Spotlighting the hidden cancer:

Improving standards of care for people living with blood cancer

This Briefing has been developed by Pfizer UK, in partnership with Blood Cancer UK through a consultancy agreement.

PP-UNP-GBR-9278 August 2024

Contents

Overview:

This Briefing has been developed by Pfizer Ltd with the help of blood cancer patient organisations and people living with blood cancer to bring together a single set of standardised principles for policymakers and regulators to act upon to improve standards of care and outcomes in blood cancer.

This Briefing works in tandem with our Patient Charter, which aims to give people with blood cancer information about what to expect from their care and help to empower them to seek the care and support they need.

Blood cancer is the fifth most common cancer in the UK, with over

41,000  new diagnoses every year, and

250,000  people living with blood cancer in the UK.[1]

There are 100 different types of blood cancer yet there is little awareness or understanding about the condition[1,2]. It is important that we spotlight this hidden cancer and make it more visible.

This Briefing recognises the current capacity and resource challenges facing the NHS workforce and its cancer services. Delivering the principles set out within this Briefing will only be possible by supporting and enabling NHS staff over a long-term basis to deliver the highest standard of care to people affected by blood cancer.

Principles:

Following extensive engagement, blood cancer patient organisations and people living with blood cancer informed us that the following six principles should be prioritised and addressed to improve standards of care, patient experience and outcomes in blood cancer. It is worth noting that these principles have been given equal importance and are not ranked in order of priority.

They are:

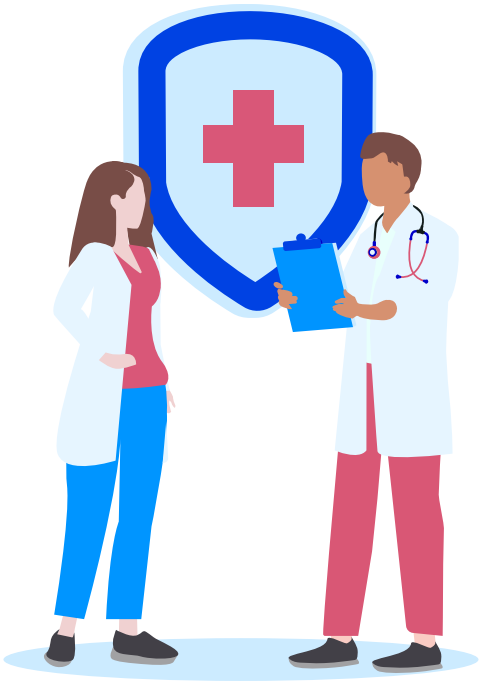
1. Blood cancer awareness
2. Shared decision making
3. Holistic and personalised care
4. Equitable access to treatment and support
5. Continuity in care and communication
6. Research and clinical trials

Next steps:

Firstly, we would like to thank you for making the decision and taking the time to read our Briefing.

We understand how hard policymakers, regulators and healthcare providers are working to deliver vital care and support to patients with blood cancer. We also acknowledge that there is an intention at a national level to improve services so that patients, including those with blood cancer have a better chance of living well with the disease. This is why we created this Briefing and the accompanying Patient Charter, to bring together insight and guidance on how we can better work together and deliver an improved experience and outcomes for those living with blood cancer.

If you are interested in discussing what more could be done or how we might deliver on some of these principles, please contact medical.information@pfizer.com.



1. Blood Cancer Awareness

According to research commissioned by Blood Cancer UK, over half of UK adults cannot name a single symptom of blood cancer[2]. This lack of awareness can impact negatively on people with blood cancer, including on their mental wellbeing if they are unable to share their concerns and worries with people around them[3,4].

A recent survey conducted by Blood Cancer UK found that, 45%  of people with blood cancer believed that lack of awareness of blood cancer is making people less likely to access the support and services they need, and to which they are entitled[19].

