

## House of Commons debate on the Cancer Strategy Thursday 22 February 2018

### Introduction

Bloodwise is the UK's specialist blood cancer 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. Blood cancer is a complex and much misunderstood disease area. Bloodwise works with all those in the sector to raise awareness, and works to ensure that all those affected get the best treatment, care and support.

### Blood cancer – the facts

- Blood cancer is the third biggest cancer killer in the UK<sup>1</sup>
- It is the fifth most common cancer overall<sup>2</sup> with over 230,000 people living with blood cancer.<sup>3</sup>
- Blood cancer patients had to see their GP significantly more times before being referred to hospital compared to other cancers. More than one in three (35%) had to see their GP three or more times, compared to only 6% for breast and 23% for all tumour types<sup>4</sup>
- Blood Cancer is by far the most common cancer amongst people aged under 30<sup>5</sup>.

### Blood cancer – the issues

#### Early diagnosis

Diagnosing some types of blood cancer 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<sup>6</sup> should be reviewed to ensure that all people with blood cancer are benefitting from early and accurate diagnosis. GPs should be encouraged to ask for a simple blood test for people displaying one or more blood cancer symptoms.

#### Living with and beyond cancer

The Cancer Strategy says that all cancer patients will have had access to a *Recovery Package* by 2020. This helps patients once their treatment has ended to return to their normal lives. It includes a health needs assessment, care planning, health and wellbeing events and a review of cancer care. However, the Package is based around the needs of people with solid tumour cancers. In recent survey responses, people with chronic leukaemia and relapsing myeloma or lymphoma say that terms such as 'beyond cancer' and 'post-treatment' are not applicable to them. In order to ensure that people with blood cancer receive sufficient on-going support, NHS England should consider how all

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

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

<sup>3</sup> Bloodwise figures taken from 10 year prevalence figures.

<sup>4</sup> National Cancer Patient Experience Survey 2016, <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

<sup>5</sup> ONS registration statistics 2015

<sup>6</sup> 'Achieving World Class Cancer outcomes: Taking the strategy forward' <https://www.england.nhs.uk/cancer/strategy/>

blood cancer patients can benefit from after-care support including ensuring the Recovery Package takes account of the unique characteristics of blood cancer.

## **Patient experience**

5,000 people a year with some slow-growing blood cancers, instead of starting treatment straight away, are put on a regime of “watch and wait”. 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 27,000 patients being monitored in this way and their families and can lead to psychological distress. Tailored psychological support must be made available to those patients on “watch and wait”.

The **National Cancer Patient Experience Survey (NCPES)** was first undertaken in 2010. It:

- monitors national progress on cancer care;
- provides information to drive improvement;
- assists commissioners and providers of cancer care;
- informs the work of the various charities and stakeholder groups supporting cancer patients.

In July 2016, the National Data Guardian, Dame Fiona Caldicott, published the findings of her review into the security of health and social care information and recommended that the public should be engaged about how their information is used. The Government accepted the recommendations including the implementation of a patient opt out. Procurement for the next three survey waves, which cover the period April 2018 – August 2021, is due to commence imminently. We are concerned that the NCPES will not continue to deliver the same high-quality data as the current survey model is not likely to be viable under the terms of the national data opt-out model scheduled to be introduced in May 2018. This is extremely concerning and will endanger the nation’s future understanding of cancer care in England.

## **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. Despite this ambition, patients often find services fragmented and therefore adds stress to their experience. This can be a particular problem for blood cancer because patients are often treated in haematology units rather than oncology. Cancer Alliances should reduce fragmentation between different stages of care for blood cancer patients by acknowledging and bridging recognised gaps between oncology and haematology departments and between primary and secondary care.

## **The Cancer Dashboard**

[The Cancer Dashboard](#)<sup>7</sup> has been developed by NHS England following a recommendation in the Cancer Strategy. It allows clinicians and others to compare performance of Clinical Commissioning Groups and identify areas for improvement. However, it only covers the four most solid tumour cancers (lung, breast, prostate and colorectal) which equates to less than half of all cancer cases. NHS England should actively work to include blood cancer in the dashboard, as the 5<sup>th</sup> most common cancer, to ensure decisions about future services don’t disregard these patients.

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<sup>7</sup> <https://www.cancerdata.nhs.uk/dashboard#?tab=Overview>