancer.

Blood Cancer UK was understandably delighted when, in 2018, adults with blood cancer in England were the first in Europe to receive innovative CAR-T therapy; followed by approval in Scotland in 2019. Unfortunately, approval for use earlier in the lymphoma treatment pathway has since diverged between nations, increasing inequality of access within the UK.

Recent decisions made by pharmaceutical companies not to pursue UK approval for CAR-T therapies and other treatments,[59] at a time when other countries are approving the same treatments, are worrying.

There is evident frustration amongst the pharmaceutical industry with the approval process, payment schemes and likelihood of reimbursement, particularly in England. Primarily, we heard that the cost-effectiveness judgement is too inflexible to meet the complex nature of treating blood cancer. There is also a responsibility on the industry not to deprioritise people with blood cancer in the UK. They should work constructively with the NHS, both generally on the approval processes, and specifically on individual drugs to reach a solution that doesn't disadvantage British patients when compared to counterparts in other countries.

Worryingly, when NICE and SMC approve a new cancer treatment, the approval also

> “The slower and inequitable uptake of innovative medicines contributes to poorer health outcomes for the UK, including for those populations currently disproportionately impacted by disease.
>
> For example, UK cancer survival rates lag behind the European average in nine out of ten cancers, with access to cancer medicines being consistently lower than most European countries.” [58]

NHS Confederation report

defines its place in the order of treatments a patient receives as their cancer progresses (known as 'lines of therapy'). This can mean that a patient may be receiving a treatment that is not necessarily in their best interests but rather, to fulfil that 'line' of treatment because the treatment they really need is only approved at the next 'line'.

When blood cancer stops responding to a cancer drug and the cancer progresses, it will not respond to any other drug of the same 'class' (drugs which use the same mechanism to kill the cancer cells), regardless of where in the pathway these have been approved. This is known as drug class refractoriness, and it would be more clinically relevant to consider this when approving blood cancer treatments rather than lines of therapy. **It is clear that the status quo is not an option if people with blood cancer in the UK are to receive the most effective treatments and have the best chance of living longer.**

Why NHS approval doesn't guarantee blood cancer treatment

Healthcare professionals and pharmaceutical companies have raised concerns that despite some drugs being approved for use on the NHS, local funding decisions mean that people with blood cancer only have access after considerable pressure from their medical team. Geographic challenges, compounded by health inequalities, may prevent patients from being offered or being able to accept the best treatments available.

Geographical disparities

While specialist centres meet the demands of delivering complex blood cancer treatments, their locations often create a significant travel burden for patients, with many telling us they did not feel able to undertake such journeys. For example, CAR-T therapy requires a minimum hospital stay of one month, but in Scotland there are only two centres providing this treatment, only one in Wales and none in Northern Ireland.[60]

> I asked for CAR-T, and they said, unfortunately not, you've got to go through standard treatment again and have another relapse before we could get you on CAR-T.
>
> **Person in remission from DLBCL after receiving CAR-T therapy**

Alongside costs, unreasonable travel impacts family, work and income, and increases vulnerability to infection, highlighting how deprivation compounds unequal access to treatments. As a result, patients will sometimes choose or be offered a less optimal treatment.[61]

Delivering blood cancer treatments locally requires close monitoring and management of potential side effects, which may not be possible in some settings.

Part of a new minimum standard of care should see the BSH consider developing a standardised process for haematology MDTs at DGHs to refer patients for specialised care. Current processes are effective but rely on established relationships between DGHs and tertiary centres, often based on personal connections which potentially could lead to some patients missing out on specialised care. However, any new process should not delay access to treatments where existing partnerships are working well.

The new Labour Government made commitments in its manifesto to developing a 'clearer route' to getting new technology and medicines approved and procured in the NHS as part of its life sciences plan, including via 'reformed incentive structures'.[48] The blood cancer community must be included in the development of these initiatives.

We need a full picture of how often the approved treatments are not being prescribed at all, why this is and what the impact on patients is.

Improving care through mutual learning

In order to deliver a minimum standard of care, the blood cancer workforce across the UK needs to be connected, with opportunities to learn from each other and scale up successful practices and protocols. We heard of uncertainty amongst healthcare professionals about how best to initiate this, particularly for new treatments.