Poor awareness can also result in delayed diagnosis, with many not being able to recognise the symptoms and seek help when they need it[2]. When people are able to get diagnosed sooner their outcomes and experiences are improved, rather than suffering the mental and physical toll a delayed diagnosis may bring[5].

Raising public awareness of blood cancer is crucial. We must prioritise awareness in two groups: the general public and primary healthcare professionals (HCPs), such as GPs.

To achieve this principle, there should be:

- Greater awareness raising of blood cancer signs and symptoms, through public awareness campaigns and more effective signposting, to ensure more people receive a timely diagnosis of blood cancer.
- Greater efforts to raise the public's awareness and understanding of the challenges faced by people with blood cancer, including effective signposting of tailored information about the disease for friends, family, and employers.
- Easy to access tools, resources, and up-to-date guidance to support primary healthcare professionals on diagnosis, supporting people with blood cancer and timely referral to specialist care.
- Greater awareness raising of blood cancer as a single entity, bringing blood cancer patient organisations together to campaign on cross-cutting challenges facing people living with blood cancer.

2. Shared Decision Making

Shared decision making is a collaborative process through which a clinician supports a patient to reach a decision about their treatment[6,7]. It ensures that individuals are supported to make decisions that are right for them. Through this, there is an effective combination of the clinician's expertise, such as treatment options, evidence, risks, and benefits working in tandem with the patient's knowledge of their preferences, personal circumstances, goals, values, and beliefs. This process empowers people living with cancer to have a say in their care and ensures the treatment they receive is right for them.

It is vitally important that we keep encouraging shared decision making and support people living with blood cancer to understand their diagnosis, treatment, and care options, so they can make fully informed decisions in partnership with their medical team.

To achieve this principle, there should be:

- ☑ Access for patients to the right information (on diagnosis, treatment, support and care) at the right time throughout their care in a format that is both easily accessible and tailored to their needs.
- ☑ Better access for people with blood cancer to their own medical records, when requested by the appropriate route, so they have all the information they need to inform decisions. This should also come with support from their healthcare provider to ensure anything contained within is explained and easily understood.

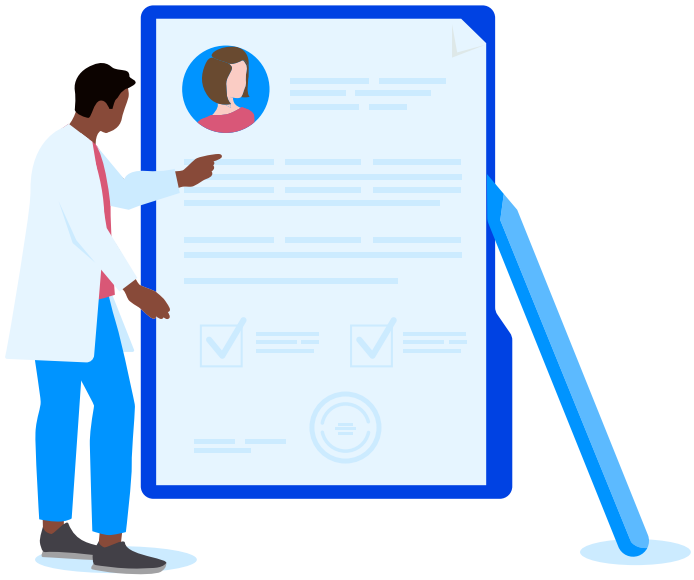
3. Holistic and Personalised Care

A holistic approach to managing people living with blood cancer throughout their care is important[8].

This principle underscores the importance of ensuring information, treatment and support is tailored to the individual's needs. When making care decisions it is important that the individual's demographics, circumstances, and needs are taken into consideration to inform a "Personalised Care Plan" that is bespoke and individualised. This personalised approach should align to the changing needs of the patient throughout their care as well.

