

**Blood  
cancer  
UK**



**Raise the profile  
reduce the harm**

Blood cancer is the fifth most common cancer, but low awareness means people affected are paying the price.

**If you're worried about blood cancer, you can speak to our team of support services nurses via 0808 2080 888 or [support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk).**

**Or if you're interested in the research and other findings featured in this report, see page 44.**

**For any other questions email [brand@bloodcancer.org.uk](mailto:brand@bloodcancer.org.uk)**

**We've been held back by the lack of political focus, delayed diagnoses, and not knowing about the benefits, services and support available to us. Blood cancer is the fifth most common cancer in the UK, and more critically the third biggest UK cancer killer, yet current awareness levels mean we're constantly overlooked.**

There is also the psychological impact of it. There are 40,000 people diagnosed with blood cancer every year, yet it remains the hidden cancer. This means that, too often, people like us don't feel that others understand what we're going through or treat our condition as seriously as they should.

While research is the only way we'll get new treatments, greater public understanding of blood cancer would make life better for those living with it. And we are only asking for the same thing that is the case with other cancers.

We believe that people with blood cancer deserve better. That's why we are supporting Blood Cancer UK's efforts to make blood cancer as well known as the other common cancers such as bowel, breast, lung, or prostate.

The task of raising public awareness of blood cancer will be difficult, and one that we will only manage to achieve through the combined efforts of many thousands of people. Our hope is this report will convince you to become one of them.

But we hope you don't stop at just reading it, there are actions you can take as someone with influence today:

1. Amplify the message – Make sure everyone knows that blood cancer is the fifth most common, and third biggest cancer killer in the UK, by sharing and retweeting our work around raising the profile of blood cancer to your own audience.
2. Advocate for the inclusion of the phrase “a type of blood cancer” in conversations and literature.
3. Ensure people with blood cancer know what support and services they are entitled to.
4. Ask the Government to ensure blood cancer is specifically considered in their cancer plans and targets.

*Franko, Louise, Paul  
and Yvonne*

# People with blood cancer deserve better

Despite being the fifth most common cancer and the third biggest cancer killer in the UK, blood cancer doesn't have anything like the public profile of the other four common cancers.

And it's not just the general public who have a lack of awareness when it comes to blood cancer – many of those affected don't understand the scale of blood cancer, or even that the condition they are affected by is a type of blood cancer.

This means blood cancer is an outlier among the common cancers, and this lack of awareness is causing ongoing harm to people affected by it. In fact, 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.

**We believe there are five reasons why we need to raise the profile of blood cancer...**

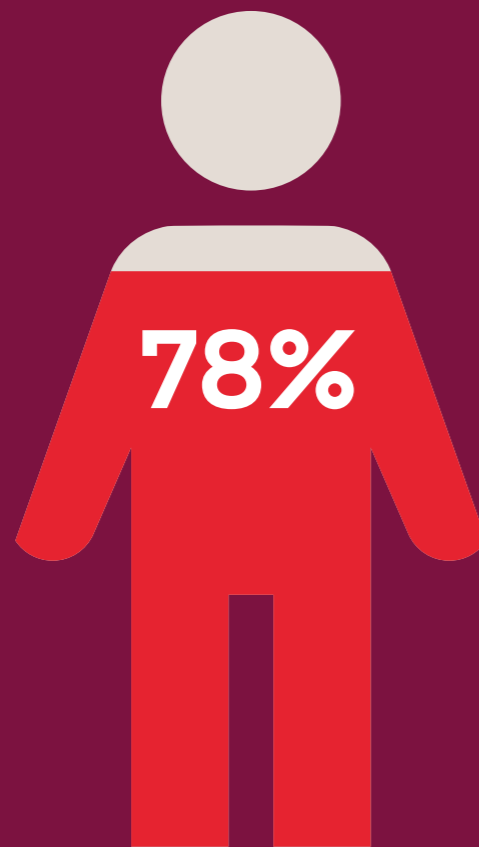
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**To reduce the harm, we must raise the profile, and we must continue to unlock research breakthroughs.**

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# 01 Because blood cancer doesn't get enough political focus

78% of people with blood cancer describe blood cancer as a hidden cancer.



## **Increasing awareness of blood cancer will be vital for improving treatment and saving lives.**

Blood cancer is the UK's third biggest cancer killer, but despite all the research breakthroughs over the last few years there is a postcode lottery for survival rates, and the UK overall survival rate lags behind those of other high-income countries.

However, while great progress in developing treatments over the last few decades has been made, too many people are still dying, and yet blood cancer does not get the same level of political focus as other common cancers.

For example, the NHS Long Term Plan does not consider the NHS blood cancer workforce, because people with blood cancer are often treated in haematology wards rather than oncology wards. Also, as many blood cancers cannot be staged, it falls outside of staging and diagnosis targets, and the data for blood cancer in the national cancer registry is much patchier than for other types of cancer.

One of the reasons for this is that leukaemia, lymphoma, myeloma, MDS and MPN are often seen as separate diseases, so it often does not feature highly among the list of the most common cancers.

This means the real impact of blood cancer is hidden in the way the statistics are reported. This is one of the reasons that while blood cancer leads to more deaths than breast cancer or prostate cancer: it does not get the same level of attention. We believe this is why 78% of people with blood cancer think it is a hidden cancer, and 42% feel that they are invisible.

This lack of political focus is acting as a handbrake on progress towards improving services and reducing the number of avoidable deaths.

**Increased political focus will go a long way in ensuring people are diagnosed faster, and they are accessing the support and services available to them.**

Right now, almost a third (31%) of people with blood cancer have to go to their GP three or more times before being diagnosed, while 58% of people with blood cancer are unaware of the support services available to them.

With 84% of our survey respondents agreeing that blood cancer doesn't get the same political focus as other cancers, it's clear that something must change.