It is clear to see that many examples of best practice exist, but there are too few opportunities to share them with their peers, or to share the equally valuable lessons that come from unsuccessful pilots/ initiatives. Time and geographic constraints limit attendance at conferences and **managers need to provide opportunities for attendees to feed back their learnings to the wider blood cancer team, health and care board and trust managers.** The MDT emerged as an important weekly space to talk about new drugs and ways to standardise care for complex patients, as did more informal routes, such as peer support Facebook groups.

More opportunities for mutual learning outside of existing blood cancer-related conferences are needed. **Charities, societies and royal colleges should identify and roll out non-conference-based platforms for sharing practices across the blood cancer workforce.**

> I didn’t really get a chance to discuss treatment options. It was kind of like 'You’re on this drug and this is the one that you’ll be taking for the rest of your life...' that was kind of it.
>
> **Person living with chronic blood cancer in Manchester**

Recommendations on clinical trials, access to drugs and treatments

Action needed on clinical trials:

Offer comprehensive and targeted support for both investigator-led and commercially sponsored clinical trials through streamlined regulatory processes, funding and access to research networks (for universities, the NHS, government departments and agencies in the UK nations that fund clinical research such as UKRI and NIHR, BSH and blood cancer charities).

Develop strategies to increase participation in clinical trials, particularly among underrepresented groups, addressing the cultural, financial and communication barriers that prevent involvement (for clinical trial leads and funders).

Outcome:

Increasing the volume and efficiency of clinical trials and involving a more representative participant pool will create a more robust, inclusive and impactful clinical research landscape for blood cancer.

Action needed on access to drugs and treatments:

The UK drug and treatment approval bodies must streamline approval processes, and they and the pharmaceutical industry should focus on ensuring patients in the UK have access to cutting-edge blood cancer treatments. This will mean both sides being more flexible (for the NHS and the pharmaceutical industry).

Assess how often, where, and why drugs approved for use on the NHS are not routinely being prescribed, and then make proposals to ensure everyone has access to the treatment recommended by their medical team (for Blood Cancer UK).

Define the minimum standard of care that supports clinical excellence and equity of access to approved treatments in all settings, including remote locations and treatment closer to home (for the NHS, blood cancer charities, societies including BSH, royal colleges and the pharmaceutical industry).

Outcome:

This will enable everyone across the UK to access the drugs and treatment they need.

Data

Driving improvement through our national data

Because we must overcome the complexities of blood cancer data to provide consistent, meaningful and comparable national data that drives improvement and allows blood cancer to be routinely included in national cancer planning and initiatives.

Connecting the dots: standardised data paves the way for research success

High-quality data is essential for researchers developing new drugs, better diagnostics and imaging, personalised treatments, and health service improvements. Yet, locating and linking data within a host of non-connected sources containing mostly unstructured data is a major challenge.

Advances such as AI have the potential to improve survival by identifying those at risk of disease progression or predicting who may best respond to treatment. Already, blood cancer data has benefitted myeloma patients, all of whom received active treatment on the successful OPTIMUM (MUK9) trial because the control arm used clinically matched data from a previous trial.[62] However, the information needed to inform these advances, such as genetic or genomic test results, is yet to be recorded in a standardised, usable way.[63]

Additionally, organised collection of liquid and tissue samples is critical for advancements in research and developing new treatments. Serial samples taken after patients are treated will drive our understanding of the natural history of blood cancers and changes that occur after treatment. This will be invaluable in developing novel strategies to overcome resistance and stop blood cancers returning.

The most comprehensive data is within regional specialist registries such as the **Haematological Malignancy Research Network** (HMRN),[64] funded in partnership by Blood Cancer UK and Cancer Research UK. HMRN collects blood cancer data from a population of four million people across Yorkshire and the Humber. It's an excellent example of how sharing information on individual blood cancer subtypes with researchers, clinicians, patients and commissioners provides the best picture of the burden of blood cancer across a population and the effectiveness of clinical practice in line with national guidelines.

Replicating the success of this regional example hinges on improving UK-wide data for blood cancer, developing a robust and sustainable workforce with both clinical and data research expertise and fostering a community of blood cancer data researchers. Beyond the UK, progress for patients with rare subtypes depends on secure, international data sharing such as the HARMONY alliance.[65]

National cancer registries: Understanding the current picture

The four nations of the UK have separate cancer registries that securely collect and store information about all cancers to plan services, drive quality improvement, and improve outcomes through research, benchmarking against other nations and identifying inequalities. **The more accurate and complete the information, the better it can demonstrate where action is needed and provide evidence to support access to new treatments.**

This means using consistent classifications, diagnostics and follow-up periods. The persistent inconsistency in the recording and reporting of myelodysplastic syndromes (MDS) and myeloproliferative disorders (MPNs) shows that this is not the case.