To achieve this principle, there should be:

- ☑ A standardised approach to providing patients with a holistic needs assessment at the start of their care and/or during their care, whereby their medical team can effectively identify and take into account all their care needs.
- ☑ A Personalised Care Plan provided to all patients that is holistic in nature and takes into consideration their demographics, circumstances, needs and preferences. This plan should keep a record of conversations, decisions made and agreed outcomes, including in the treatment phase. It should also take an adaptable approach to a patient's changing needs throughout their care.



4. Equitable access to treatment and support

There is a clear disparity in treatment pathways and a geographical inequality in access to treatment[9,10]. While this is sometimes unavoidable due to the nature of specialist treatments, enabling people to access the treatment they need and not allowing them to be precluded from receiving it due to their location is important.

There is also a need to expand access to genetic and biomarker testing, which is crucial to enabling patients to benefit from precision medicine and personalised care. However, there is currently a variation in access to testing across the UK depending on local funding arrangements. The National Genomic Test Directory has been essential to supporting access to testing, but there is a need for it to be broader, more transparent and offer clarity on how these tests will be funded locally[11].

There is also an inequity in access and outcomes for people from ethnic minority backgrounds, and these individuals are less likely to receive tailored information about their care[12]. For instance, people from Black, Asian, and other ethnic minority are four times more likely to have delays in referral for their blood cancer diagnosis[12].

As well as disparities of this nature, there are also variable approaches to signposting to support for people who need it. A recent survey of people with blood cancer from Blood Cancer UK

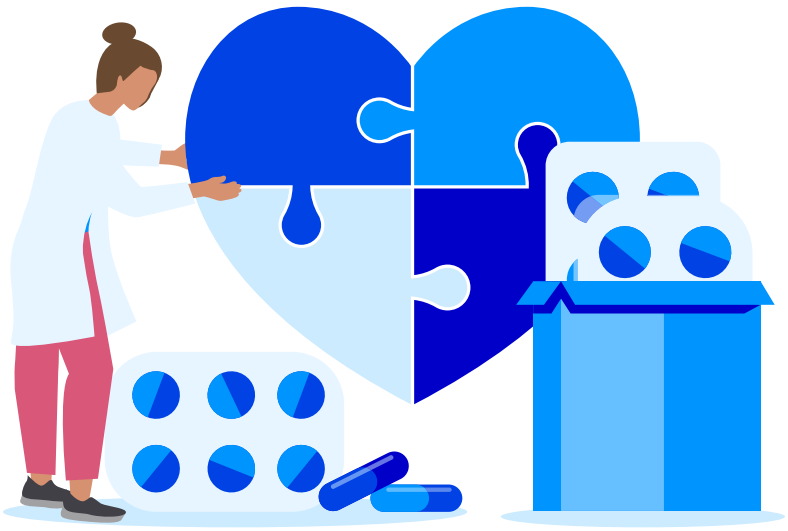
suggested that at the point of diagnosis, 58% of participants were not aware of any potential support that might be available to them[19].

Ensuring equitable access to treatment and support must also extend to tailored psychological and emotional support from the point of diagnosis. People with blood cancer face different challenges to those with solid tumours. This can make living with a blood cancer isolating or difficult to talk about, leading to a significant impact on their mental and emotional wellbeing.

For example, unlike other cancers, blood cancer has less visible physical signs and symptoms[21]. This can make the disease less tangible; in some cases, it contributes to a public perception that their disease is not as serious as other, more visible forms of cancer. This combined with the lack of public awareness of the disease, means patients can find it difficult to talk about the unique challenges they face with others.

To achieve this principle, there should be:

- Equal and fair access to, tailored and personalised support for all blood cancer patients irrespective of their blood cancer type, treatment phase and treatment
- Equal and fair access to treatment for all blood cancer patients with a focus on standardising and funding treatment options more widely across the UK to reduce unwarranted geographical inequalities
- Greater access to complex testing, such as genetic and biomarker testing, and specialised services at a local level where necessary and proportionate.
- Better signposting to patient organisations at the point of diagnosis to alleviate challenges faced by people living with blood cancer.
- An allocation of resources to enable greater access to psychological support to help patients. This includes clear signposting to mental health resources for patients at all stages of their treatment and care/after care.
- An expansion to the availability of support networks for people with blood cancer, given these are less well-established networks than some of the bigger solid tumour types.
- Greater access to information on the wider support available to people living with blood cancer, covering areas such as employment and financial support.



