

# The 'HIDDEN' CANCER

The need to improve blood cancer care

The first report of the



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All-Party Parliamentary Group  
**on Blood Cancer**

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January 2018

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This report was compiled by Bloodwise who provide the Secretariat to the All-Party Parliamentary Group on Blood Cancer.



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# Foreword

by Henry Smith MP, Chair of the APPG on Blood Cancer



Every 14 minutes someone is diagnosed with a blood cancer and there are an estimated 240,000 people living with blood cancer in the UK today. Blood cancer is Britain's fifth most common cancer and third biggest cancer killer, claiming more lives each year than breast or prostate cancer. However, the knowledge and awareness of blood cancer among the general public and policymakers is very low.

The APPG on Blood Cancer was founded in June 2016 bringing together Parliamentarians with a passion to improve care and services for blood cancer patients. Our aim is to raise awareness of the disease, those challenges faced by patients and to campaign for improvements in patient experience and outcomes. Like most of my fellow APPG officers and members, I have a personal connection to blood cancer, having

lost my mother to acute myeloid leukaemia several years ago. I have seen first-hand the terrible real-life effects of blood cancer.

My fellow officers and I are pleased, therefore, to present our first report, *The 'Hidden' Cancer – The need to improve blood cancer care*. We are grateful to all those who provided evidence to the inquiry, including blood cancer charities, clinicians and, most importantly, patients. This report focuses on five of the six priority areas identified in the 2015 Cancer Strategy (*Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020*).

Our overwhelming finding is that, whilst the Cancer Strategy is a welcome document that makes many important recommendations on improving patient experience and outcomes, the specific needs of blood cancer patients are not being fully met. The experience of blood cancer patients is different to that of solid tumour cancer patients and so general cancer services are not always effective in meeting their needs.

This report makes important recommendations on how to make improvements and ensure that we all work together to raise awareness of blood cancer. It is also a call to the Government and NHS to ensure that blood cancers and needs of blood cancer patients are properly addressed. My hope is that the practical

recommendations set out here will help to shape the future of blood cancer care and that these hidden cancers will be placed firmly on the political agenda.

A handwritten signature in blue ink that reads "Henry Smith". The signature is fluid and cursive, with a period at the end.

**Henry Smith**  
Chair, APPG on Blood Cancer

## The Officers of the APPG are:

### Chair:

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(Conservative, Crawley)

### Vice Chair:

Colleen Fletcher MP  
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### Vice Chair:

Maggie Throup MP  
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### Officer:

Jim Shannon MP  
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### Officer:

Nick Thomas-Symonds MP  
(Labour, Torfaen)

### Officer:

Jess Phillips MP  
(Labour, Birmingham Yardley)

# Executive summary

Although there has been progress in blood cancer patient care and research in recent years, it is apparent from evidence submitted to the inaugural APPG Blood Cancer inquiry that patients and their families sometimes feel let down by a lack of specific policy attention and action.

There are more than 100 blood cancers. They have different symptoms and require tailored treatment which can make

understanding the diseases challenging and complex. However, it is clear from the responses received that the majority of these challenges, and certainly the ones with policy solutions, are shared, and a community approach to these is welcome. Work undertaken by the Government on the Cancer Strategy and Cancer Workforce Plan, and work by groups such as the APPG on Cancer reviewing progress are very welcome. But much more needs to be done to

ensure that the needs of blood cancer patients, which can often be different from other cancers, are met – and that those affected can feel confident that their care will be comprehensive, effective and tailored to them.

The terms of reference for the inquiry were purposefully broad and the chapters loosely based around the five most relevant priorities in the Cancer Strategy.

## The recommendations are grouped under the following ‘Guiding principles’:

- 1 Develop and support initiatives to raise awareness of blood cancer and improve early diagnosis
- 2 Blood cancer patients, and their experiences, should be at the heart of cancer policy making
- 3 Living with and beyond cancer policy initiatives should recognise the unique needs of people with blood cancer
- 4 Increase funding for research in blood cancer with a focus on improving access to treatment for patients
- 5 Ensure NHS commissioning and other processes work for blood cancer patients now.

## These guiding principles lead to the following priority recommendations, which we believe need action now:

- *Early diagnosis:* Diagnosing blood cancers can be complex, as symptoms, such as back pain or tiredness, are often misunderstood or misdiagnosed. Delays in blood cancer diagnosis can have a major impact on a patient’s quality of life and overall outcome and earlier diagnosis would make a difference for many, but not all, blood cancers.

In order to change this, recommendations for early diagnosis in the Cancer Strategy should be reviewed to ensure that all people with blood cancer are benefitting from early and accurate diagnosis. GPs should undertake a simple blood test for people presenting with one or more blood cancer symptoms.

- *Patient experience:* Some patients with some chronic blood cancers will never be cured. Instead, they will be put on a regime of “watch and wait” upon diagnosis, where their cancer is monitored for potentially many years before it has progressed to a point where treatment

needs to start. This can be difficult for the patient and their family and can lead to psychological distress.

To improve patients' experience, tailored psychological support must be made available to those patients on "watch and wait".

- *Living with and beyond cancer:* The Cancer Strategy says that all cancer patients will have had access to the Recovery Package by 2020. This 'Package' helps patients once their treatment has ended so they can return to their normal lives.

In order to make this change, NHS England should consider how all blood cancer patients can benefit from after-care support including ensuring the Recovery Package takes account of the unique characteristics of blood cancer.

- *Research:* Unlike treatment of solid tumour cancers, blood cancers are often not treatable using surgery or radiotherapy. This means that blood cancer is more dependent on the development of new drugs, and being able to access them, in order to continue improving patient outcomes.

Ongoing, stable Government investment in blood cancer research, including in clinical trials infrastructure, is required to capitalise on the UK's position as a leader in blood cancer research. This will deliver benefits for patients and help Government reach ambitions outlined in the UK Life Sciences Industrial Strategy.

- *NHS commissioning:* The Cancer Strategy sets out how clinical leaders should work together in Cancer Alliances with those affected by cancer to decide on how local care and services should be delivered. Respondents gave evidence of fragmented services and how this had affected patient experience.

Cancer Alliances should reduce fragmentation between different stages of care for blood cancer patients by bridging recognised gaps between oncology and haematology departments, for example, and between primary and secondary care.

The full list of recommendations is available at the back of the report but we believe that swift and comprehensive action in the above priority areas would have a significant impact on outcomes for blood cancer patients now, and in the future. This cannot be achieved by any one individual or organisation but through collaboration between: patients; patient groups; Government; NHS England; Clinical Commissioning Groups; healthcare professionals; and Sustainability and Transformation Partnership (STP) members.



*For many patients blood cancer is something that they have to live with for the rest of their lives. Your blood is everywhere and you can't just cut out the affected area and do a bit of chemo to stop it from spreading. You're also not treated on cancer wards but in haematology departments and as a result can feel much more isolated and unaware of some of the support that's available."*



*"I think for most blood cancer patients, there are less 'visible' scars (e.g. from a mastectomy) which give the general impression that somehow this group of cancers are less serious than solid-tumour ones. Not having a certain organ (e.g. bowel, lung, prostate) associated somehow makes it more abstract to the general public, which makes it more difficult to explain and raise awareness."*

Patient views



# Introduction

The APPG on Blood Cancer's first inquiry focuses on five of the priority areas identified in the 2015 Cancer Strategy for England<sup>i</sup> which are most relevant to blood cancer patients: early diagnosis; patient experience; living with and beyond blood cancer; developing a modern health service; and commissioning.

