



All Party Parliamentary Group on Blood Cancer

Inquiry into Blood Cancer Care in the NHS

Call for Written Evidence

About the APPG on Blood Cancer

The purpose of the APPG on Blood Cancer is to raise awareness and promote the needs of blood cancer patients in parliament, with government, NHS, and charity stakeholders, and ensure policies affecting blood cancer patients, their families and carers are patient-centred and evidence-based.

Blood cancer is the UK's third biggest cancer killer, claiming more lives each year than breast or prostate cancer. Blood cancer is the fifth most common cancer with almost 38,000 people diagnosed every year and 230,000 people living with blood cancer in the UK. However, the knowledge and awareness of blood cancer among the general public and political audiences is very low.

Introduction to the inquiry

The All Party-Parliamentary Group on Blood Cancer launched (Wednesday 15 March) an inquiry into blood cancer care in the NHS. The inquiry, the first undertaken by the APPG, will look at all aspects of blood cancer, including awareness, diagnosis, patient experience, commissioning of services and clinical research.

Blood cancer is a complex and often misunderstood disease area. There are many differences in the patient journey in comparison to those of other cancers, and this inquiry will seek to understand more about the care patients are receiving, identify areas of best practice and recommend where improvements are required.

The inquiry will look at five areas of care identified as priorities in the Independent Cancer Taskforce's report [Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020](#), and will seek to identify what services patients require, where their needs are currently being met, and where services need to be extended or amended to account for the specific needs of blood cancer patients.

The inquiry will gain expert opinion from patients, clinicians, researchers and NHS staff, summarising findings and recommendations in a report to be published later this year.

The APPG will hold oral evidence sessions and also invite written evidence from stakeholders including patients, carers, patient organisations, and all those involved in delivering blood cancer care.

The inquiry will cover five main areas, reflecting five of the Cancer Taskforce's priorities:

- Public awareness and early diagnosis
- Patient experience
- Living with and beyond blood cancer
- Access to medicines and support for research
- NHS commissioning

Call for written evidence

The All Party Parliamentary Group on Blood Cancer inquiry into Blood Cancer in the NHS welcomes views from all those involved in using or delivering blood cancer care on how current services are provided, identify where there are gaps in provision, and how improvements could be made.

While the APPG on Blood Cancer is a cross-UK group, health services are devolved to each of the nations. Though the inquiry will focus on the implementation of the Cancer Strategy for England, the group is keen to learn from examples of good practice in Scotland, Wales and Northern Ireland and would therefore encourage representatives in the devolved nations to contribute to the inquiry.

To maximise engagement with patients, carers and patient organisations the inquiry is also inviting responses via an online form <http://bloodwise.appg.sgizmo.com/s3/>

The deadline for online and written responses is 27 April. The APPG Secretariat, provided by Bloodwise, will be managing all the response and can be contacted at appg@bloodwise.org.uk

Terms of reference

1. Public awareness and early diagnosis

Blood cancer is the 3rd biggest cancer killer in the UK, and 5th most common cancer. However, public awareness of the disease is still very low. The signs and symptoms of blood cancer are often vague and have similarities to other benign conditions. This can cause patients to be misdiagnosed, or prevent them from seeking medical attention as quickly as they should.

Questions

- 1.1 What improvements can we make to ensure we diagnose blood cancer early?
- 1.2 What types of blood cancers are most challenging to diagnose early and why?
- 1.3 How can we improve awareness of the signs and symptoms of blood cancer?
- 1.4 What support do patients need at diagnosis?
- 1.5 Are there any improvements needed at this stage, and what are they?
- 1.6 What can be done to improve awareness of blood cancer among the general public, decision makers and healthcare professionals?

2. Patient experience

The Cancer Strategy pledges to put patient experience on a par with clinical outcomes. The inquiry is interested to hear what the patient experience is like in blood cancer, and where improvements could be made. The inquiry is keen to hear any examples of blood cancer patients require a specific element of care or support that may not be gained from standard care, or any areas where patient experience is better or worse than in other cancers.

Questions

- 2.1 What areas of patient care are the most successful at meeting patients' needs?
- 2.2 Which areas of patient care are the least successful at meeting patients' needs?
- 2.3 In what way can the blood cancer patient experience differ from that of solid-tumour cancers?
- 2.4 What kind of support or intervention would bring about the most significant improvement in patient experience, and how could these be achieved?

3. Living with and beyond blood cancer

Support in this area is of particular relevance to blood cancer patients – many of the chronic blood cancers mean people can live with their blood cancer for many years. Patients on “watch and wait” may have to live with their blood cancer for years before treatment has even begun. The differences in the treatment and care pathway of some blood cancers means specific packages of care may be required.

Questions

- 3.1 What is your experiences Cancer Recovery Package?
- 3.2 Does the current Cancer Recovery Package meet the needs of blood cancer patients?
- 3.3 What can be improved?
- 3.4 What should best practice care and support look like for people living with and beyond blood cancer?
- 3.5 Which areas of care for those living with and beyond blood cancer are in most need of improvement?

4. Developing a modern service, including access to new medicines and support for research

Access to new drugs is crucial for cancer care, particularly in blood cancer. Treatment almost entirely consists of drugs, as the common treatments of surgery and radiotherapy used for solid tumour cancers are rarely appropriate in blood cancer. The inquiry will look at the experience of blood cancer patients in accessing new and innovative treatments, and whether their experience differs from other areas of cancer. On the research

side, the UK is a world leader in blood cancer research, and the inquiry will look at how the research sector can be maintained and grown in the years ahead.

Questions

- 4.1 Are blood cancer patients able to access the treatments they need?
- 4.2 Are their experiences similar or different to other clinical areas in accessing treatments?
- 4.3 What are the major challenges facing blood cancer research, and how these can be overcome?

5. NHS commissioning

There have been many changes to NHS commissioning processes and structures, in particular the commissioning of specialised and highly specialised services relevant to blood cancer. The inquiry seeks to understand how commissioning of these services, such as stem cell transplants, are working for patients, and identify any areas of improvement required.

Questions

- 5.1 Does the commissioning of NHS services work for blood cancer patients?
- 5.2 Are there significant areas where commissioning is working well/poorly?
- 5.3 Are there any improvements needed in the commissioning of services, and what are they?
- 5.4 What should the focus of Cancer Alliances and Vanguard be to improve patient outcomes and experience in blood cancer?

Submitting your evidence

All submissions should be sent to Chris West at the APPG Secretariat, by email to appg@bloodwise.org.uk or by post to:

Chris West
Secretariat APPG Blood Cancer
Bloodwise
39-40 Eagle Street
London WC1R 4TH

Evidence should be submitted by 5pm on Thursday 27 April 2017.

If you have any questions please do not hesitate to contact appg@bloodwise.org.uk

We may publish the written or online evidence that we receive. If you do not wish your evidence to be made public then please let us know.

Next steps in the inquiry

A report, based on the oral and written evidence with recommendations on improving blood cancer care in the NHS will be published later in the year.