**“I was diagnosed with a leukaemia called chronic myeloid leukaemia (CML) in A&E. CML is quite different from other leukaemias and other types of blood cancer, as it’s a chronic condition I’ll be living with for the rest of my life.**

I joined Blood Cancer UK’s policy panel, because I want politicians to make a difference not just for those living with blood cancer but also for all those people who are yet to be diagnosed. I’m really keen to keep raising the profile of blood cancer within Parliament, because politicians have a responsibility to ensure we get the best healthcare possible.

More political focus could bring greater attention to blood cancer symptoms, which are often non-specific, and need greater recognition from the public and GPs. This is particularly important because many blood cancer patients are getting diagnosed in A&E – which is what happened to me.

The ongoing lack of political focus on blood cancer has affected many of us in the community. I know many struggle to access therapies, new innovations and treatments, or even clinical trials based on where they live rather than clinical necessity. As a blood cancer community we deserve equitable access no matter where in the UK we live.

Blood cancer deserves the same attention as the other ‘high profile’ cancers. Blood cancer is the fifth most common cancer in the UK, and more critically the third biggest UK cancer killer which makes it difficult to accept being classified under the generic ‘other’ category.

Blood cancer needs to stop being separated into leukaemia, lymphoma and myeloma classifications. If we’re all under the banner of blood cancer – which we are, it’s all cancer of the blood system after all – that gives us a much more powerful base to combat it and raise awareness of it. Breast cancer has more than 15 different varieties, but we only refer to it as breast cancer. We need to start doing the same with blood cancer. We will never feature on any politician’s radar if we are always grouped in the ‘other’ category.”

**Paul, who lives with chronic myeloid leukaemia (CML)**



**Blood cancer deserves the same attention as the other ‘high profile’ cancers. Blood cancer is the fifth most common cancer in the UK, and more critically the third biggest UK cancer killer which makes it difficult to accept being classified under the generic ‘other’ category.**

**If the Government and NHS leaders focus more on blood cancer, treatments and outcomes will improve.**

**During the Covid pandemic, we've seen the transformative difference it can make when blood cancer is looked at as a whole.**

Everyone with blood cancer was considered part of the same group because they were all at higher risk from Covid, and we were able to successfully campaign to change the vaccine priority list; to improve access to priority supermarket slots; and to improve roll-out of vaccines for the immunocompromised.

Speaking on behalf of everyone with blood cancer meant we had a much louder voice than if we had just been speaking on behalf

of people with leukaemia, lymphoma, or myeloma. The same thing will happen if we're able to group data about these conditions together as 'blood cancer' data.

By raising awareness of blood cancer as a common cancer, we can also raise awareness of the deaths that could be avoided. This will put pressure on the Government and NHS to make the changes needed to ensure our survival rates don't continue to lag behind other high-income countries.



Image via: <https://members.parliament.uk/member/4370/portrait>

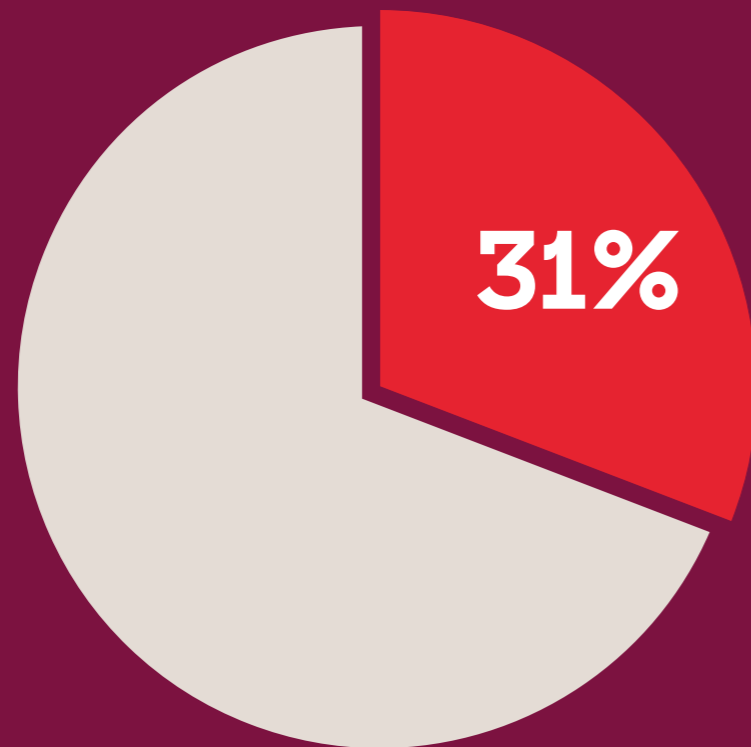
My dad was diagnosed and now lives with a blood cancer, which is why I'm proud to use my platform as an MP to amplify the voices of the blood cancer community. But too few in Parliament understand that blood cancer is the fifth most common cancer and third biggest cancer killer in the UK. This has to change.

**Jess Phillips MP, Chair of the All Party Parliamentary Group on Blood Cancer.**

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# 02 Because people are less likely to be diagnosed quickly

31% of people with blood cancer have to go to their GP three or more times before being diagnosed.



## Lack of awareness of blood cancer symptoms among both the public and healthcare professionals is leading to late diagnoses and avoidable deaths.

The Cancer Patient Experience Survey shows that 16% of people with blood cancer wait at least three months between first thinking something might be wrong and seeking medical attention, and one in 30 of them wait over a year.

We believe that the lack of awareness of blood cancer, and by proxy blood cancer symptoms, is one of the reasons for this. We know that half of UK adults cannot name a single blood cancer symptom; it stands to reason that if more people knew about blood cancer and its symptoms, more people would seek medical attention sooner, which would lead to quicker diagnosis and lives saved.

Then when people do reach out to their GP, they are often not diagnosed quickly enough. In fact, almost a third (31%) of people with blood cancer have to go to their GP three or more times before being diagnosed, whereas in breast cancer this figure is only 7%.