Blood cancer has not received the policy attention it deserves and it was felt that the APPG's first report should review the issues and provide a platform for future debate.

The inquiry heard from: patients, healthcare professionals, researchers, carers, charities and NHS bodies. More than 150 formal responses were received, with the majority from individual patients. Two oral evidence sessions were held in September 2017.

## Cancer Strategy for England priorities

- 1 Spearhead a radical upgrade in prevention and public health.
- 2 Drive a national ambition to achieve earlier diagnosis.
- 3 Establish patient experience as being on a par with clinical effectiveness and safety.
- 4 Transform our approach to support people living with and beyond cancer.
- 5 Make the necessary investments required to deliver a modern high-quality service.
- 6 Overhaul processes for commissioning, accountability and provision.

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i. Achieving World Class Cancer Outcomes – A Strategy for England 2015-2020

# Chapter 1

## Raising public awareness and speeding up early diagnosis

### Why is awareness of blood cancers so low?

Blood cancer is the third biggest cancer killer in the UK<sup>ii</sup> and the fifth most common cancer overall<sup>iii</sup>. Despite this, awareness and understanding of blood cancer remains too low. Reasons for this include the fact that symptoms of blood cancers can be similar to the symptoms of feeling ‘run down’ or flu, such as fatigue, night sweats, weight loss, bruising and pain.

Myeloma symptoms were identified by respondents as a classic example of the challenge of diagnosis – elderly myeloma patients reporting symptoms of back ache and bone pain will likely be told it is simply part of the ageing process.<sup>iv</sup>

- There are many different types of blood cancer, some of which are very rare. This is an additional challenge when seeking to increase awareness.
- Blood cancers often have long and complex names, which are difficult for patients and the public to understand and remember. The lack of the word ‘cancer’ within the specific disease name can be a complicating factor.

Many patients and clinicians reported that the increasing use of the overarching term “blood cancer” had helped newly diagnosed patients understand that their disease was part of a wider clinical area, with a community of health professionals, charities and other patients to support them.

Low awareness of blood cancers can cause problems including delays to diagnosis, feelings of anxiety and isolation, and difficulty finding information and support. It is clear that raising awareness of blood cancer has an important part to play in improving many aspects of the patient journey and should continue to be a priority for the blood cancer community.

### How do we raise awareness of blood cancer to improve patient outcomes?

Consultation respondents identified three main audience groups where increased awareness could help improve patient outcomes.

The key groups are:

- 1 The general public
- 2 GPs
- 3 Cancer policy decision makers

“Raising awareness amongst health professionals and members of the public. Get blood cancer awareness up there with other major cancers as I always see campaigns in media for every other cancer but blood cancer. It’s pretty depressing how low public awareness is.”

Blood cancer patient

### The general public

Many patients felt that this was an important issue that needs to be addressed and that better public knowledge of symptoms would result in more people with symptoms seeking medical intervention earlier. However, there were words of caution from some healthcare professionals, who felt that awareness-raising should be handled carefully so as to ensure that no undue concern is caused.

Patients and clinicians agreed that raising awareness of blood cancer had been left behind other common cancers. Whilst acknowledging that the complexities around blood cancer meant an awareness campaign along the lines of NHS England’s successful “Be Clear on Cancer” campaigns would be difficult to achieve, respondents felt that raising awareness of blood cancer and its symptoms should continue to be a goal.

ii. Cancer Research UK, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality/all-cancers-combined>

iii. Cancer Research UK, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero>

iv. Myeloma UK, <https://www.myeloma.org.uk/wp-content/uploads/2016/07/Myeloma-Patient-Experience-Report-2016.pdf>

“As a mother of a child with leukaemia, I had no idea his initial symptoms (bruising in particular) were anything to worry about. We all know the warning signs for meningitis but not many know the signs for blood cancer.”

Blood cancer patient carer

The majority of blood cancer awareness-raising activity is currently being led by the charity sector. For example, the Lymphoma Association's work around Lymphatic Cancer Awareness Week, Leukaemia Care's "Spot Leukaemia" campaign, and Bloodwise's work to raise awareness of blood cancer and the need for further research into kinder and better treatments.

To tie in with Blood Cancer Awareness Month in September 2017, the Make Blood Cancer Visible campaign, organised by the pharmaceutical company Janssen and supported by nine UK blood cancer charities, featured an art installation in central London to raise awareness of the 104 people diagnosed with blood cancer each day.

Many respondents felt that these campaigns should continue – and, if possible, be extended – with opportunities explored to increase partnership in awareness-raising and seeking to engage Parliament, the Department of Health and NHS England.

Responses also highlighted the fact that some blood cancers, such as myeloma, are more common in African-Caribbean communities, and that more work is required to engage and inform these communities about blood cancer and its symptoms.

## Supporting General Practitioners

Many patients reported their frustration with having to see a GP a number of times before their blood cancer was diagnosed. However, it was also acknowledged that recognising and diagnosing blood cancer symptoms can be very difficult.

Again, it was noted that charities were providing support tools to healthcare professionals and these were welcomed. Some healthcare professionals said more attention should be paid to blood cancer in general medical education and training.

### Myeloma UK's Myeloma Diagnosis Pathway

Myeloma UK worked with GPs and myeloma experts to produce an "at a glance" tool for GPs, which sets out the myeloma diagnosis pathway. This pathway makes it as simple as possible for GPs to recognise the symptoms of myeloma, which tests to undertake and information on how to refer patients.

The charity raised awareness of the pathway through online promotion on GP educational sites and has asked their supporters to take the information to their GP surgeries when attending appointments. To date, they have reached around 8,000 GPs.

### Informing cancer policy decision makers

We heard that blood cancer was seldom front of mind for cancer policy decision makers. Policies that are designed to provide broad benefit to patients with solid tumours, and that do not actively consider the quite different

needs of people living with blood cancer, have unintentionally led to many people being disadvantaged and sometimes, poorer patient outcomes.

## Improving blood cancer diagnosis

### The early diagnosis challenge

Delays in blood cancer diagnosis can have a major impact on a patient's quality of life and overall outcome, but early diagnosis is a complex issue.

In some blood cancers, diagnosing early is not regarded as a priority for improving patient outcomes. For example, in the case of chronic lymphocytic leukaemia (CLL) and some types of lymphoma, upon diagnosis a patient will be commonly put on a regime of "watch and wait"<sup>v</sup>, where their cancer is monitored for potentially many years before it has progressed to a point where treatment needs to start. Therefore, in such cases the speed of diagnosis is of little significance to the treatment options or patient outcome but can have a detrimental psychological effect. At the other end of the spectrum, blood cancers such as acute myeloid leukaemia have such a rapid onset that patients are often diagnosed in Accident and Emergency just hours after symptoms begin.

