

Cancer in the Long-Term Plan for the NHS

About Bloodwise

Bloodwise is the UK's leading blood cancer research charity. We fund world leading research and offer expert information and support to anyone affected by the different types of blood cancer, from leukaemia, lymphoma and myeloma to the rarest blood cancers that affect just a handful of people. We are proud to be part of the Blood Cancer Alliance of charities and draw attention to its response which should be considered alongside this paper.

About blood cancer

- Blood cancer is the third biggest cancer killer in the UK¹
- It is the fifth most common cancer overall² with over 240,000 people living with the disease.³
- Unlike the treatment of solid tumour cancers, blood cancer is usually not treatable using surgery or radiotherapy. This means it is even more dependent on the latest drugs being available on the NHS.
- Blood cancers, unlike many other cancers, are not linked to lifestyles.

Long-Term Plan for the NHS – Recommendations from Bloodwise

1. NHS England needs to ensure that access to, and funding, for the very latest drugs and treatments are central to the long-term plan.
2. NICE and NHS England need to review the mechanisms for appraising blood cancer treatments so that it does not discriminate against therapies with small patient numbers or early-stage data and better utilises real world clinical data.
3. People living with blood cancer should be able to access specific emotional and psychological support.
4. Blood cancer should be included in the cancer dashboard.
5. NHS England should progress with a vague symptoms pathway and Recommendation 22 of the 2015 Cancer Strategy which proposed a self-referral process, via a nurse telephone triage, in cases of suspected cancer.

¹ Cancer Research UK, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality/all-cancers-combined>

² Cancer Research UK, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero>

³ Bloodwise data taken from 10 year prevalence figures.

Questions from NHS England

1. What are your top three priorities for improving cancer outcomes over the next five and ten years?

Priority One: Access to new medicines and treatments

Unlike the treatment of solid tumour cancers, blood cancer is usually not treatable using surgery or radiotherapy. This means it is even more dependent on the latest drugs being available on the NHS. For example, according to the latest Cancer Patient Experience Survey:

- 11% of blood cancer patients had radiotherapy compared to 55% of breast cancer patients;
- 12% of blood cancer patients had surgery compared to 77% of breast cancer patients.

There is a disappointing lack of emphasis in the current cancer strategy on the importance of, and access to, cancer medicines and this is reflected in the consultation questions on the ten year plan which focus only on prevention, diagnosis, quality of life and care. We note that the Cancer Drugs Fund is currently underspent.⁴ NHS England needs to ensure that access to, and funding for, the very latest drugs and treatments are central to the new ten-year plan.

There have been three recent significant decisions regarding treatments for blood cancer on the NHS:

- CAR-T cell therapy has been approved to treat children and young people with acute lymphoblastic leukaemia⁵.
- CAR-T cell therapy has been turned down for the treatment of adults with aggressive types of non-Hodgkin lymphoma (although there has been a call for further evidence)⁶.
- NHS England changed its mind and allowed Ibrutinib to be used for patients with chronic lymphocytic leukaemia (CLL) after three years remission⁷.

These decisions illustrate the cost challenges facing NICE and NHS England in relation to blood cancer in that they are often expensive and for a relatively small group of patients. CAR-T cell therapy is an example of an innovative new treatment which is potentially life-saving. By approving CAR-T therapy to treat childhood leukaemia on the Cancer Drugs Fund and investing in the infrastructure needed to make it available, the NHS has shown it is

⁴ House of Commons Hansard Answer 134287, 29 March 2018

⁵ <https://www.england.nhs.uk/2018/09/nhs-england-announces-groundbreaking-new-personalised-therapy-for-children-with-cancer/>

⁶ <https://www.nice.org.uk/news/article/feedback-encouraged-to-allow-use-of-life-extending-treatment-on-nhs-for-those-with-blood-cancer>

⁷ <https://www.england.nhs.uk/wp-content/uploads/2018/08/letter-ibrutinib-cll-response-for-release-aug-2018.pdf>

willing to take a chance on these life-saving cancer treatments if enough evidence is available and a price can be agreed.

