

Charities call on NHS to treat blood cancer equally in decision-making

Blood cancer is the UK's third biggest cancer killer, with over 15,000 deaths a year. It is the UK's fifth most prevalent cancer, with 40,000 new diagnoses every year. Yet, from awareness, to diagnosis, to information, care and support, blood cancer patients are less likely to see their needs fully met than patients with the four most common cancers- breast, colorectal, lung and prostate.

The Blood Cancer Alliance, a group of 15 leading blood cancer charities, undertook an evidence review to inform a new report that explores the unmet needs of people with blood cancer across the UK. The key findings include:

- 3 out of every 10 blood cancer (30%) cases in England are diagnosed after presenting to the NHS as an emergency – when their disease is likely to have progressed and they have significant health complications. This is compared with just 3% in breast cancer, 7% in prostate cancer, and 21% in colorectal cancer.
- The number of patients who had to see their GP five or more times before being referred for specialist treatment is double that of patients with other cancers in England.
- 10% fewer blood cancer patients report that they fully understand their condition than those with solid tumour cancer.
- The median impact on a blood cancer patients' finances is £181 per month, compared with £120 in breast cancer and just £52 in prostate cancer.

The Alliance is now calling for the NHS to treat blood cancer patients as equal to those with the four most common cancers in NHS policy making and decision making. As a basic measure, the Alliance is asking that NHS England add data on blood cancer patients to the Cancer Data Dashboard it uses as a key information source for cancer strategies. This would give NHS England overview of the five most common, and biggest cancer killers.

Caitlin Farrow, Chair of the BCA's Policy Group, said: *People with blood cancer are less likely than people with other cancers to report positive experiences across their care and treatment. The NHS leadership and the Government must therefore give greater focus to their specific needs and improve their experience.*

In terms of diagnosis alone, the number of blood cancer patients who had to see their GP five or more times before being referred to specialist treatment is double that of patients with other cancers. This disparity is unacceptable, and is just one example of where blood cancer patients fare worse than patients with more common cancers.

Adding blood cancer information to its principal cancer data dashboard would mean NHS England could take an equal approach, understanding and considering the needs of blood cancer patients alongside those with the four most common cancers.

Henry Smith MP (Chair of the APPG on Blood Cancer): *“Blood cancer is the UK's third biggest cancer killer, yet it is often forgotten by leading policymakers when it comes to policy reports. It is unacceptable that from awareness, to diagnosis, to information, care and support the needs of blood cancer patients are too regularly neglected.*

“Ensuring blood cancer is treated equally to the four most common cancers in policy making and decision making is imperative to improving outcomes for blood cancer patients. New cancer policies and tactics must be tested in more complex cancers like blood cancers, to make sure they work for blood cancer patients. The NHS and Government have a pressing

responsibility to provide blood cancer patients with fair treatment and guarantee cancer policy takes account of their specific and complex needs.”

NOTES TO EDITORS

- The Cancer Data Dashboard was developed as a result of the 2015 Cancer Strategy for England. The integrated dashboard is managed by Public Health England and brings together data from CCG, provider and national levels.
- It provides a broad set of indicators that deliver a granular understanding of local health economy performance across 4 major site-specific cancers only; Breast, Colorectal, Lung and Prostate. The dashboard is principally for the eyes of clinical leaders, commissioners, providers and policy/political stakeholders, giving a top-level view of clinical performance.
- The dashboard includes indicators for Incidence, Survival (1yr, 5yr and 10yr), Mortality, Patient experience scores, Route to Diagnosis, Operational service performance, local smoking rates and screening uptake data.
- The five most common cancers are:
 1. Breast
 2. Prostate
 3. Lung
 4. Bowel
 5. Blood
- The five biggest cancer killers are:
 1. Lung
 2. Bowel
 3. Blood
 4. Prostate
 5. Breast

KEY EVIDENCE REVIEW FINDINGS

Psychological support

- A blood cancer diagnosis, and blood cancer treatment, can have a very significant impact on patients' mental health. CPES data shows that **blood cancer patients are less likely to be offered information about psychological support than patients with other cancers** (86% to 88%). The contrast is particularly significant when comparing blood cancer patients with breast or prostate cancer patients (86% to 92%/91%).
- The way in which a blood cancer diagnosis is delivered to patients is incredibly important. Sensitivity is paramount to supporting patients to deal with the emotional impact of their diagnosis. The percentage of blood cancer patients **reporting that their diagnosis was handled sensitively was lower than among patients with other cancers, and particularly when compared with breast cancer**. (Haematology scores: England 84%, Scotland: 86%, Wales 79%. Breast Scores: England 89%, Scotland: 89%, Wales 88%). Indeed, only 38% of patients reported to Blood Cancer UK in a 2019 survey that their clinicians were not definitely sensitive to their emotional needs at diagnosis.

- While research has yet to be completed in the UK as to why the disparity in support for emotional and psychological patient need exists between cancer types, it is important we seek to close this gap. The complexity and uncertainty of a blood cancer diagnosis often leads to severe emotional impact on the patient. **It is unacceptable that they are less likely to be offered support than if their diagnosis was for a solid tumour cancer.**

Diagnosis

- Early diagnosis is critical to increasing the chance of positive outcomes in cancer treatment. This is as true in blood cancer as it is in other cancers. However, **blood cancer patients experience significantly worse delays to diagnosis than patients with breast, lung, colorectal and prostate cancers.**
- It remains the case that **3 out of every 10 blood cancer (30%)** cases in England are diagnosed after presenting to the NHS as an emergency – when their disease is likely to have progressed and they have significant health complications. This is compared with just **3% in breast cancer, 7% in prostate cancer**, and 21% in colorectal cancer (Blood Cancer Dashboard data).
- The number of patients who had to see their GP five or more times before being referred for specialist treatment is **double that of patients with other cancers in England** (5% vs. 10% CPES 2019), and nearly double in each of the regions.
- The **disparity** between patients' experience of blood cancer diagnosis in comparison to other common cancers needs to be **addressed urgently** in order to improve blood cancer outcomes, and achieve equity of treatment of patients across the whole of cancer.

Information

- Blood cancers are complex conditions, often with incredibly complex treatment options. It is vital that patients are able to understand their condition and their options.
- This is why it is of concern that over **10% fewer blood cancer patients report that they fully understand their condition than those with solid tumour cancer.** There may be correlation between this and the fact that blood cancer patients are more likely to report that their test results were not explained to them in an understandable way, and are less likely to report that the potential side effects of treatments were explained to them.
- There needs to be **greater focus on ensuring information is presented to patients with the same clarity as it is to other cancer patients.**

Public awareness

- Blood cancers are complex conditions, and symptoms are often difficult to identify by both patients and healthcare professionals. Despite that issue, only **one Government sponsored national cancer public awareness campaign has specifically mentioned blood cancer symptoms.** This is unacceptable, particularly in the context of the disparity in diagnosis times between blood cancer and other cancers.

Financial

- Cancer has the ability to have a worrying impact on a patient's finances, as well as their physical health. Time taken off work to attend treatment is a major cause, as well as the sheer cost of attending hospital for treatment, and costs associated with adapting patients' lives and lifestyle to accommodate the physical impact of the disease and its treatment.
- **Blood cancer patients are likely to suffer a more significant impact on their finances than those with the big four cancers.** The median impact on a

blood cancer patients' finances is £181 per month, compared with £120 in breast cancer and just £52 in prostate cancer.