However, earlier diagnosis would improve patient outcomes for many blood cancers, including myeloma, several types of high-grade or aggressive non-Hodgkin lymphomas, such as diffuse large B-cell lymphoma, and a range of T-cell lymphomas.

v. 27,000 people with blood cancer (13% of all people living with blood cancer) are on "watch and wait" in the UK, statistic obtained from Haematological Research Network (HMRN) by Bloodwise, <https://bloodwise.org.uk/info-support/blood-cancer/watch-wait>

Many blood cancer patients have to see their GP more than once before being diagnosed. Myeloma, for example, is very difficult to diagnose, with the National Cancer Patient Experience Survey (NCPES) routinely showing that myeloma patients are most likely to present to their GP three times or more before a diagnosis is made.

“*Train doctors more to know the signs and piece together the puzzle. I had several symptoms of Leukaemia but this was missed as each symptom/problem was looked at in isolation and no-one put everything together to see the whole picture. This was mainly due to having to see different doctors on each of my visits to the GP—had I seen one doctor each time they might have spotted things earlier.*”

Blood cancer patient

### Ideas to improve early diagnosis

Some of the barriers to early diagnosis of blood cancer are common across other cancers and disease areas. Systemic issues such as social and cultural barriers to attending a GP clinic, the limited time GPs have in a consultation to explore generic symptoms, and patients misreading or under-reporting symptoms are common, and require a system-wide approach.

For speeding up the diagnosis of blood cancer specifically, some clinicians felt that a change in approach was required. Screening people with low-level symptoms, or no symptoms at all, is an accepted medical practice in other cancers, – for example, breast cancer – yet there was often no

similar approach to testing for a blood cancer, despite the fact that this diagnosis can often be made with just a simple blood test.

Diagnosing blood cancer early is not the only challenge – with more than 100 different types of blood cancer, delivering an accurate diagnosis is vital. This means using the most up to date disease classification that fully incorporates current standards for molecular diagnosis. Patients who do not receive accurate diagnosis will not fully benefit from treatment

“*The NHS should embrace genetic sequencing at scale and digital pathology. This, combined with machine learning (where computer programmes look at data and come to a diagnosis), traditional imaging and routine simple blood test, can provide faster, accurate, personalised, higher quality and cheaper diagnostic services.*”

Professor Paresh Vyas,  
Professor of Haematology,  
University of Oxford

tailored to their condition. A number of steps were suggested that could help clinicians improve the diagnosis process.

- **Improving education for GPs and medical students about blood cancer.** Whilst GPs do not need to be experts on all blood cancers, and should not be expected to be, improving knowledge of the symptoms would help.
- **Review ‘Significant Event Analysis’ evidence:** The Cancer Strategy includes a commitment that “all GPs should be required to undertake a Significant Event Analysis for any patient diagnosed with cancer as a result of an emergency admission”. This allows lessons to be learnt

from each patient diagnosed following an emergency admission, and would be a valuable source of information.

- **Ensuring diagnostic centres, currently being established under the Cancer Strategy, take account of blood cancer patients and deliver at the standard of the current best available UK blood cancer diagnostic services.** These centres are still at the pilot stage – as they progress, it will be important to ensure that these play a part in improving the speed and accuracy of blood cancer diagnosis.

### Support needed at diagnosis

Patients responding to the consultation went to great lengths to detail the support they felt was needed at diagnosis. Key concerns included:

- *Understanding diagnosis/treatment*

Only 60.3% of blood cancer patients understood their diagnosis, which is the lowest percentage of all cancer types surveyed, in comparison with 78% for breast cancer, the highest percentage, and 73.2% for all solid tumour cancers combined<sup>vi</sup>.

- *Emotional and psychological support*

Emotional and psychological support is a high priority for many blood cancer patients. The impact of a cancer diagnosis is enormous. Those placed on “watch and wait” can feel extremely anxious at receiving a cancer diagnosis but not starting treatment.

- *Access to information*

Blood cancer charities and patient groups have developed numerous patient support and information tools tailored for each blood cancer. But patients can still find it difficult to find this information.<sup>vii</sup>

vi. National Cancer Patient Experience Survey 2016 <http://www.ncpes.co.uk/reports/2016-reports/national-reports-1/3572-cpes-2016-national-report/file>

vii. 1 in 4 (25.7%) patients with blood cancer were not given adequate information about their specific type of cancer, National Cancer Patient Experience Survey 2016, <http://www.ncpes.co.uk/reports/2016-reports/national-reports-1/3572-cpes-2016-national-report/file>

## Bloodwise – Blood Cancer Connect

In 2015, Bloodwise conducted a major Patient Need research project to better understand the needs of blood cancer patients. The research showed that blood cancer patients feel they are different to solid tumour patients, with a perceived lack of relevant information, support or signposting available in comparison, which can lead to feelings of isolation.

In response to these issues, Bloodwise are piloting a new online support tool, Blood Cancer Connect. The tool gathers up-to-date information from leading Information Standard accredited organisations, and highlights relevant peer-to-peer or specialist

services available locally and online, filtering these specifically for the user. This personalised library can be shared privately or publically on Blood Cancer Connect so that other users going through similar experiences can see which resources have been helpful.

Blood Cancer Connect aims to increase access to relevant information and support, increase confidence of patients, carers and healthcare professionals in the accuracy and reliability of information provided, and reduce feelings of isolation.

[bloodcancerconnect.org.uk](http://bloodcancerconnect.org.uk)

## Summary of findings

### Early diagnosis

- 1 Recommendations for early diagnosis in the Cancer Strategy should be reviewed to ensure that all people with blood cancer are benefitting from early and accurate diagnosis. GPs should undertake a simple blood test for people displaying one or more blood cancer symptoms.
- 2 Improve GP education and training to increase knowledge of blood cancer symptoms.

### Support at diagnosis

- 3 Improving and simplifying access to the wealth of information sources for patients and carers continues to be important, particularly given the relatively low percentage of blood cancer patients who say they understand their diagnosis.
- 4 NHS England should continue to work with charities, patients and healthcare professionals to ensure that emotional and psychological support is available to patients and their families from the point of diagnosis.

### Awareness

- 5 Effective campaigns increasing awareness of blood cancer should be expanded, using wider collaborations incorporating NHS England, Department of Health, Parliament and industry.
- 6 More work should be undertaken to improve awareness of blood cancer amongst black and minority ethnic (BME) communities by the Department of Health, Sustainability and Transformation Partnerships (STPs) and charities.

# Chapter 2

## Improving Patient Experience

The Cancer Strategy pledges to put patient experience on a par with clinical outcomes. Patients gave us their perspectives, both positive and negative.

### Positive patient experiences

*“I found my situation ideal and I think everyone should get that. I was admitted to the haematology ward the same day I was diagnosed and got to meet the consultant, docs and nurses that would be looking after me. I stayed in hospital for a week and met a social worker that supported me too.”*

Blood cancer patient

### Access to a Clinical Nurse Specialist (CNS)

Patients and patient groups noted the improvement in patient experience for those who had access to a CNS throughout their care. Access to a named CNS has been identified by patients as the single most important thing that improves their experience.

Providing access to a CNS is a target in the Cancer Strategy and this target is supported by all those in the blood cancer community. There is evidence ‘that this access is increasing’<sup>viii</sup>. However, one in

ten blood cancer patients still do not have a named CNS which has a negative impact on their experience of blood cancer care. Work is being undertaken by NHS England to see how this level of support could be replicated by an alternative model of care<sup>ix</sup> and this is welcome.