As of September 2018, there are a further 60 blood cancer drugs awaiting a final appraisal by NICE illustrating the challenge it will face as research and clinical trials produce even greater advances in our knowledge of treatments. NICE and NHS England will need to review the process for appraising blood cancer drugs and therapies so that it does not discriminate against therapies with small patient numbers and early-stage data. There needs to be better use of real world clinical data.

Priority Two: Support for people living with a blood cancer diagnosis

The experience of many people living with blood cancer is very different to people with solid tumour cancers. Many people live for years following their diagnosis whilst receiving, for example, chemotherapy on a monthly basis or taking a daily chemotherapy pill. Approximately 27,000 people are living on watch and wait, where they have received a blood cancer diagnosis but do not start active treatment. Patients giving evidence to the APPG on Blood Cancer inquiry⁸ said that the phrase *living beyond cancer* does not apply to them because they will never live without blood cancer and it is part of their daily lives. Very few have yet had access to the recovery package. NHS England should ensure that people living with blood cancer are able to access specific emotional and psychological support.

Alongside cancer, mental health is a major Government priority. We are looking for reassurances from NHS England and ministers that the significant mental health needs of people with cancer, and blood cancer specifically, are being considered as part of both programmes of work.

For example, 3000 mental health therapists have been co-located in GP surgeries. A parliamentary answer⁹ confirmed that cancer as a general condition forms part of the training. Whilst appreciating the complexity of such training, we are seeking reassurance that people living with blood cancer can rely on the therapists to have an understanding of the differences between their disease and solid tumour cancers.

Priority Three: Improvement in data collection

Improvement in data collection and reporting of blood cancer is essential in order to rapidly identify challenges faced by blood cancer patients, identify gaps in provision, establish benchmarks and allow them to be considered as a single cohort.

Clinical Commissioning Groups and Cancer Alliances do not group blood cancer into a single disease area, unlike the National Cancer Patient Experience Survey (NCPES), which

⁸ https://bloodwise.org.uk/sites/default/files/documents/appg_report_on_blood_cancer.pdf

⁹ Written Answer 150005 to Henry Smith MP from Steve Brine MP, 5 June 2018

means blood cancer receives less attention and resource. A major step forward in this regard would be the inclusion of blood cancer in the cancer dashboard, which currently only covers breast, colorectal, lung and prostate cancers.

Blood cancer is reliant on molecular diagnostics and a range of other pathology techniques in order to diagnose it effectively. Fully understanding the precise type of blood cancer and relevant mutations is therefore crucial for haematologists to choose the most effective treatments and estimate a person's chances of survival.

In order to improve both quality of data collection and rates of diagnosis, NHS England and NICE should ensure that Improving Outcomes Guidance recommendations relating to integrated diagnostic reporting and the formation of Specialist Integrated Haematological Malignancy Diagnostic Services (SIHMDS) are being adhered to¹⁰. Haematologists have emphasised that better coding of samples will enable both faster diagnosis and more effective treatment.

2. What can be done to ensure:

a. More cancers are prevented

It is important to note that blood cancers, unlike many other cancers, are not related to lifestyles and therefore the policy agenda in this area is largely not relevant to blood cancer.

However, some blood cancers can be caused by underlying conditions. For example, myelodysplastic syndromes (MDS) share a common tendency to develop into acute myeloid leukaemia over time. There are certain factors that may increase the likelihood of developing MDS including previous chemotherapy with or without radiotherapy – this treatment may have been given in the past, usually for other cancers.

b. More cancers are diagnosed early and quickly?

The number of GP visits needed before blood cancer is diagnosed is significantly higher than for other cancers as illustrated by the latest CPES data below. This is partly due to the fact that common symptoms of blood cancer, such as back pain, tiredness and bruising, are experienced by many people who don't have blood cancer and that a GP will see, on average eight cases of cancer per year, one of which will be blood cancer.