This delay is one of the reasons that 30% of blood cancer cases are diagnosed after presenting to the NHS as an emergency. This is compared with just 3% in breast cancer and 7% in prostate cancer.

**It's data like this which suggests to us that the general public and our healthcare system simply isn't as responsive when it comes to spotting blood cancer symptoms as they should be.**

We believe that the lack of focus on blood cancer holds back the awareness of blood cancer symptoms. By raising the profile of blood cancer, we hope to get people diagnosed sooner. So that people affected by blood cancer can enjoy more time with their families, rather than suffering the mental and physical toll delayed diagnoses cause. Ultimately, raising the profile of blood cancer could save lives.

**“I was diagnosed with Hodgkin lymphoma shortly after having my daughter. I originally saw my GP complaining of swollen glands in my neck. I knew lumps meant cancer, so I booked a GP appointment for the very next day, but my symptoms were dismissed.**

Looking back, I don't think they treated me with the urgency they should have because I don't think my GP understood the symptoms of blood cancer themselves. Plus, I don't think they really understood that it's prevalent in any age. Instead, they told me I was just a tired and hormonal new mum. Originally, I took them at their word that it wasn't cancer, because why would you not?

I didn't give up though, over the next eight months, I continued to attend my GP with a number of symptoms, and I was constantly told it wasn't cancer. So much so that when I eventually asked for my medical notes, I saw they had described me as a 'cancer phobic'.


In the end, I requested a private referral. In total my diagnosis took 11 months, but it would have taken much longer. Because of the ordeal I went through to get it, finally having an official diagnosis was a relief. Especially as I thought I was going crazy, as the GPs kept telling me it was all in my head and there was nothing to worry about.

Finding out what it was, and that it could be treated was a major turning point and a huge weight off my shoulders.

After being diagnosed late, my first line of treatment didn't work. So in the end, what was meant to be six months of chemo became 19 months of chemo as well as radiotherapy and other treatments. Plus, I had to have a donor bone marrow transplant, which could have been completely avoided had I been diagnosed sooner.

Late diagnoses also take a toll on our mental health. I was a new mum when I was diagnosed, which meant I wasn't around for a huge chunk of the early years with my kids. That makes me angry, but by far the thing that riles me up the most is that I'm one of the lucky ones, I'm still here to see my children grow up, but for many a late diagnosis means they don't start treatment in time. It's infuriating that we've made no progress speeding up diagnoses, that's why we need to raise the profile of blood cancer and its symptoms.”

**Louise, who is in remission from Hodgkin lymphoma**



**After being diagnosed late, my first line of treatment didn't work. So in the end, what was meant to be six months of chemo became 19 months of chemo as well as radiotherapy and other treatments. Plus, I had to have a donor bone marrow transplant, which could have been completely avoided had I been diagnosed sooner.**



**For many people,  
the sooner they  
are diagnosed, the  
better their chance  
of surviving.**

**Research breakthroughs over the last few decades mean that there are now better treatments for blood cancer than ever before. But for these to be effective, in many cases, it's vital that people get treatment as quickly as possible.**

We believe that to get people diagnosed quickly, we must raise the profile of blood cancer and by proxy its symptoms. Among both the general public and healthcare professionals, we are much more likely to be able to raise awareness of the symptoms of blood cancer, rather than the multiple symptoms of each different type of blood cancer.

We can also get more awareness by talking about blood cancer, which affects 40,000 people a year in the UK, as opposed to talking about many different types of blood cancer, which each affects a relatively small number of people each year.

If we all familiarise ourselves with the symptoms of blood cancer...

- Unexplained weight loss
- Unexplained bruising or bleeding
- Lumps or swellings
- Shortness of breath
- Drenching night sweats
- Persistent, recurrent or severe infections
- Unexplained fever
- Unexplained rashes or itchy skin
- Pain in your bones, joints or stomach
- Fatigue
- Paleness

...We can not only be our own advocates, but allies to people affected by blood cancer, so that no one leaves it too late to go to the GP, and when they do go, they're given the tests and treatment they need with no delays.

Raising awareness of common symptoms, will enable people to advocate for their own health, and ensure GPs have blood cancer embedded into their brains so no matter how small the symptom it registers as a red flag worth investigating.

**Heidi Smith, Support Services Nurse, Blood Cancer UK**

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# 03 Because people are less likely to understand what is wrong with them

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



**For people with blood cancer to process their diagnosis and take back control over their health, it's vital for them to understand what their diagnosis actually is.**

Yet the Cancer Patient Experience Survey shows that people with blood cancer are less likely to leave their diagnosis fully understanding what is wrong with them compared to people with other types of cancer. In blood cancer, just 68% fully understand their diagnosis, compared to 81% of people with breast cancer or bowel cancer.

There are a number of reasons for this, not least that blood cancer is a complex disease. These are terms derived from Latin and Greek, which do not give any sense of what is going wrong in the body, whereas 'blood cancer' is something most people can understand.

**One thing that would aid understanding would be if people were told their condition is a type of blood cancer - rather than being left to make sense of terms like leukaemia, myeloma or lymphoma.**

Yet despite 88% of people affected by blood cancer agreeing that people should be told they have a type of blood cancer at diagnosis, three quarters (76%) of people with blood cancer say they were not told this at diagnosis.

Our survey suggests that 19% of people living with blood cancer have still never been told they have blood cancer by a healthcare professional. Even worse, 6% of people who completed our survey found out for the first time that they had a blood cancer diagnosis in the survey itself, while 2% found out they had a type of cancer.

The likelihood of people finding out via our survey that they had a type of blood cancer doubled for the over 85s (8% vs 4% of 45-55s), those with a secondary level education (8% vs 4% undergraduate degree level), those with a below-average income (8% vs 4% above-average income), and those who classify themselves as an ethnic minority (14% vs 6% who classify themselves as white).\*

This is a situation unique to blood cancer, as people affected by the other four common cancers - breast, lung, bowel, and prostate - have their condition explained to them as a cancer at the very beginning.