*“A specialist CNS nurse for all patients is a must”*

Blood cancer patient

Having a CNS as a single point of contact made it much easier for patients to ask questions

about their care and receive the information they needed. A CNS was also able to inform them of the different health and social care support services available and how to access them. Patients reported that nurses were available by mobile phone, email and text message. Patients were highly appreciative of having access to such expertise as and when they needed it.

*“I get all I need from my haematology nurse.”*

Blood cancer patient

### Anthony Nolan Post-Transplant Specialist Nurses

By April 2018, Anthony Nolan will have funded nine Clinical Nurse Specialist (CNS) posts in stem cell transplant centres across the UK. As well as helping patients with the physical and emotional side-effects of their stem cell transplant (a potentially curative treatment for blood cancer), they also provide practical support such as help getting back to work or school. Anthony Nolan's research shows that patients greatly value having a single point of contact at the transplant centre who they can get in touch with if they have any questions or concerns – one patient commented that CNS “were a sort of champion for us”. Through funding these CNS posts and sharing best practice, Anthony Nolan is aiming to improve standards of post-transplant care across the country.

viii. National Cancer Patient Experience Survey 2016, <http://www.ncpes.co.uk/reports/2016-reports/national-reports-1/3572-cpes-2016-national-report/file>

ix. National Cancer Patient Experience Survey 2016, <http://www.ncpes.co.uk/reports/2016-reports/national-reports-1/3572-cpes-2016-national-report/file>

## Areas for improvement

Patients were asked about areas of their treatment where their experience could have been improved. They told us the following:

- Post-transplant support: The overall care and support that patients receive after a stem cell transplant was identified as an area in need of improvement. Treatment by stem cell transplant has some of the most severe long-term effects of all cancer treatments.
- Access to a CNS.
- Decisions about me, without me: many blood cancer patients reported that they had not been involved in decisions about their care. Research from Myeloma UK showed that only seven out of ten patients were included in the decision-making process. Their research also showed that one in every three myeloma patients felt that the side-effects of their treatment were not fully explained to them<sup>x</sup>. These issues were referenced by patients with other blood cancers.
- Access to appropriate emotional and psychological support for patients and carers: patients on “watch and wait” said specific emotional support was required to help them come to terms with what was happening to them. Patients spoke about the impact of their diagnosis on their partner and children.
- Financial advice - patients felt information and support was sometimes lacking. Questions such as how to discuss your treatment with your employer, the financial implications of having time off work, and how to manage issues around health and

travel insurance were frequently raised by patients.

- Need for development of, and access to, ‘kinder’ treatments: many treatments are highly toxic and can be very difficult for patients to tolerate. This is a particular issue for children undergoing treatment. Much is being done in research to make this a reality, with precision medicine and targeted therapies meaning new treatments are being developed that will still effectively treat the cancer whilst having fewer side effects or long-term late effects.<sup>xi</sup>
- Care plan for blood cancer patients: healthcare professionals raised concerns that too few blood cancer patients were given a care plan.<sup>xii</sup>

## Why does the blood cancer patient experience differ from others?

Some patients with some chronic blood cancers will never be cured. Instead, they will require treatment for the rest of their lives with their cancer being managed as a long-term condition.

“I have little expectation of a cure and I live with the knowledge that symptoms will recur multiple times. There is no ‘big fight and then move on’; rather I have to accept this unwelcome guest will always be with me and my family.”

Blood cancer patient

The progression of several blood cancers means the patient journey will often be different compared to many standard solid tumour

cancers. In some blood cancers, all patients can be expected to relapse. Myeloma patients will all relapse within two to three years of treatment and remission and many types of lymphomas that will relapse at some point. This raises significant psychological challenges for patients, who spoke of being on a “cliff edge” waiting for the appointment when they would be told their cancer had returned. In such cases, support for patients who may not be receiving active treatment is crucial.

“The explanation of the treatment I would receive was very good, as was information about clinical trials I could take part in, but there was little information or support concerning coping with the emotional impact of the diagnosis, and the long-term impacts of the disease and side effects of the treatment I would receive.”

Blood cancer patient

Many respondents spoke about the problems associated with blood cancers often appearing to be “hidden”. A patient may be waiting to start treatment, undergoing active treatment or have just finished treatment, yet not display any obvious signs of ill health. Patients reported feeling like a “fake cancer patient”.

It is understandable that many cancer services are initially focused on the more common solid tumour cancers. However, when rolling out initiatives to improve cancer care, including the Cancer Strategy, it is important that those planning, managing and delivering care are aware of these differences – to ensure that cancer care packages are suitable for blood cancer patients.

x. Myeloma UK, <https://www.myeloma.org.uk/wp-content/uploads/2016/07/Myeloma-Patient-Experience-Report-2016.pdf>, Accessed [Nov 2017]

xi. Bloodwise, Childhood blood cancer: The quest for a kinder cure 2017, <https://bloodwise.org.uk/sites/default/files/documents/Bloodwise-Childhood-Cancer-Report-2017.pdf>

xii. 32.9% of blood cancer patients report being given a care plan compared with 33.3% of all tumours combined, National Cancer Patient Experience Survey 2016, <http://www.ncpes.co.uk/reports/2016-reports/national-reports-1/3572-cpes-2016-national-report/file>

## Summary of findings

- 1 Tailored psychological support must be made available to patients on “watch and wait”.
- 2 Patients should have access to the full range of emotional and psychological support services throughout their treatment, for themselves and their families.
- 3 As recommended by the Cancer Strategy, all blood cancer patients should have access to a Clinical Nurse Specialist or equivalent model of support.
- 4 Review post-transplant care to eliminate the inconsistencies across the country.
- 5 The development of kinder, less toxic treatments is crucial in reducing the impact of treatment, and reducing side effects and after effects – this must remain a priority for the research community.
- 6 Increase the number of patients who have a cancer care plan.
- 7 Decision makers responsible for drawing up national and local guidance for improving cancer patients' experiences must be aware of the differences in blood cancer patient journeys. This will ensure that newly developed services meet patients' needs.

# Chapter 3

## Living with and beyond blood cancer

Increasingly patients with blood cancer are living for many years after their diagnosis. Many of these patients are thankfully cured whilst others remain well controlled with ongoing treatments. However, both groups of patients can accumulate a burden of late and long-term effects of their cancer and its treatment.

The success of treatment is therefore being challenged by late complications affecting hormonal, reproductive, cardiovascular, respiratory, neurological, digestive and other systems, even other new cancers, and not forgetting the often psychological burden of living with and beyond cancer and its treatment.

Government and the NHS need to help people with blood cancer now, and also need an opportunity to learn how to prepare for the type of healthcare models that will be required more and more in the future, as people with solid tumours live longer with and beyond cancer.

### Current support for people living with and beyond blood cancer

A common issue was the need for support once treatment had ended. Whilst undergoing treatment, patients would be having regular (and sometimes constant) access to healthcare professionals monitoring their care, and being on hand to answer any questions.