Key data from latest (2017) Cancer Patient Experience Survey¹¹

Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?

¹⁰ <https://www.nice.org.uk/guidance/ng47/resources/haematological-cancers-improving-outcomes-pdf-1837457868229>

¹¹ <http://www.ncpes.co.uk/index.php/reports/2017-reports>

Type of Cancer	Proportion who saw their GP their GP 3 or 4 times
Breast	2.4%
Colorectal	13.7%
Prostate	12%
Lung	15%
Blood	16.9% - HIGHEST AMONGST ALL CANCER GROUPS

The prognosis of some blood cancers, such as myeloma and Acute Myeloid Leukaemia (AML), would significantly benefit from earlier diagnosis but too many are being diagnosed via emergency presentation as illustrated by the figures below.

Proportion of diagnoses presented as an emergency¹²

Type of Cancer	Proportion of cases presented as an emergency
Breast	5%
Colorectal	26%
Prostate	10%
Lung	39%
All blood cancers	28%
Acute myeloid leukaemia	54%
Multiple myeloma	37%

Analyses by the NCIN on the route to diagnosis (2006-2008) have shown that for AML, myeloma and NHL emergency presentation was more common amongst deprived populations.¹³

NHS England should progress with Recommendation 22 of the 2015 Cancer Strategy which suggested a process through which patients can self-refer for a first investigative test via a nurse telephone triage, if they have a red-flag symptom that would always result in a test¹⁴. We also support the recommendation made by the All Party Parliamentary Group on Blood Cancer that GPs should routinely undertake a simple blood test when a patient displays one or more blood cancer symptoms¹⁵.

¹² www.ncin.org.uk/publications/data_briefings/routes_to_diagnosis_exploring_emergency_presentations

¹³ http://www.ncin.org.uk/publications/data_briefings/deprivation_and_blood_cancer_survival_in_england

¹⁴ https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

¹⁵ APPG on Blood Cancer report, January 2018,

https://bloodwise.org.uk/sites/default/files/documents/appg_report_on_blood_cancer.pdf

Piloting a vague symptoms pathway, also recommended by the Cancer Taskforce report 2015, and establishing these pathways in all Cancer Alliances by 2023 should be a priority. Rare and less common cancers can present with vague symptoms, so a clear pathway for vague symptoms, from GP to secondary care, that includes safety netting to ensure all patients have cancer ruled out, diagnosed or another condition diagnosed, is essential to stop people from repeatedly visiting GPs or being 'ping-ponged' from primary care to secondary care. The development of a vague symptoms pathway also has the potential to improve productivity and efficiency of the NHS.

We welcome the ten pilot Rapid Diagnostic and Assessment Centres (RDACs) as "one-stop shops" to diagnose patients with vague or unclear but concerning symptoms, often characteristic of hard to diagnose cancers like blood cancers. We look forward to the evaluation of these centres expected in December 2018 and to understanding what proportion of the people referred to these centres were suspected of having blood cancer¹⁶.

We note, however, that clinical opinion provided to Bloodwise suggests that while non-specific lymphoma symptoms could be diagnosed more quickly via RDACs, many blood cancers require blood tests which are already available. The highly specific nature of referral pathways and symptoms being investigated by the RDACs could also mean blood cancer is missed.

Bloodwise, like many other charities, are working to inform primary care and the public about the symptoms to look out for. We would like support from NHS England and the Department of Health and Social Care for these initiatives.

c. People can maintain a good quality of life during and after treatment?

As stated above, the experience of many people living with blood cancer is very different to people with solid tumour cancers. NHS England should ensure that people living with blood cancer are able to access specific emotional and psychological support.

Alongside cancer, mental health is a major Government priority. We are looking for reassurances from NHS England and ministers that the significant mental health needs of people with cancer, and blood cancer specifically, are being considered as part of the both programmes and of work.

