

Blood Cancer Alliance research project for tender: **Blood cancer data across the UK**

About the BCA:

The Blood Cancer Alliance (BCA) is a membership organisation, made up of 14 blood cancer charities. To date, the work of the BCA has focused on understanding the experience of those diagnosed with blood cancers, how these are common to the many types of blood cancer, and how working together can be more effective in making change on the challenges those affected by blood cancer face.

The BCA sees data, information and evidence as important tools in the understanding and monitoring of patient experience over time. This project aims to support our needs in this area.

Tender process:

- Applications to be received by 6pm on 7th December 2023
- Interview with Chair of the BCA Policy Group: 12th, 13th and 14th December 2023
- Tender awarded by 20th December 2023

Deadline for work to be delivered:

- Start in January 2024, subject to contracting and be delivered in March 2024.

The issue:

Blood cancers are a heterogeneous group of cancers; some are acute, whilst others develop slowly. Some are highly curable, whilst others are incurable and require long term treatment. There are varying outcomes dependent on age at diagnosis, both due to biology of disease and the available treatment options.

In order to fully understand the impact of the different factors on blood cancer patient outcomes, access to data is vital. Charities play a huge role in holding decision makers to account, but they cannot do this without data being made available to them. Access to data across the blood cancer diagnosis pathway varies by nation. There are also inconsistencies within UK nations that prevent analysis.

Ideally, these data sets must be presented at varying degrees of specificity, so all groups can work at different levels of specificity (all blood cancer vs. broad cancer types vs. one condition) to achieve change and to better understand inter and intra group differences.

Essential research questions:

- What data on blood cancer patients:
 - Is collected and not in the public domain at all?
 - Is collected, but only published at all blood cancer level?
 - Is collected but only published at individual disease type level (e.g. all leukemia, all lymphoma, all myeloma, other)?
 - Is collected but only published in groups based on ICD-10 codes (e.g. B cell acute lymphoblastic leukemia?)
- All questions above to be examined in each of the four UK nations (England, Wales, Scotland, Northern Ireland)
- Data of particular interest are:
 - Quality of Life
 - Cancer waiting times
 - Emergency presentation
 - Stage of diagnosis
 - Faster diagnosis standard

Desirable research questions (if budget allows):

- What efforts are made to ensure charities/patient groups are aware of publicly available data?

Outputs:

- 1-2 page document outlining the issue and making recommendations for data that need to be made available to charities/in the public domain
- A visual summary (e.g. heat map, traffic light system) to illustrate the issue
- 2-3 social media cards for the BCA to use to promote the work

Evaluation metrics:

- Delivery of the project to time
- Obtaining meetings with data stakeholders using the document

Budget: £7,500

Points of contact:

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