When treatment ended, patients would be sent home. Patients spoke of feeling like they had “fallen off the end of a conveyor belt”, with no-one to talk to about after effects, dietary needs, and when they could start to resume every day activities they had enjoyed before treatment started.

“ I believe living with blood cancer doesn't mean pretending it doesn't exist, but rather accommodating it and living with it openly and honestly. Support to achieve that would be fantastic, but I don't know what that looks like!”

Blood cancer patient

Another common response, particularly for patients and professionals working in myeloma, was that patients required access to rehabilitation and physiotherapy services beyond the point when they were no longer in secondary care.

Other patients pointed out that due to the chronic nature of their blood cancer, the common term “beyond cancer” was not appropriate. Patients with chronic leukaemia or relapsing myeloma or lymphoma were clear that they never felt “beyond” their disease, and felt that terms like “post-treatment” and “recovery” were not applicable to them.

Patients also referenced the invaluable support provided by charities. Again, signposting to these resources was crucial to ensure that all patients were aware of the support available to them.

## The Lymphoma Association: Live your Life – living with and beyond lymphoma programme

The Lymphoma Association identified that although the living with and beyond cancer programme has a psychological support element, people affected by lymphoma and other blood cancers (especially ones that behave in a similar way to chronic diseases) feel that their experience is different from other cancers and consequently want lymphoma-specific support. In response, the charity launched their own programme, Live your Life – living with and beyond lymphoma, funded by the Big Lottery Fund. This is

a support programme of online, print, audio-visual and educational resources that have been designed, in partnership with lymphoma CNSs, patients and carers, to help people affected by lymphoma around the UK when they might feel isolated, neglected and are finding it hard to move on with their lives. An evaluated programme with measured outcomes, this is just one example of many where the voluntary sector can offer services above and beyond what statutory services alone can achieve. It indicates a need for commitment from the NHS to working more closely, collaboratively and supportively with the wider voluntary sector in order to improve overall outcomes for people affected by blood cancer.

## Post-transplant support

For patients treated with a stem cell transplant, the transplant itself is only the beginning of a long journey to rebuild their lives. By 2020, it is predicted there will be over 16,000 people living post-transplant, and a significant proportion of these people will be experiencing the long-term side effects of their treatment and will require specialist support<sup>xiii</sup>.

Given the potential severity of the physical and psychological implications of a transplant, patients should expect to be offered comprehensive care to help overcome them. However, current NHS provision of high-quality post-transplant care is not consistent across England. Respondents said that NHS England should review the care that patients are receiving post transplant. The clinical community and charity sector were able to deliver a number of services to address these issues, helping patients come to terms with the physical, emotional, psychological and financial concerns post transplant.

## The Cancer Recovery Package

The Cancer Strategy says that all cancer patients will have had access to the Recovery Package<sup>xiv</sup> by 2020. This helps patients once their treatment has ended so they can return to their normal lives. Some patients have received all or some of the different elements of the Recovery Package but may not have been told that it was part of a formal package of care.

“ I don't know what that (the Recovery Package) is. I was diagnosed went on a set treatment plan and hopefully would come out in remission. Everyone just appeared to hope and wait and see. I never felt I had a recovery package.”

Blood cancer patient

Healthcare professionals were clear that improving the experience of patients living with and beyond blood cancer was a priority and welcomed the Cancer Strategy's focus on this area of care. However, they were keen to emphasise that the Strategy must ensure patient outcomes and experiences have genuinely improved and not allow delivery of the Recovery Package to become a tick-box exercise.

## Summary of findings

- 1 For many people blood cancer is a long-term condition – their experience is different from patients with other types of cancer and the term “living beyond” is irrelevant to them. NHS decision makers at national and local level should ensure specific attention is given to blood cancer patients who are on chronic treatment, “watch and wait”, or have relapsing disease, to ensure that standard care packages meet their needs.
- 2 NHS England should consider how all blood cancer patients can benefit from after-care support including ensuring the Recovery Package takes account of the differences in blood cancer.
- 3 NHS England should review the care currently provided to patients post stem cell transplant to ensure all patients can access the support they need.

xiii. Data provided and analysed by the British Society of Blood and Bone Marrow Transplantation

xiv. The Recovery Package has four main interventions: Holistic Needs Assessment and Care Planning, Treatment Summary, Cancer Care Review, and Health and Wellbeing Events. These elements form part of an overall support and self-management package for people affected by cancer – physical activity as part of a healthy lifestyle, managing consequences of treatment, and information, financial and work support. <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package>

# Chapter 4

## Access to new treatments and support for research

The last decade has seen unprecedented progress in the development of new drug, cellular and transplant therapies for patients with blood cancer in the UK. This pace of development of new and often effective therapies shows every sign of accelerating. The scale of the NHS and the underpinning infrastructure of National Institute for Health Research (NIHR) makes the UK an excellent location to assess novel therapies in clinical trials. Current levels of support need to continue, or increase, to maintain this pace of change.

Access to new treatments is crucial for cancer care, particularly in blood cancer. Unlike treatment of solid tumour cancers, blood cancers are often not treatable using surgery or radiotherapy. This means that blood cancer is more dependent on the development of new drugs, and being able to access them, in order to continue improving patient outcomes. These treatments can often be expensive if they are developed for a rare blood cancer with small patient populations.

In recent years, a number of new drugs have been developed to treat blood cancers, which have significantly improved the way in which we treat patients. However, at a time of growing financial pressure on the NHS, the increase in new treatments being developed has raised a number of questions about how access to innovative and effective medicines can be guaranteed.

The Government's Accelerated Access Review (AAR) of 2016 was a welcome development in setting out how access to new and effective treatments and diagnostics could be sped up. However, there are challenges in implementing the recommendations of the AAR without addressing the wider constraints facing NHS finances.

### The new system

In 2016, the Cancer Drugs Fund (CDF) was amended as part of a new process for assessing cancer drugs. The new CDF, which provides temporary funding for a new treatment whilst additional data can be gathered, provides short-term funding and can enable a new drug to move to routine commissioning.

However, there has been concern that for some blood cancers, particularly rare blood cancers, this temporary data collection phase will not be long enough to secure sufficiently robust data, due to the small number of patients affected. New treatments for rare diseases can often be expensive, as they are typically innovative and used in very small populations. Therefore treatments for rare blood cancers have historically found it difficult to gain approval from NICE prior to the 2016 reforms.

Continued monitoring of the CDF will show whether the new process is working in practice.

Under the new system, several new blood cancer treatments have been approved by NICE to enter into routine commissioning by the NHS in England. This has allowed many patients to benefit from innovative medicines that significantly improve outcomes. For positive approvals, it should be noted that these treatments have often received negative draft guidance from NICE, before negotiation with the manufacturer has led to final positive guidance. Whilst the ultimate outcome is positive for patients, this approach creates significant anxiety for patients thinking that a new life-changing, sometimes life-saving, treatment may not be available. In these cases, the final negotiation between NICE and the manufacturer should be undertaken before draft negative guidance is issued in order to prevent patients experiencing the stress and anxiety of waiting.