For example, 3000 mental health therapists have been co-located in GP surgeries. A parliamentary answer¹⁷ confirmed that cancer as a general condition forms part of the training. Whilst appreciating the complexity of such training, we are seeking reassurance that people living with blood cancer can rely on the therapists to have an understanding of the differences between their disease and solid tumour cancers.

¹⁶ House of Commons written answer, 134294, 29 March 2018

¹⁷ Written Answer 150005 to Henry Smith MP from Steve Brine MP, 5 June 2018

d. People with cancer have a good experience of care?

Care co-ordination is very challenging for blood cancer patients, particularly as they move between local and specialist haematology teams, and also between haematology and oncology. Cancer Alliances should be vehicles for better care co-ordination, allowing patients to move seamlessly between care providers.

Macmillan Cancer Support has undertaken extensive work on the role of Clinical Nurse Specialists and, in particular, highlighted the fact their increased workloads has included them undertaking work, such as rebooking appointments, which does not need a CNS intervention. In partnership with Imperial College Hospital, Macmillan have developed a navigator role to help people living with cancer understand and access local support. We welcome this initiative¹⁸.

3. *How can we recruit, train and retain the workforce to deliver the changes we need and priorities you have shared?*

The complexity of blood cancer treatment and recovery requires specialist multi-disciplinary teams (MDTs) to be assembled for patients depending on their disease, treatment and symptoms. The rarity of some blood cancers means that these teams must be assembled from different specialist care centres across the UK. New technology can make it significantly easier for such MDTs, and we would urge NHS England to consider the role of digital innovation in improving access to MDTs, and also in care co-ordination, within the 10-year plan.

We are concerned about the Royal College of Pathologists' prediction that there is expected to be a 28% vacancy rates amongst histopathologists by 2021¹⁹.

As discussed above, one of the major challenges is the need to ensure people living with blood cancer as a chronic condition are able to access mental health and emotional support. Therefore, any consideration of the 'cancer' workforce needs to take a holistic approach to the experience of patients beyond their purely clinical treatment and ensure there is sufficient psychological support.

4. *How can we address variation and inequality to ensure everyone has access to the best diagnostic services, treatment and care?*

We understand that Cancer Alliances have a strong role to play in reducing national variation in care and services, and we support their ongoing progress in this area. Measures to address fragmentation in commissioning between local and national commissioners would also help to address variation in access to services suffered by blood cancer patients with complex needs across the UK.

¹⁸ <https://www.imperial.nhs.uk/our-services/cancer-services/macmillan-cancer-partnership/macmillan-cancer-navigators>

¹⁹ Reported to the APPG on Blood Cancer, 4 September 2018

As mentioned above, ensuring that haematological malignancy diagnostic services are fully integrated will enable specialists to have timely access to the fullest information about a person's blood cancer at the point of diagnosis.

Within blood cancer, we would support the roll out of education programmes within Black, Asian and Minority Ethnic communities to ensure information about symptoms, how to access treatment, and how to access recovery services, is equally available to all.

The incidence of blood cancers does not vary across socio-economic groups. Despite this, significant differences are seen in the outcome for patients depending on the level of deprivation in the area in which they live. Significantly lower survival is evident for people living in more deprived areas with chronic lymphocytic leukaemia, chronic myeloid leukaemia, Non-Hodgkin lymphoma and myeloma.²⁰ A recent study by the University of Sheffield demonstrated that adults living with acute lymphoblastic leukaemia in deprived areas of England have 15-20 per cent higher risk of dying.²¹

Possible explanations for this pattern include differences in the stage of disease at presentation, the impact of comorbidities and access or compliance with effective treatments.

²⁰ http://www.ncin.org.uk/publications/data_briefings/deprivation_and_blood_cancer_survival_in_england

²¹ <https://www.sheffield.ac.uk/news/nr/leukaemia-deprived-areas-poorer-survival-1.760259>