**“I was diagnosed with a type of blood cancer called myeloma. At that point, I had no idea what myeloma was. And nobody explained to me that it was a type of cancer. I had no idea what treatment was involved with it, and what was likely to happen to me, because nobody sat down to explain it to me.**

It wasn't as if I was despondent and not listening to what the doctors were telling me. If anything, it was the opposite. I really wanted someone to sit me down and tell me absolutely everything, but instead it felt like they were always talking at each other using medical language, and I was just a guest in their conversation about me.


The diagnosis penny only dropped after I'd had 3 MRIs, a CT scan and a PET scan and was told I was going for radiotherapy the next day, it was only after all of these tests that someone eventually said, 'oh by the way, myeloma is a type of cancer' I don't remember if they said it was a type of blood cancer. I don't imagine they did as the conversation was so brief. It made me feel alone and isolated, I definitely didn't feel like a human being, just a patient on their tick list.

Eventually I had to sit down and look 'myeloma' up and see what was going on myself, because nobody sat down and explained it to me. Dr Google is a very scary person to find out your life expectancy from. Luckily for me, my search results were the worst-case scenario, but I didn't know that when reading every word over and over again. Having a healthcare professional sit me down and talk about these things would have changed my whole experience.

That's why I now volunteer for Blood Cancer UK on their forum. As unfortunately so many of us are left with questions after our diagnosis. By answering people's questions and putting their mind at ease, in many ways I'm trying to fill the knowledge gap I was left to deal with alone when I was initially diagnosed.

Raising the profile of blood cancer so it's as well known as the other cancers will be a huge step forward in ensuring no one feels left to figure out their diagnosis by themselves.”

**Franko, who is in remission from multiple myeloma**



**Eventually I had to sit down and look 'myeloma' up and see what was going on myself, because nobody sat down and explained it to me. Dr Google is a very scary person to find out your life expectancy from.**

**Understanding  
your condition, for  
many, can be the first  
step towards regaining  
a sense of control.**

**Making sure everyone affected by blood cancer knows that their condition is a type of blood cancer may not completely solve the problem of people not understanding their diagnosis, but it would be a big step in the right direction.**

It is a step change that many are already calling for – 80% of people with blood cancer and 84% of healthcare professionals agree this is needed.

We believe there are four critical stages of being diagnosed in which the term “blood cancer” should be used:

1. the conversation where the person is told they have the condition;
2. the follow-up conversation with nurses that happens after diagnosis in many (but not all) cases;
3. the health information, both online and offline, which the person is signposted to;
4. the follow-up diagnosis letter the person gets confirming their diagnosis.

We have heard from some healthcare professionals that they sometimes avoid using the term “blood cancer” for fear of causing unnecessary distress. But our research shows that many people who are not told this at diagnosis go on to learn this later, with 13% of people with blood cancer finding out via either the internet or a health information booklet.

This issue is particularly important for helping overcome existing health inequalities, as our research suggested that people affected by blood cancer who were of Asian, black, mixed or other ethnic origin were almost twice as likely to find out that the condition they were affected by was a type of blood cancer via the internet.

Finding out you have a type of blood cancer is always going to be hard, but it’s much better that people hear it from a healthcare professional, who can set the context for people’s individual condition, and answer any questions or concerns.

If our newly diagnosed patients are not told they have blood cancer, they can become alarmed when they later discover that they do. Having a complete diagnosis allows the patients to understand their treatment options along with areas of care and support they may need.

**Gemma Trout, Senior Support Services Nurse, Blood Cancer UK**

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# 04

## Because people are less likely to access the support and services they need

58% of those with blood cancer were not aware of ANY support potentially available to them when diagnosed.



58%

**In many cases, people are not only unaware their condition is a type of blood cancer, but they do not even know it is a type of cancer.**

Our survey of people with blood cancer suggested that at the point of diagnosis 58% of them were not aware of any potential support that might be available to them.

Any cancer diagnosis can cause financial hardship, but unfortunately, the data tells us that a blood cancer diagnosis is more financially costly than other types of cancer.

Yet despite this, just a quarter (25%) of people with a diagnosis were aware of help with health costs (such as free prescriptions), only 15% knew they were entitled to larger financial benefits (such as PIP, ESA and Carers Allowance), while only 9% knew that their blood cancer diagnosis made them eligible for one-off grants and loans to help with the extra costs cancer can cause. We also found that awareness was even lower for those on a below-average income – the very people who could benefit the most from accessing the financial help they are entitled to.

And it's not just financial benefits people weren't aware of: only 12% knew they have legal protections under the Equality Act – information that could help many people in discussions with their employer.

We've also heard from our community that they've been turned away from cancer support services, because those running them don't recognise certain types of blood cancer as being a cancer.

Raising awareness of blood cancer could help address this. In our survey, 45% of people with blood cancer believe that lack of awareness of blood cancer is making people less likely to access the support and services they need.

**We know that our services make a huge difference to people's lives, giving them a sense of ownership and control over the condition. But people are less likely to use these services if they do not know that their condition is a type of cancer or blood cancer.**

**“Unfortunately, one of the things we find on the support services team at Blood Cancer UK, is that people affected by blood cancer don’t realise what support and services are available to them, or even worse, they don’t realise that as a cancer patient they are entitled to these services.**

When people do find us, we often hear ‘oh I wish I knew about all of this sooner,’ be that financial aid which could have helped pay the bills, employment protections which would have helped in discussions with HR, access to dieticians and physiotherapy, counselling and alternative therapies like massage, as well as simple things like free wigs, parking and prescriptions, as even the little things can make a big difference.