There are two main areas that need to be addressed if we are to ensure long-term and sustainable patient access:

- *Combination therapies* – due to the complex nature of blood cancer treatment, many patients are treated with combinations of drugs. There have been examples where the NICE appraisal process will deem a new drug as not cost-effective, not due to the cost, but the cost of the combination medicines it will be used with. In some cases, it has been shown that even if a new drug were

provided for free, the cost of the already-approved combination drugs would still cause the new drug to be deemed not cost-effective.

- Many blood cancer treatments have *multiple indications* as they can be used to treat several different types of blood cancer. Companies will set a different price for a drug's indication in different blood cancers – different patient populations, dosages and treatment pathways will affect the price. This practice of different prices for a drug's different indications is standard practice in European markets, including the NHS in Scotland. However, the system in England is still unable to account for this, which is causing delays to drugs being approved.

Consideration is urgently required for a complete review of the drug appraisal process to establish how new and effective treatments can be provided for patients at a price the NHS can afford on a long-term basis. Only by industry, NICE, NHS England and the Government working together effectively will a sustainable system be delivered. Starting this joined up discussion earlier in the drug development process was regarded by many respondents as a crucial step in improving the current approval system.

## Challenges for blood cancer research

A major contributor to the success of UK blood cancer research has been significant long-term charitable investment, which has grown a large and strong research base that has helped produce relatively good survival rates. The downside of this is that blood cancers are often deemed to be “doing well enough” by Government funders.

Blood cancers are a major component of cancer mortality rates and unlike other cancers, primary prevention through lifestyle change cannot reduce disease burden, so investment in research is critical. But the benefit of investment in blood cancer reaches further. The nature of blood cancer for both discovery research and clinical trials means that it is often at the vanguard of cancer research, and learnings from the field have wider benefits.

This inquiry and a variety of previous reports have identified the UK health market as having a significant advantage in undertaking research due to the existence of the NHS. A large, integrated healthcare system makes it easier to undertake large research projects, in comparison to the USA and Germany. However, some clinicians and researchers who responded to the consultation felt that the NHS does not always maximise this advantage. Greater collaboration is required between pharmaceutical companies, academia, research charities, NHS England, the NIHR and devolved Government bodies to ensure there is increasing investment in academic clinical trials and research studies.

Research charities play an important role in this setting and a range of charities have made important investments in accelerating blood cancer trials. These include the pan blood cancer Trials Acceleration Programme, the Myeloma UK Clinical Trial Network and the newly formed IMPACT network for stem cell transplant trials. The Trials Acceleration Programme was included in the Life Sciences Industrial Strategy<sup>xv</sup> as an exemplar of how an early phase trials programme can create rapid access to patients and underpinning science, and use these to establish powerful industry partnerships.

xv. Life Sciences Industrial Strategy - A report to the government from the life sciences sector <https://www.gov.uk/government/publications/life-sciences-industrial-strategy>

## Accelerating blood cancer clinical trials

*Funders: Bloodwise (TAP); Anthony Nolan, Leuka, NHS Blood and Transplant (IMPACT); Myeloma UK (Myeloma Clinical Research Network)*

The Trials Acceleration Programme (TAP) represents a novel national trials infrastructure for all types of blood cancer which was established by the charity Bloodwise in 2012 in response to the dramatic increase in the number of potential new drugs for the treatment of blood cancer.

Based on a 'hub and spoke' model, a central trials acceleration hub hosted by Birmingham Health Partners facilitates trial set-up and delivery within a national network of 13 major blood cancer centres, each with dedicated research nurse funding and collectively covering a catchment region of 20 million. This integrated delivery structure has significantly

reduced trial set-up time from 30 to nine months at the same time as accelerating patient recruitment.

In total the TAP has facilitated recruitment of over 1000 patients across a portfolio of 19 early phase trials and resulted in industry partners bringing around £150 million of potentially life-saving new treatments to patients across the UK. The TAP model is now being applied to stem cell transplantation in blood cancer, through the recently launched IMPACT partnership, and a similar model for Myeloma trials (the Myeloma UK Clinical Research Network) is already established.

This infrastructure has the potential to further establish the UK as a globally unique environment for the rapid delivery of practice-informing studies, in turn driving inward investment by the global pharmaceutical sector.

Charities have invested significantly in these networks, making a significant difference to people with blood cancer. So much more could be achieved, however, with strategic investment from Government. If the Government is to meet the ambitious 50% five-year growth target for clinical trials set out in the UK Life Sciences Strategy, it will also be vital to invest in successful delivery models. There are two components to the opportunity – firstly, investment in the funding of existing trial networks and secondly, the provision of additional resources to the UK Clinical Research Network (UKCRN) to support blood cancer trials.

Currently, the market access system is designed to provide access to large Phase III trials funded by pharmaceutical companies, but increasing clinical research network support for academic trials is crucial in order to address the imbalance between commercially funded and academic research. This is not an "academic" consideration – academic-led trials can ask questions about combinations of treatments and patient groups that are a priority

for the NHS. Experience has shown that increasing network support cannot be achieved by asking the UK Clinical Research Network to reprioritise. Growth will not be achieved without increasing the UKCRN budget. It is telling that initiatives like TAP and IMPACT would not be able to function without charitable funding of research nurses and other core staff to run trials on the ground.

Biological samples from patients are critical to clinical research including, but not limited to, the clinical trials setting. However funding for sample banking has not been given national priority and finding funding to bank samples, even when a clinical trial has been supported, is often extremely difficult. In blood cancer, national sample-banking resources are limited and successful examples such as the Bloodwise-funded Childhood Leukaemia CellBank and the UK CLL Trials Biobank, are often supported by charities. Biological samples from blood cancer patients are significantly easier to process and their value has impact beyond blood cancer.

## Clinical trials

Low patient numbers can often make it difficult to get clinical trials set up in blood cancer, and patients can find it hard to get on available trials. This is an issue that is already faced in other rare cancers and will become more common as cancer is more accurately classified into diseases with smaller numbers of patients

According to 2016 the National Cancer Patients Experience Survey, only 33.8%<sup>xvi</sup> of blood cancer patients are asked if they would like to be on a trial – this figure has been declining in recent years. In order to support research, increase the number of patients able to access new medicines, and ultimately improve patient outcomes, more clinicians should be initiating a discussion about research.

A more joined-up approach is required in order to answer key clinical research questions. Too often research can be conducted in silos, whereas a more constructive approach would involve increased dialogue within the research community. The UK Myeloma

xvi. National Cancer Patient Experience Survey 2016, <http://www.ncpes.co.uk/reports/2016-reports/national-reports-1/3572-cpes-2016-national-report/file>

Forum and associated research groups have made steps towards achieving this though there is still plenty of scope to build and develop this concept.

### UK Myeloma Forum

In myeloma and other blood cancers, there is a need for a clear and joined-up approach or “blueprint” for key clinical research questions which need to be answered to improve patient outcomes in the UK. The UK Myeloma Forum, which aims to improve the care of patients with myeloma through the development and promotion of trials, has made substantial steps towards this and these efforts should be built upon. This is particularly important to make the best use of a small patient population and to ensure efficient use of grant funding.

There is a lack of infrastructure, resource and capacity within individual transplant centres to support clinical trials and research into stem cell transplantation. Transplant centres are not currently sufficiently resourced to develop effective data collection. This is an obstacle to implementation of clinical trials, and hampers retrospective analysis of patient outcome data.