Bringing equity to cancer care through comparable data calls for a collaborative approach from all four nations, and effort and investment in four key areas:

1. UK-wide comparable reporting

The complexity of the 150 blood cancer subtypes demands more precise categorisation. Reporting unrelated blood cancers together can be, at best, meaningless and, at worst, misleading. For example, collectively reporting survival for all types of leukaemia obscures the extremely low survival rates of specific types, like AML.[66] Nationwide adoption of the

ICD-O-3 system that defines blood cancers by cell origin and behaviour is essential and has been shown to be possible by the National Disease Registration Service (NDRS).

Progress in action

The Get Data Out programme from NDRS publishes detailed statistics from cancer registrations in England, providing data in groups that will provide meaningful answers but protect anonymity. The programme has successfully refined blood cancer into 42 groups defined by ICD-O-3 codes.

2. Adequate infrastructure and an expert workforce

A stable, experienced workforce is essential to accurately register blood cancers. Organisational changes and increasing mandatory tasks must not result in the development of blood cancer data being left behind that of solid tumours or stalled completely. **Ongoing training in blood cancer and the development of robust technical infrastructure capable of handling increasingly detailed data are more critical than ever.**

3. Capturing a holistic view of drug treatments

Information about cancer treatments, known as Systemic Anti-Cancer Therapy (SACT), is collected by cancer registries only in England and Scotland, where electronic prescribing systems are used. SACT data provides powerful information about the effectiveness of treatments in routine practice.

4. Increasing need for molecular and laboratory test data

Complex laboratory tests play an essential role in diagnosing, selecting treatment, and monitoring blood cancer. Treatments are now available that target specific genetic changes, yet there is no way of assessing their performance at a population level, such as, the effectiveness of a treatment for people with AML who have an FLT3 mutation.

Significant progress has been made at NDRS to develop the architecture to receive genetic and genomic test information for solid tumours. To prevent further health inequalities, blood cancer must be included as this work develops, with resources and expertise invested to extend these capabilities to all UK registries. This requires secure and seamless transmission of information from laboratories,[23] and the development of laboratory frameworks as planned in **Scotland**.[67]

Progress in action

In England, SACT data has contributed to NICE approving the use of seven new blood cancer drugs for use in the NHS, which were previously only available through the Cancer Drugs Fund.

SACT data for blood cancer is highly complex as treatments are given over long periods, during which individual patients may need dose adjustments. Increasingly, treatments are taken orally or at home. As the mainstay of blood cancer treatment, it is essential that the national picture is complete and researchers are supported to access, develop and use SACT data to improve outcomes.

Equitable access to advanced diagnostics unlocks better outcomes

The ambition for the NHS in England, as set out in the NHS Long Term Plan, is that 'by 2028, 75% of people with cancer will be diagnosed at an early stage (stage one or two)' [NHS]. The 10-year vision for Scotland, which is to reduce the number of cancer diagnoses at a late stage from 42% to 24%, recognises that 'not all cancers can be conventionally staged.'[68]

Blood cancer falls into this category.

Blood cancer staging does not align with the convention for solid tumours of size, lymph node involvement, and metastasis (spread). When staging is possible, the tests used will be very specific to an individual subtype. **Thus, including stageable blood cancers in national staging objectives requires equal and efficient access to all necessary diagnostic modalities across the UK.**

Variations between trust data blur the national picture

Improvement initiatives rely on a national data picture. In England, the Cancer Staging Completeness dashboard includes myeloma and lymphoma, but completeness is 35% and 50%, respectively, with large variation between trusts.[10] While these figures may reflect digital maturity, healthcare professionals emphasise that often treatment cannot be delayed for all staging tests to be completed.

73% of healthcare professionals support the recognition of blood cancer as a category in the NHS Cancer Registry.[69]

Source: **Blood Cancer UK**

Proxy measures for unstageable blood cancers

We support the Blood Cancer Alliance recommendation that the number of emergency presentations at hospitals by patients should be used as a measure for non-stageable blood cancers and that the corresponding national target for reducing late diagnosis should be applied.