At the moment, we have a lot of people come through the support line who are struggling financially and just don’t realise that there is help available to them. Unfortunately, this has been increasing recently due to the cost of living crisis. Blood cancer can put such pressure on people’s finances. For instance, having to reduce working hours due to the ongoing toll of treatment and side effects, not to mention travelling to appointments, hospital car parking, and prescriptions. As many blood cancers are chronic conditions,

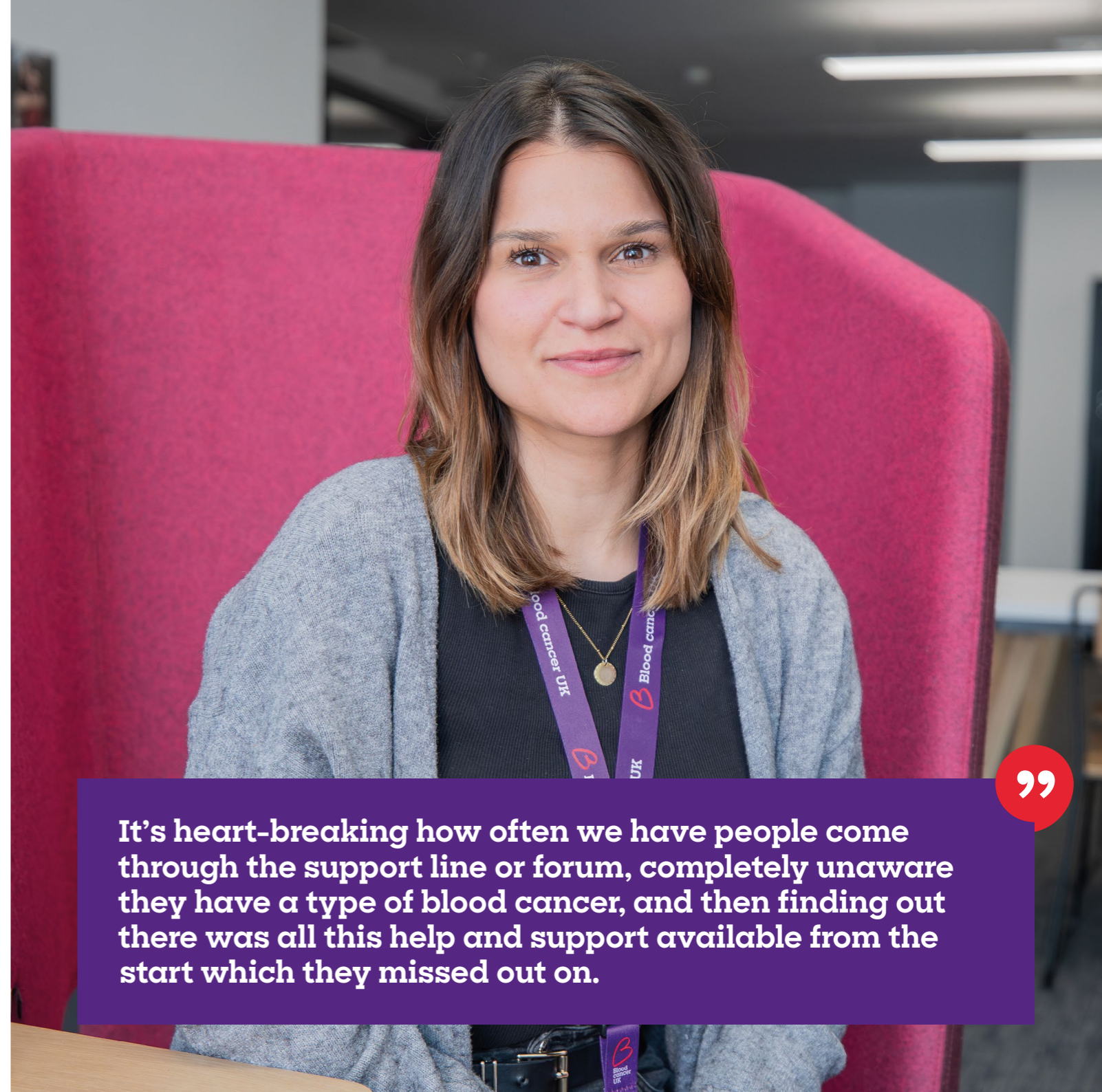
these additional costs will be with people for life – so it really does add up.

Understandably this can be really hard and anxiety inducing for people, no matter their circumstances. We have people on all sorts of income levels call us because they can’t sleep at night and are worried about how they’re going to pay the bills, as it’s simply not clear that there’s help available to them – be that in the form of benefits, eligibility for freebies, or one-off grants for health-related costs.

It’s heart-breaking how often we have people come through the support line or forum, completely unaware they have a type of blood cancer, and then finding out there was all this help and support available from the start which they missed out on.

It seems that the word ‘cancer’ is the key to unlocking the support, services and benefits that the blood cancer community is entitled to. This is why we simply have to raise the profile of blood cancer, so everyone knows that their individual diagnosis is in fact a type of blood cancer, and that they’re not just eligible but entitled to help which can put their mind at ease and improve their quality of life.”

**Alice Randall, Senior Digital Support Services Officer, Blood Cancer UK**



**It’s heart-breaking how often we have people come through the support line or forum, completely unaware they have a type of blood cancer, and then finding out there was all this help and support available from the start which they missed out on.**



**By raising awareness  
of blood cancer, we  
can help people get the  
support they need.**

**There is a lot of support available to people with blood cancer to help them as they adjust to their condition, whether that is financial, legal or someone to talk to.**

Making blood cancer as well-known as other common cancers could help unlock that support for the people who need it. That could help lead to less financial hardship for people with blood cancer, and more protection against things like discrimination at work.

As a charity that delivers support services, we know the important role that our services, and the services run by other charities, play in helping people with blood cancer manage their condition and access support that improves their quality of life.

But the stark fact is that these services are not reaching enough people and our own experience tells us that it is often people from ethnic minority groups, in particular, who are missing out.

The more we can increase awareness of blood cancer, the more people will know about the support available to them.