## Summary of findings

### Research

1 Ongoing, stable Government investment in blood cancer research, including in clinical trials infrastructure, is required to capitalise on the UK’s position as a leader in blood cancer research. This will deliver benefits for patients and help Government reach ambitions outlined in the UK Life Sciences Industrial Strategy.

### Access to treatments

- 2 Continue to monitor the new Cancer Drugs Fund to ensure it allows sufficient time for data capture with regard to rare blood cancers.
- 3 There should be earlier engagement between drug manufacturers and NICE to improve the drug appraisal process and maximise the opportunity for new treatments to be approved.
- 4 A review of NICE processes should be undertaken to review how drugs used in combination and/or with multiple indications can successfully negotiate the NICE appraisal system.

# Chapter 5

## Making NHS commissioning work for blood cancer patients

The Cancer Strategy sets out how clinical leaders should work together in Cancer Alliances with those affected by cancer to decide on how local care and services should be delivered.

The Alliances sit above Clinical Commissioning Groups (CCGs), Sustainability and Transformation Partnerships (STPs) and providers, and agree activities to improve local cancer outcomes. Our respondents commented on how these bodies are operating and whether this has made a difference on the ground.

### Commissioning of blood cancer services

Many patients and clinicians spoke of the balancing act involved in providing high quality, easily-accessible haematology centres. Some patients spoke of having to travel significant distances in order to be treated in a haematology centre.

However, whilst acknowledging that extended travel could be troublesome, some clinicians were of the view that reconfiguring services and merging haematology centres was the most effective way to provide treatment. Patients should be treated as close to home as possible, but they argued that for some types of blood cancer (such as acute leukaemias and aggressive forms of myeloma and lymphoma) it was not possible for them to be treated at the local hospital.

A consistent thread throughout the submissions of patients and health professionals has been the quality and quantity of support services provided by the blood cancer charity sector. Many felt that when commissioning local services, Cancer Alliances should familiarise themselves with the information, support, peer-to-peer contact and support groups being provided by charities. A more structured approach to commissioning essential patient support services and utilising charities could help address some of the issues experienced during and after care.

Due to advances in our understanding of blood cancer and the development of new treatments, some chronic blood cancers, though currently incurable, can be managed successfully for many years as a long-term conditions. Some health professionals felt that this presented a huge opportunity to change the way care was provided for these patients, moving towards models long-established for the treatment of other chronic diseases, such as diabetes. Though this was possible, some felt that there was sometimes a reluctance within the NHS to move cancer care out of standard oncology settings. This model of care would not be appropriate for all patients (and would only be pursued after discussion and agreement with the patient), but embracing more community care and care closer/within patients' homes should be a considered for chronic blood cancers.

The issue of low awareness of blood cancers was raised again by respondents with regards to commissioning. As with the general public and healthcare professionals, some felt that low awareness amongst commissioners might mean that blood cancer services were not front of mind for local decision makers. This could cause difficulties if commissioners were not aware of the differences in patient journeys in blood cancer, and lead to patients receiving suboptimal care.

Finally, it was noted that there was often frustration at the pace at which funding was provided for Cancer Alliances. There was acknowledgement that appropriate planning had to be undertaken, but the delay in funds being made available to Cancer Alliances was felt by some to be preventing the Cancer Alliances from doing their job.

### Commissioning of stem cell transplantation

On the treatment option of stem cell transplantation, clinicians, patients, and the charity Anthony Nolan raised some specific areas where commissioning of care could be improved.

It was felt that there was still a lack of clarity over who has responsibility for providing timely access to high-quality

post-transplant care. The official policy states that NHS England commissions treatment from 30 days before transplant until 100 days post transplant, at which point, responsibility moves to the local CCG. However, research by Anthony Nolan shows this division of responsibility was not being adhered to nationwide, with many CCGs unclear of the specific arrangements they were required to provide<sup>xvii</sup>. This leads to fragmented care, with CCGs not being properly supported to provide the complex post-transplant care that patients require.

Furthermore, there is no clinical basis for implementing this change in responsibilities at 100 days. Patients are likely to need specialist support for far longer than this so many felt transferring responsibility for care at this arbitrary point would increase the fragmentation. Reviewing this 100-day cut-off should be a priority for NHS England, with clinicians and blood cancer charities willing to participate in putting alternative arrangements in place.

## Where should Cancer Alliances focus their attention?

Fragmentation of services was raised several times, with gaps between primary and secondary care, between oncology and haematology departments, and as patients tried to navigate the many different healthcare services and professionals that form their treatment pathway. Alliances should look at how these gaps can be overcome, and actively engage patients in the planning of services to ensure they are truly patient led.

Many respondents felt that Cancer Alliances had a key role to play in providing and/or signposting patients to emotional and psychological support during and after care. As previously

noted, the charity sector should be regarded as a willing and able partner in achieving this goal.

Access to clinical trials, and ensuring more patients were being told about research, was also regarded as a priority for Alliances. With too many patients reporting that research or trials had never been mentioned to them throughout their treatment, the Alliances were well placed to make sure more introductory discussions were happening.

Finally, Alliances should lead on efforts to better engage BME communities with blood cancer information, support and care services.

## Summary of findings

- 1 Cancer Alliances should reduce fragmentation between different stages of care for blood cancer patients by bridging recognised gaps between oncology and haematology departments, for example, and between primary and secondary care.
- 2 Cancer Alliances should look for more opportunities to involve blood cancer patients and charities in the provision of care and support.
- 3 Local decision makers should look for opportunities to bring care of chronic blood cancers closer to the patient where appropriate.
- 4 NHS England should review arrangements for care of blood cancer patients post transplant.

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xvii. FOI request to NHS England from Anthony Nolan, December 2016

# Recommendations

We propose that a guiding principle should be followed for blood cancer patients and their treatment under each of our themes.

Theme	Principle	Summary of Findings	Audience
Public awareness and early diagnosis	Develop and support initiatives to raise awareness of blood cancer and improve early diagnosis	<p><b>Early diagnosis</b></p> <ul style="list-style-type: none"> <li><i>Recommendations for early diagnosis in the Cancer Strategy should be reviewed to ensure that all people with blood cancer are benefitting from early and accurate diagnosis. GPs should undertake a simple blood test for people displaying one or more blood cancer symptoms.</i></li> <li>Improve GP education and training to increase knowledge of blood cancer symptoms.</li> </ul> <p><b>Awareness</b></p> <ul style="list-style-type: none"> <li>Effective campaigns increasing awareness of blood cancer should be expanded, using wider collaborations incorporating NHS England, Department of Health, Parliament and industry.</li> <li>More work should be undertaken to improve awareness of blood cancer amongst BME communities by the Department of Health, Sustainability and Transformation Partnerships (STPs) and charities.</li> </ul> <p><b>Support at early diagnosis</b></p> <ul style="list-style-type: none"> <li>Improve and simplify access to the wealth of information sources for patients and carers.</li> <li>NHS England should continue to work with charities, patients and healthcare professionals to ensure that emotional and psychological support is available to patients and their families.</li> </ul>	<p>Government</p> <p>NHS England</p> <p>CCGs</p> <p>Cancer Alliances</p> <p>Blood cancer community</p>
Patient Experience	Blood cancer patients, and their experiences, should be at the heart of cancer policy making.	<ul style="list-style-type: none"> <li><i>Tailored psychological support must be made available to those patients on “watch and wait”</i></li> <li>Patients should have access to the full range of emotional and psychological support services throughout their treatment, for themselves and their families.</li> </ul>	<p>Government</p> <p>NHS England</p> <p>CCGs and Cancer Alliances</p>