5. Continuity in care and communication

There is a level of care that all patients should be able to expect. Much of this is outlined in national guidelines, yet in reality patients' experiences of their care varies[10], especially given the variety of different cancers that fall under the umbrella of blood cancer. It is therefore crucial to establish continuity of care across a patient's treatment and care pathway and recognise the need for a dedicated clinical nurse specialist (CNS).

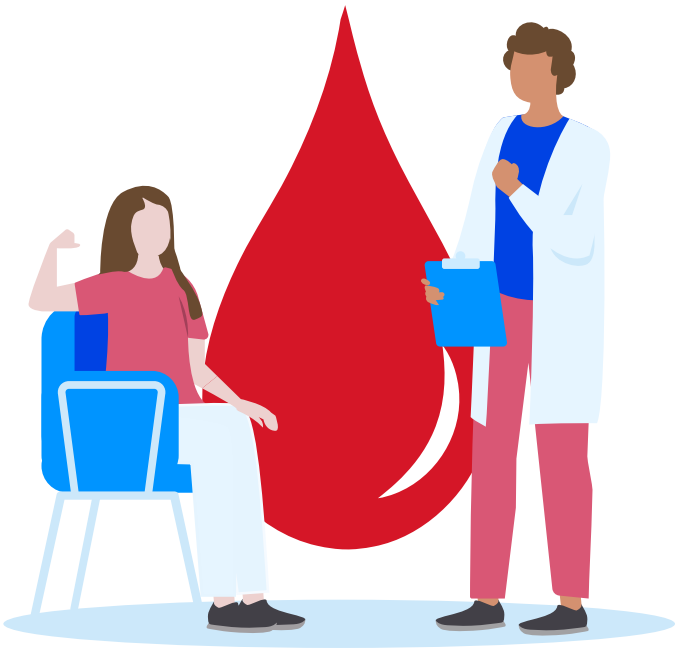
A CNS is an invaluable part of a blood cancer patient's medical team who provides specialist support from the point of diagnosis. Their role includes ensuring a Personalised Care Plan is in place and is followed so the needs of the individual are met and advocating on their behalf throughout their care[14].

Watch and wait patients, as well as patients who are post treatment, can particularly feel a lack of support and isolated[3,13]. Having a dedicated CNS/clinician/key worker can better support people living with blood cancer, improve shared decision making and improve the experience of the whole medical team[14,15,16].

A lack of resources, particularly a lack of a specialised workforce, within the current healthcare system has made it difficult for people with blood cancer to have access to CNSs. This has made one of the most difficult times in their lives even more challenging. We need to ensure that people with blood cancer have access to a dedicated CNS from diagnosis and throughout their care, regardless of their treatment plan.

To achieve this principle, there should be:

- A dedicated point of contact (e.g., clinician, key worker, or CNS) assigned to a patient from the point of diagnosis who is there to provide support, ensure continuity in care and help address any questions they may have throughout their care. It will be crucial to ensure the NHS has sufficient resource and capacity to make this a reality for everyone living with blood cancer, so that they can be empowered to be involved in decisions about their care.
- Clear and transparent communications between multidisciplinary teams and, where required, other hospital teams regarding a patient's care so that the concerns and needs of the patient can be appropriately addressed.
- Ensure regular and informative communication between a patient's hospital team and their GP throughout their care.



6. Research and Clinical Trials

Research enables us to improve care, deliver innovative treatments and manage risks associated with blood cancer. However, gaps remain in our understanding of the causes of blood cancers and how to best treat them. Most blood cancers are not treatable using surgery or radiotherapy, which means the pipeline of new and innovative treatments is vital. However, evidence suggests that there is an inequality in access to clinical trials[10]. With the geographical distribution of clinical trials limited to specific regions in the UK, there is a need to consider how access can be improved to ensure people are able to receive treatments that could benefit them regardless of where they live.