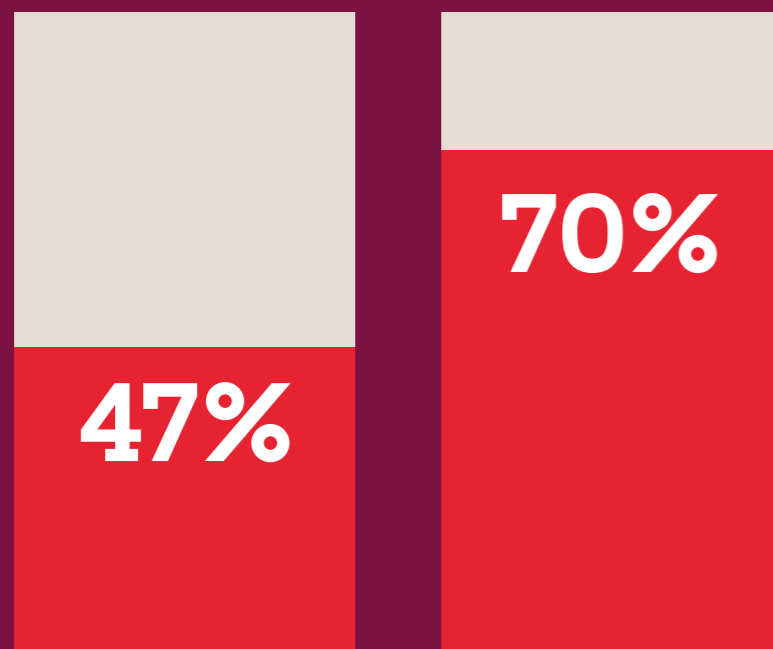
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We know that often the information given by a person’s medical team is focused on the condition itself. Sadly, there is less emphasis and less time available in appointments to talk through other types of support and how families can access these support services at any stage.

**Gemma Trout, Senior Support Services Nurse, Blood Cancer UK**

# 05

## Because people are missing out on being part of a supportive community

47% of people with blood cancer do not feel part of any community, despite 70% saying this is important to them.



**When people are diagnosed with blood cancer, they are often told they have a subtype such as chronic lymphocytic leukaemia or follicular lymphoma. This leads to them thinking their condition is relatively rare.**

As a result, people do not know there is a large community of people who are going through similar experiences – when in reality, there’s roughly 280,000 people living with or in remission from blood cancer in the UK.

Our survey showed that 47% of people with a blood cancer diagnosis do not feel part of any community – be that their sub-type condition (e.g. lymphoma), the blood cancer community, or even the cancer community. Yet 70% say this is important to them.

And for people affected by blood cancer who are of Asian, black, or mixed ethnicity, finding a supportive community is even more likely to be important (75% vs 63%). With the proportion of these people saying it was extremely or very important to them being almost double that compared to people from a white background (49% vs 29%).

While there are important nuances between the different types of blood cancer, and each person’s circumstances are unique to them, there are also lots of similarities in experiences between types of blood cancer.

For example, many of the blood cancer community experience problems getting diagnosed quickly and suffer the psychological impact of this later.

Also, people with blood cancer are more likely to need chemotherapy or be put on watch and wait. Similarly, people with blood cancer’s weakened immune system means they are more likely to wrestle with the social and mental impact of shielding.

All of these things and many more unite people across the blood cancer community.

**By considering leukaemia, lymphoma and myeloma as different conditions, we risk people missing out on the benefits of building supportive relationships with others going through similar experiences, and of being part of a larger community that they can draw strength and comfort from.**

We believe the lack of awareness of blood cancer is stopping people from knowing the support they need is readily available.



**“When I was first diagnosed with AML, I didn’t think I needed a support network. I was simply getting my head around the diagnosis and the treatment. But when my treatment ended, I realised I would find it really beneficial to connect with people who knew what I was going through and what I’d been through.**

So I joined a network for people living with or in remission from different types of blood cancers, including leukaemia, myeloma and lymphoma. And it’s one of the best things I’ve ever done. Initially, I didn’t know any other adult with leukaemia, I thought leukaemia was something only children got. I definitely hadn’t heard of blood cancer. So knowing there was a like-minded community out there was a turning point.

Looking back, I now wonder if it would have been helpful to have my support network from the beginning of my blood cancer journey, as despite our different diagnoses, we have so much in common, and we really support each other through the good and the bad.

I think it’s really important that the support networks are representative, not only of different types of blood cancer, but also a diverse range of people within the community as well. Especially, as we

know that cancers don’t discriminate by any means. One of the things that I was really passionate about when joining a community was the importance of diverse representation.

Having said that, I am the only black person in our support group. But actually, in the grand scheme of things that doesn’t matter, because the commonality that comes through is we’ve all had a lived experience of a blood cancer, and that’s the thing that binds us, irrespective of where we come from, what our beliefs are, what our culture is. Our shared lived experience is irrespective of our backgrounds. And that has been really powerful for me. I’m so grateful for the connection I’ve made with those people. It’s a connection so powerful it’s turned strangers into family.

I do wonder that if more people knew they had a type of blood cancer, as opposed to just their specific condition, maybe more people from all walks of life would realise a wider support network is ready and waiting for them. By raising the profile of blood cancer, I hope everyone can access a community that lifts them up, and makes them feel seen, no matter who they are or what condition they have.”

**Yvonne, who is in remission from acute myeloid leukaemia (AML)**



**Looking back, I now wonder if it would have been helpful to have my support network from the beginning of my blood cancer journey, as despite our different diagnoses, we have so much in common, and we really support each other through the good and the bad.**

**At Blood Cancer UK, we have shown what can happen when people affected by blood cancer join together as a community.**

**Our online forum is a brilliant example of how people affected by blood cancer can get vital support from people who are going through the same things.**

One of the best things about the forum is that it is often people with one type of blood cancer giving support to someone with another type of blood cancer.

We also know that when it comes to getting support from other people going through the same thing, it often works best when people are a similar age, from a similar background, or live in the same area. With a community of hundreds of thousands of people with blood cancer, people are much more likely to find the right support for them.