Hidden in plain sight: Raise the profile, reduce the harm

Blood cancer is an outlier among the common cancers, where lack of awareness is causing ongoing harm to people affected by it. Blood cancer must not be overlooked in national cancer planning and initiatives. 62% of people with a blood cancer diagnosis believe the blood cancer community is let down by a lack of awareness, and 91% of people affected by blood cancer believe the community would benefit if blood cancer was as well-known as other cancers.[69] For people affected by blood cancer, greater awareness and political focus would mean that they are more likely to have a timely diagnosis, benefit from widespread understanding that they have cancer and access the support, services and community they need.

76% of people with blood cancer say they were not told their condition was a type of blood cancer at diagnosis.[69]

Source: Blood Cancer UK

Increasing public awareness of blood cancer has never been more important. Too often we hear of people not being told they have a type of blood cancer at diagnosis, only to find out later, on their own. We also hear from those who are told they have blood cancer at diagnosis, but their GPs do not recognise it as such, denying them essential support, such as medical exemption certificates for free prescriptions.

Because everyone deserves access to optimal care

Recommendations on data

Action needed:

National blood cancer data collected, analysed and reported by national cancer registries should be consistent and comparable between UK nations. It should include treatment, diagnostic and demographic data and provide meaningful statistics based on cell morphology and behaviour (for UK national cancer registries).

Blood cancer should be routinely included as a distinct category alongside solid tumours when reporting on key metrics such as prevalence, healthcare utilisation and other appropriate benchmarks (for the NHS).

Outcome:

Standardised and comparable data generates meaningful statistics that will improve blood cancer survival across the UK and reflect the increasing use of targeted treatments.

Exposing blood cancer health inequalities

Blood cancers do not discriminate, yet evidence shows that the experience of diagnosis, treatment and outcomes can differ dramatically based on factors such as ethnicity, socioeconomic status and geography.

In creating this Action Plan, these health inequalities became a persistent theme through both research and our engagement with healthcare professionals and people with blood cancer. While we have included examples of these inequalities throughout this report, we also wanted to collate a snapshot of what we have uncovered to highlight the breadth of the challenge and the urgency for action.

Race and ethnicity:

- Ethnic minorities are **four times** more likely to experience delays in referral for a blood cancer diagnosis.[4]
- Healthcare professionals may avoid using 'blood cancer' at diagnosis for fear of distress. However, research shows this approach left **13%** of people with blood cancer finding out they have a cancer via the internet or information booklets. This lack of transparency is particularly concerning for ethnic minorities, who are almost **twice as likely** to learn about their blood cancer diagnosis this way.[69]
- Black or mixed-race blood cancer patients with leukaemia have a **37%** chance of finding a 10/10 matched unrelated stem cell donor compared to **72%** for white patients.[70]
- Ethnic variation was seen for patients meeting the 28-day Faster Diagnosis Standard for NSS Pathways per month by ethnic group: **73.5%** of white patients compared to **46.8%** of black or black British and **48.3%** of Asian or Asian British patients.[29]
- The incidence of some types of blood cancer is almost three times higher in people of certain ethnic minorities.[71] Yet, **less than a third (32%)** of those from ethnic minority communities reported being offered the opportunity to participate in a clinical trial, and **less than half (43%)** felt that they understood the information given to them about the clinical trial.[35]
- Ethnicity was recorded in only **54.7%** of cancer registrations in Wales, while in Northern Ireland, ethnicity is not recorded in the primary data sources submitted to the cancer registry.[72,73]

Deprivation:

- **10-20%** of patients from the most deprived backgrounds are most likely to miss an outpatient appointment.[74]
- There are more cancer deaths in more deprived populations than in less deprived. In Scotland, cancer mortality rates that include the COVID-19 period are **74%** higher in the most deprived populations compared to the least deprived.[75]
- Despite treatment according to national/international guidelines, patients with CLL from the least deprived backgrounds in Cardiff and the Vale had significantly better survival compared to those from the most deprived backgrounds.[5] Deprivation was associated with a more advanced stage of CLL at presentation and significantly worse survival after the first treatment had been received.
- Between 2011 and 2019, **890,000 people in England died earlier** than they would have done if they were in the least deprived fifth of the population. Each year, the number increased and rose further, by 24,000 in 2020.[76]

Geographical location:

- Rural North Scotland has **4.9 oncologists** (medical consultants who treat all cancers) per 100,000 older people, compared to **9.1** in the urban South East.[80]
- Just three centres can provide CAR-T therapy across the devolved nations. This means people with blood cancer in Scotland, Wales and Northern Ireland can't always receive treatment close to home. The costs of unreasonable travel impacts family, work and income, highlighting how deprivation compounds unequal access to treatments.
- As a result of logistical challenges, patients will sometimes choose or be offered a less optimal treatment;[61] an outcome corroborated by **two-thirds** of centres providing or referring patients for CAR-T, who say that there may be inequalities in referrals, including those at a distance from a specialist centre.[77]

A critical barrier to addressing these inequalities is the inadequacy of available data. Current data collection methods often fail to capture details that would reveal intersectionality across these social factors, making it difficult to establish a clear picture of how these factors specifically contribute to disparities in blood cancer care.