		<ul style="list-style-type: none"> <li>• As recommended by the cancer strategy, ensure all blood cancer patients have access to a Clinical Nurse Specialist or equivalent model of support.</li> <li>• Review post-transplant care to eliminate the inconsistencies across the country.</li> <li>• The development of kinder, less toxic treatments are crucial in reducing the impact of treatment, and reducing side effects and after effects – this must remain a priority for the research community.</li> <li>• Increase the number of patients who have a cancer care plan.</li> <li>• Decision makers responsible for drawing up national and local guidance for improving cancer patients’ experience must be aware of the differences in blood cancer patient journeys to ensure newly developed services meet patients’ needs.</li> </ul>	
<p>Living with and beyond blood cancer</p>	<p>Living with and beyond cancer policy initiatives should recognise the unique needs of people with blood cancer</p>	<ul style="list-style-type: none"> <li>• <b><i>NHS England should ensure all blood cancer patients can benefit from after-care support and that the Recovery Package takes account of the different experience of people with blood cancer.</i></b></li> <li>• NHS decision makers at national and local level should ensure specific attention is given to blood cancer patients who are on chronic treatment, “watch and wait”, or have relapsing disease to ensure that standard care packages meet their needs.</li> <li>• NHS England should review the care currently provided to patients post stem cell transplant to ensure all patients can access the support they need.</li> </ul>	<p>Government NHS England CCGs and Cancer Alliances</p>
<p>Access to new treatments and support for research</p>	<p>Increase funding for research in blood cancer with a focus on improving access to treatment for patients</p>	<ul style="list-style-type: none"> <li>• Ongoing, stable Government investment in blood cancer research, including in clinical trials infrastructure, is required to capitalise on the UK’s position as a leader in blood cancer research. This will deliver benefits for patients and help Government reach ambitions outlined in the UK Life Sciences Industrial Strategy.</li> <li>• Continue to monitor the new Cancer Drugs Fund to ensure it allows sufficient time for data capture with regards to rare blood cancers</li> <li>• There should be earlier engagement between drug manufacturers and NICE to improve the drug appraisal process and maximise the opportunity for new treatments to be approved.</li> </ul>	<p>Government NICE Blood cancer community</p>

NHS commissioning

Ensure NHS commissioning and other processes work for blood cancer patients now.

- A review of NICE processes should be undertaken to review how drugs used in combination and/or with multiple indications can successfully negotiate the NICE appraisal system.

- ***Cancer Alliances should reduce fragmentation between different stages of care for blood cancer patients by bridging recognised gaps between oncology and haematology departments, for example, and between primary and secondary care.***

- Cancer Alliances should look for more opportunities to involve blood cancer patients and charities in the provision of care and support.

- Local decision makers should look for opportunities to bring care of chronic blood cancers closer to the patient where appropriate.

- NHS England should review arrangements for care of blood cancer patients post-transplant.

Government

NHS England

CCGs and Cancer Alliances

# Acknowledgements

We are grateful to everyone who has worked with us throughout this Inquiry. We received over 150 formal responses from patients, healthcare professionals, researchers, carers, charities and NHS bodies. We would like to thank each and every person and organisation that took the time to respond and feed into this report.

## Witnesses (Oral evidence sessions)

**Professor Stephen O'Brien**,  
Professor of Haematology,  
University of Newcastle

**John Reeve**,  
Patient Advocate

**Professor Paresh Vyas**,  
Professor of Haematology,  
University of Oxford

**Dr Robert Marcus**,  
Consultant Haematologist

**Professor John Snowden**,  
Director of Blood and Bone  
Marrow Transplantation,  
Sheffield Teaching Hospitals  
NHS Foundation Trust

## Written submissions

We would like to thank the following for submitting written evidence and responding to our survey. In particular, we are very grateful to the 112 blood cancer patients and their carers who took the time to respond to the survey and share their experiences.

**Anthony Nolan**

**Myeloma UK**

**Lymphoma Association**

**Dr Sophie Otton**,  
Consultant Haematologist,  
North Bristol NHS Trust

**Dr Sateesh Nagumantry**,  
Consultant Haematologist,  
Peterborough City Hospital

**Dr Jonathan Cullis**,  
Consultant Haematologist,  
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**Dr Vivienne Andrews**, Consultant  
Haematologist, BMI

**Oonagh Sheehy**,  
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**Natasha Jones**,  
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**Lisa Daniels**,  
Clinical Nurse Specialist,  
Gloucester Hospitals NHS  
Foundation Trust

**Orla McCourt**,  
Physiotherapist,  
Inpatient Haematology,  
University College London  
Hospitals NHS Trust

We would also particularly like to thank Bloodwise, Secretariat for the group, for their efforts in driving this inquiry and producing this final report.





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All-Party Parliamentary Group  
**on Blood Cancer**

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## The Group's members are:

**Chair:** Henry Smith MP (*Conservative, Crawley*)

**Vice Chair:** Colleen Fletcher MP (*Labour, Coventry North East*)

**Vice Chair:** Maggie Throup MP (*Conservative, Erewash*)

**Officer:** Jim Shannon MP (*DUP, Strangford*)

**Officer:** Nick Thomas-Symonds MP (*Labour, Torfaen*)

**Officer:** Jess Phillips MP (*Labour, Birmingham Yardley*)

Lord Campbell of Pittenweem (*Liberal Democrats*)

David Hanson MP (*Labour, Delyn*)

Lord Mendelsohn (*Labour*)

Baroness Morgan of Drefelin (*Crossbench*)

Jo Swinson MP (*Liberal Democrats, East Dunbartonshire*)

The Secretariat to the APPG is provided by **Bloodwise** [bloodwise.org.uk](http://bloodwise.org.uk)  
The blood cancer research charity

## In addition, the APPG is proud to have the support of the following organisations:

**ACLT**

[aclt.org](http://aclt.org)

**Anthony Nolan**

[anthonymolan.org](http://anthonymolan.org)

**CLL Support Association**

[cllsupport.org.uk](http://cllsupport.org.uk)

**CML Support**

[cmlsupport.org.uk](http://cmlsupport.org.uk)

**Leukaemia CARE**

[leukaemiacare.org.uk](http://leukaemiacare.org.uk)

**Lymphoma Association**

[lymphomas.org.uk](http://lymphomas.org.uk)

**Lymphoma Out Loud**

[lumpedwithlymphoma.org](http://lumpedwithlymphoma.org)

**MDS UK**

[mdspatientsupport.org.uk](http://mdspatientsupport.org.uk)

**Myeloma UK**

[myeloma.org.uk](http://myeloma.org.uk)

**The Basil Skyers Myeloma Foundation**

[basilskyersfoundation.org](http://basilskyersfoundation.org)

**WMUK**

[wmuk.org.uk](http://wmuk.org.uk)