And when we do come together as one entire blood cancer family, we're not just more likely to uplift one another, but we're more likely to amplify our collective voice so that people take note and listen to the needs of all those who are part of the blood cancer community.

Plus, the more people with blood cancer who join together as one community, the more money we will raise for research, and quicker we will reach the day when blood cancer is finally beaten.

We often hear from people who feel isolated in their experiences and want to connect with others. But it can be a challenge to find support when someone's condition does not contain the words 'blood cancer'. People might search for their specific condition and therefore miss out on the connection and support from others in the blood cancer community. Especially when there are many shared themes and experiences across the different types of blood cancer.

**Tanya Kumar, Support Services Officer, Blood Cancer UK**

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# To reduce the harm we must raise the profile and continue to unlock research breakthroughs

As despite our efforts, blood cancer remains the third biggest cancer killer in the UK.

**3rd** more than 16,000 blood cancer deaths each year

2nd

1st

**At Blood Cancer UK, our mission is to beat blood cancer. We can only achieve this by raising the profile of blood cancer and funding research to bring forward the day when no lives are lost.**

But despite huge progress through joint research efforts, 15,000 people in the UK still die of blood cancer every year, and there are many more who are counted as “surviving” but still die as a result of blood cancer or from the effects of their treatment, sometimes many years later. Ultimately, our mission to beat blood is being blocked by the low profile and splintered perceptions of blood cancer.

Because without people with direct experience of blood cancer knowing it’s blood cancer, we’re missing opportunities to dramatically grow investment and support for exciting research innovations. Such as, disease pathways that look at how diseases develop so we can prevent them, CAR-T and cellular therapies, genomic medicine, and how to improve diagnosis. As these breakthroughs simply aren’t happening fast enough.

Ultimately, without the greater understanding of blood cancer we’ve described in this report, we can’t unlock vital funding, which means it will take longer to get to the day when blood cancer is beaten.

**“I’m a Professor of Tumour Virology at the University of Sussex. My research team works on a virus called Epstein-Barr virus, which causes certain types of blood cancer.**

I have been funded by Blood Cancer UK since 2012. During that time, we’ve been trying to understand the ways in which the virus that we work on causes blood cancer.

The more research that we can do to understand the pathways involved in turning a cell cancerous, the better treatments and outcomes we can unlock for people with a diagnosis.

One of the things I love about working with Blood Cancer UK, is the fact that you have an opportunity to become part of a community, where it is possible to meet fundraisers many of whom are themselves affected by blood cancer.

It’s incredibly motivational to talk to those people. I really enjoy experiencing their drive and determination first-hand. Some of the fundraisers I’ve met have given up huge amounts of their time, done amazing fundraising events, and raised lots of money as a result. To know that somebody is doing

that on behalf of your research is so inspiring and humbling. I think it really helps you to appreciate the funding that you receive and to try to make the absolute most of it.

That’s why I think it’s so important to shine a light on the key discoveries that are being made in the blood cancer field, so that people know where the funding is going and what impact the funding has, and how that can take us one step closer to beating blood cancer.

But to do that, we need to raise the profile of blood cancer, because blood cancer is the third biggest cancer killer and most people aren’t aware of that. By publicising the fact that a range of conditions such as leukaemia, lymphoma and myeloma are all blood cancers, we can raise the profile of blood cancer as a whole. This will help us direct our efforts into raising more money to fund more lifesaving research.”

**Michelle West, Professor of Tumour Virology, University of Sussex**



**The more research that we can do to understand the pathways involved in turning a cell cancerous, the better treatments and outcomes we can unlock for people with a diagnosis.**

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**We're at a turning point: thanks to breakthroughs we've already funded.**

We can see real potential for research that will stop people dying from blood cancer within a generation, which is why we're doubling our fundraising efforts to bring this day closer.

If there is one thing our community has proved time and again since we were founded in 1960 it's this: funding research into blood cancer leads to breakthroughs that save lives.

Childhood leukaemia is an example of this. When our charity was started, just 1 in 10 children survived. Today, that has increased to 9 in 10. And we have seen big increases in survival in common types of blood cancer such as chronic lymphocytic leukaemia and myeloma.

The more that blood cancer is seen as a common type of cancer, in the same way that breast cancer and prostate cancer are, the more people will join the cause of funding the research that will finally beat it. And the more success stories we can have across the blood cancer spectrum.

For instance, the increased profile of prostate cancer as a health issue over the last 15 years has led to a big increase in funding for this type of cancer. We need to learn from this and do the same for blood cancer.

After all, our progress to date has been incredible, imagine what we can achieve with the right profile!

As a charity, we have ambitious plans to double the amount we're investing in research in the next five years. Delivering on that will save a significant number of lives and take us closer to the day when blood cancer is finally beaten.

But we are unlikely to achieve this unless more people and organisations help us get blood cancer much more widely understood than it is at the moment.

Research breakthroughs require time and money. But we're in a race against time, so we need to double our fundraising efforts. The more money we raise, the more researchers we can fund, and the faster we'll get the breakthroughs we need.

**Sarah McDonald, Deputy Director of Research, Blood Cancer UK**

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# What can you do to help raise the profile of blood cancer?

We hope this report has convinced you that raising public awareness of blood cancer will make a significant positive difference to the lives of people affected by it.

This is why at Blood Cancer UK we are on a mission to get blood cancer recognised as one of the five most common cancers.

But we can't do it on our own.

Like everything else we've ever achieved as a charity, delivering this change will depend on the efforts of the thousands of people who come together for a common cause. So, if you're reading this and are asking if you can help, the answer is yes.