Without robust data, we cannot begin to address the root cause of existing inequalities or monitor the effectiveness of initiatives aimed at reducing them.

IN SUMMARY

By improving data collection, engaging communities, and ensuring equitable access to healthcare services for people with blood cancer, we can make sure everyone, regardless of background, has the opportunity to access optimal care.

Attributions

Survey, interviews & focus groups

Some of the insight featured in this report comes from a 2024 survey commissioned by Blood Cancer UK and conducted by Supernova. 535 people from all four nations of the UK responded to the survey, made up of 475 people with blood cancer in the UK diagnosed within the last five years and 60 people who care for someone aged 18 or over with blood cancer who received their diagnosis within the last five years. Respondents were recruited to the online survey via Blood Cancer UK's database and link sharing.

Additionally, Supernova conducted 24 interviews with blood cancer consultants and nurses to learn more about their experiences of delivering blood cancer care across the UK.

The insight was complemented by four focus groups run by Blood Cancer UK between November 2023 and February 2024 with blood cancer healthcare professionals and people living with blood cancer, diagnosed in the preceding four years.

Data from the Primary Care Epidemiology Team at Oxford

Data sources & methods (for the social deprivation graph on page 14)

Welsh cancer survival rates by deprivation were retrieved from published estimates available here, where methodology is also provided: **https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/cancer-reporting-tool-official-statistics/cancer-survival/cancer-survival-documents/cancersurvivalwales-datatables-2002-2020-xlsx/** All other estimates were from data extracted from the cancer registry.

In Wales, myeloma was defined by ICD-10 C90. For other nations, cancer types were classified according to the HAEMACARE-25 classification scheme.

Cases diagnosed from 1 Jan 2016 to 31 Dec 2019 for all except Wales, where diagnoses were from 1 Jan 2015. Cases were followed up for death until 31/12/2022 (Scotland, England), 31/03/2023 (Wales).

Survival estimates were age-standardised according to International Cancer Survival Standards (ICSS). Error bars represent 95% Confidence Intervals.

We discourage comparison of deprivation gradients between nations because (i) each nation uses a different deprivation index and quintiles of these are not comparable; (ii) different types of life tables were used for each analysis. All life tables were age, sex, and calendar-time specific. Life tables in Scotland and England were additionally stratified by deprivation quintiles.

Attributions

This study has received research ethics approval under the Central University Research Ethics Committee (CUREC) with reference R90783/RE001.

This project involves data derived from patient-level information collected by the NHS, as part of the care and support of cancer patients.

The English hospital, cancer and mortality data are collated, maintained and quality assured by the National Disease Registration Service which is part of NHS England. Access to the data was facilitated by the QResearch Trusted Research Environment and the NHS England Data Access Request service. The QResearch ethics approval is by the East Midlands-Derby Research Ethics Committee [reference 18/EM/0400]. NHS England bears no responsibility for the analysis or interpretation of the data.

The authors would like to acknowledge the eDRIS team (Public Health Scotland) for their support in obtaining approvals, the provisioning and linking of data and facilitating access to the National Safe Haven. Approval to access data from Scotland was granted by the Public Benefit and Privacy Panel for Health and Social Care (PBPP), project number 2324-0146.

Statistics from Wales were produced by the Welsh Cancer Intelligence and Surveillance Unit, Data, Knowledge and Research Directorate and Public Health Wales.

CONCORD

For further information about data quality control, methodology and survival estimates for the countries shown in the graphics and other countries, please see the **CONCORD-3 summary article**.[13] An extensive set of additional tables, maps and graphics is available in a **270-page web-appendix**.

To find further data from the CONCORD team, please scan this QR code.

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Because together we will beat blood cancer

To discuss this report and its findings, please contact policy@bloodcancer.org.uk.

We're here to support anyone personally affected by blood cancer. Get in touch if you have a specific question, or just want to talk through how you're feeling.

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On the front cover: Trish, living with multiple myeloma, a type of blood cancer

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