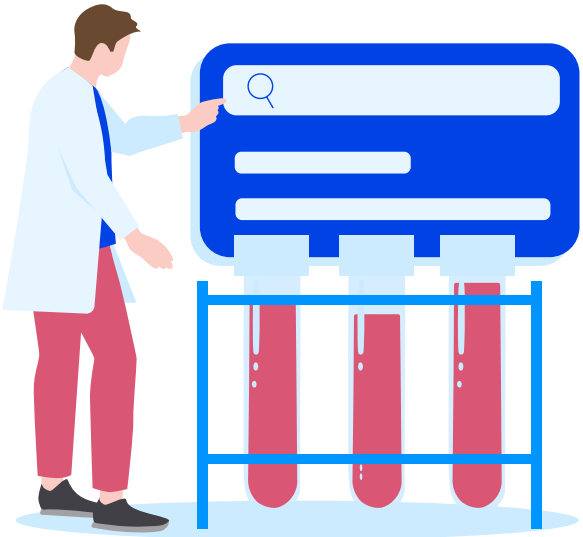
In May 2023, Lord O'Shaughnessy published his report reviewing clinical trials in the UK. In his report he made several recommendations, including improving the resources of the Medicines and Healthcare products Regulatory Agency (MHRA), enhancing transparency and accountability for clinical trial activities, incentivising participation by healthcare professionals, and prioritising this research in the NHS[17]. This report has drawn attention to the improvements that can be made in UK clinical trials, and his recommendations should apply to those concerned with blood cancer.

We welcome the recent progress the Medicines and Healthcare products Regulatory Agency (MHRA) has made to restore clincal trials assessments within statutory timescales, and would continue to encourage commitments to ensure access is improved for people across the UK[20].

Patients from ethnic minority backgrounds are frequently underrepresented in clinical trials, and also more likely to be less informed about clinical trials due to the lack of transparecy and accessiblity in this information. There is a need to ensure clinical trials are designed to work for patients from all backgrounds, trust is built between research teams and patients, patients are involved in the research process, and for information about trials to be accessible[10,18].

To achieve this principle, there should be:

- Equal and fair access to clinical trials for all patients by addressing the inequity of access to clinical trials, which includes increasing awareness of their availability for ethnic minorities.
- Greater investment from the Government into blood cancer research to improve our understanding of these diseases and access to new innovative treatment options.
- Regulators and policymakers to continue to support the timely setup and roll out of clinical trials with appropriate and proportionate levels of funding and resource.
- Increasing patient awareness of new or ongoing research that is available, ensuring that that the focus is not solely on interventional studies. This can be enhanced by the development of accessible information about research and clinical trials so that when a treating clinician informs their patients about them, that individual can feel fully informed.
- Implementation of a feedback mechanism to patients and the wider public on the outcomes of research studies, which is accessible and understandable to everyone.
- Research proposals for new innovative treatments to include or have more emphasis on quality of life.
- Commercial research to be simpler in terms of design, to enable easier setup and roll out of the study. Delivering this also has the potential to reduce the burden on the healthcare system.
- Greater awareness for patients to the availability of clinical trials earlier in their care



Acknowledgements

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We would like to express our deepest gratitude to Blood Cancer UK for collaborating with us in developing this Briefing. Sharing of their expert knowledge, guidance and insights has been invaluable and vital in the creation of this document. Their ceaseless dedication and commitment to people living with blood cancer has truly been motivating and inspiring.

We would also like to hugely thank the patient organisations, people living with blood cancer and others for their contribution to the development of this Briefing by sharing their insights and/or priorities. Creation of this Briefing would not have been possible without their invaluable inputs which has informed the very foundation of the principles set out within this document as well as brought to the forefront some of the key challenges facing people living with blood cancer.

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