If you're part of the blood cancer community here are five things you can do TODAY to help us raise the profile of blood cancer:

1. If you're affected by blood cancer, when you're talking to friends and family about it, consider adding six words : 'It's a type of blood cancer'.
2. If you know healthcare professionals who treat people with blood cancer, ask them if they tell their patients that their condition is a type of blood cancer. And if they don't do this regularly, talk to them about the positive difference this can make.
3. Tell your friends that blood cancer is the UK's fifth most common cancer, and that leukaemia, lymphoma and myeloma are all types of it.
4. Use whatever platform you have to help us spread the message. Whether it's talking about it on social media, putting it up on a local noticeboard, or writing to your MP, every small action we take to spread the message will add up to transformational change.
5. Sign up to our e-newsletter on our website at [www.bloodcancer.org.uk](http://www.bloodcancer.org.uk). It will include all the latest news about our campaign on this, so it's the best way to learn about new ways you can help.

Or perhaps you're a Parliamentarian, a healthcare professional, a researcher, or simply interested in raising the profile of blood cancer. You can help by:

1. Amplifying the message – Make sure everyone knows that blood cancer is the fifth most common, and third biggest cancer killer in the UK, by sharing and retweeting our work around raising the profile of blood cancer to your own audience.
2. Advocating for the inclusion of the phrase "a type of blood cancer" in conversations and literature.
3. Ensuring people with blood cancer know what support and services they are entitled to.
4. Asking the Government to ensure blood cancer is specifically considered in their cancer plans and targets.

# The survey behind the statistics

The majority of the insights featured in this report come from a 2023 study commissioned by Blood Cancer UK and conducted by market research agency Supernova.

In total, the online survey reached 2,571 people. This can be broken down into 1,442 people living with blood cancer, 1,059 with a personal connection to someone with blood cancer and 70 healthcare professionals, including specialist doctors and clinical nurse specialists, who actively care for and treat people with blood cancer.

The anonymous survey covered a variety of topics including but not limited to: how people talk about blood cancer; the language of healthcare professionals; the need for and impact of category establishment; awareness of the scale of blood cancer. We also asked questions which helped us understand the demographics and personal circumstances of survey participants.

Multiple sample sources were used to maximise reach and the demographic profile of the sample was allowed to fall out naturally to maximise the sample size; if a person was living with blood cancer,

had a personal connection to someone with blood cancer or was a relevant health care professional, they qualified to take part. The regional spread of the sample closely reflects what is representative for the UK and our sample also represents the spectrum of different types of blood cancer diagnoses.

We observed skews on gender and age relative to what we might expect to see UK wide and within the blood cancer community. Furthermore, despite multiple sample sources, we also observed some skews when looking at the ethnicity, income and education level of our sample.

That said our large sample size means we have the ability to look at subgroups within all of these metrics, ensuring all marginalised groups' voices are represented and included where differences of statistical significance exist (at the 95% confidence level). If any data is based on a sample size of less than 50, these have been called out for ease of reference.

## In addition to the statistics that came from this survey, we have also incorporated findings from other research into the report, as follows:

Key facts booklet, Blood Cancer UK, (2022)

- Blood cancer is the fifth most common cancer in the UK
- Blood cancer is the third biggest cancer killer in the UK
- 40,000 people are diagnosed with blood cancer every year
- There's roughly 280,000 people living with or in remission from blood cancer in the UK
- 15,000 people in the UK still die of blood cancer every year
- When our charity was started, just 1 in 10 children survived. Today, that has increased to 9 in 10.

Blood Cancer UK and YouGov Research, (2022)

- Half of UK adults cannot name a single blood cancer symptom

Cancer Patient Experience Survey (2021)

- 31% of people with blood cancer have to go to their GP three or more times before being diagnosed, whereas in breast cancer this figure is only 7%.
- 16% of people with blood cancer wait at least three months between first thinking something might be wrong and seeking medical attention, and one in 30 of them wait over a year.
- In blood cancer, just 68% fully understand their diagnosis, compared to 81% of people with breast cancer or bowel cancer.

Cancer Patient Experience Survey follow up survey, Blood Cancer UK and Anthony Nolan (2019)

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

Blood Cancer Data Dashboard (2019-2021)

- 30% of blood cancer cases are diagnosed after presenting to the NHS as an emergency. This is compared with just 3% in breast cancer and 7% in prostate cancer.

Burns, R. et al. (2016) 'Economic burden of malignant blood disorders across Europe: A population-based cost analysis', *The Lancet Haematology*, 3(8)

- A blood cancer diagnosis is more financially costly than other types of cancer.

Allemani, C. et al. (2018) 'Global surveillance of trends in Cancer survival 2000–14 (Concord-3): Analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries', *The Lancet*, 391(10125), pp. 1023–1075.

- UK overall survival rate lags behind those of other high-income countries.

\*The base size for those with blood cancer who classified themselves as Asian, black, mixed or another ethnic origin is 35 and the base size for those who self-classified as having a White background is 1397; the difference is statistically significant.

# Thank you

We'd like to thank everyone that made this report possible.

From the people who took the time to complete our survey, to those who so generously shared their stories with us all and agreed to be featured in this report - Paul, Louise, Franko, Yvonne, Michelle and Alice, we couldn't be more grateful!

We'd also like to thank all those at Blood Cancer UK and in the blood cancer community at large who have dedicated time and energy into shaping this very important work, as well as our trusted partners who have gone on this journey with us - including the wonderful team at Supernova Insight, and Cloud9 Media.

But most of all, we want to thank you for reading this report, and for helping us raise the profile of blood cancer, so that together we can reduce the harm the blood cancer community faces as a result of the ongoing lack of awareness.

**So, from all of us at Blood Cancer UK, thank you!**

**Because together  
we will be the  
generation that  
beats blood cancer**

**If you're worried about blood cancer, you can speak to our team of support services nurses via 0808 2080 888 or [support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk).**

**For any other questions email [brand@bloodcancer.org.uk](mailto:brand@bloodcancer.org.uk)**



# Raise the profile, reduce the harm.

To find out more about this project, or  
to donate to our ongoing efforts to beat  
blood cancer, scan the QR code.



**Blood  
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