

Do you have any suggestions for how to raise awareness of the causes of cancer and how it can be prevented? (500 words)

While the underlying causes of solid tumour cancers are relatively well understood, this is not currently the case for many blood cancers. More work must be undertaken to understand this further - particularly if we are to achieve evidence-based strategies and public awareness campaigns on prevention that support reduced incidences for all cancers, including blood cancer.

Many blood cancer patients are at heightened risk of secondary cancers, which patients and community and primary care providers must have a better understanding of in order to access or give good information on preventative measures that can reduce patient risk. Solid tumour cancer patients are also at risk of developing blood cancer as a secondary cancer, which must also be effectively communicated. Targeted awareness campaigns at community level should be explored by the Government to address these issues.

It is also important to note that awareness alone will not prevent cancer. It is essential that people also have awareness of, and access to support for healthier behaviours which reduce the risks of cancer, such as high-quality nutrition, regular exercise and help to stop smoking. This support needs to be delivered in a way that recognises and targets health inequalities.

Do you have any suggestions for how to raise awareness of the signs and symptoms of cancer? (500 words)

The symptoms of blood cancer are often overlooked and are non-specific. Therefore targeted, public awareness campaigns are important to educate people about these signs and symptoms. The Blood Cancer Alliance recommends the Government should deliver a national public awareness campaign focusing on the potential signs and symptoms of blood cancer. A national blood cancer awareness campaign could be linked to the 'Help Us Help You' campaign, however this must take into account existing health inequalities, and be accessible to all groups. Careful targeting and tailoring will be necessary to make sure any public awareness campaigns include those who are not fluent in English, those who are not digitally literate, and people from disadvantaged socio-economic groups.

Different ages, genders and ethnicities experience different signs and symptoms of blood cancer and may require uniquely targeted awareness campaigns as a subsidiary of a national awareness campaign. For example, blood cancer is predominantly experienced by older patients, and awareness campaigns should therefore in principle be targeted at people with older age groups. Leukaemia is also the most common childhood cancer, and therefore a campaign targeted toward parents on the signs and symptoms of the disease would be effective.

Alongside a targeted public health campaign, the Alliance wants to see an improvement in signs and symptoms information available within primary care settings, and community care and support outlets, such as pharmacies.

The Alliance would particularly like to see an increase in the awareness of the signs and symptoms of blood cancer among GPs. Where routes to diagnosis are clear, for example the

simple blood tests available for leukaemia, it should be ensured that wider policies and challenges do not prevent this from happening. Examples here include ensuring adequate awareness of symptoms and appropriate actions among GPs, and ensuring that practical or logistical challenges such as shortages of blood test tubes do not have a negative impact on diagnoses.

We would also like to see more funding and resources put toward increasing the availability and usage of Non-Specific Symptom pathways in primary care settings. Awareness of the NSS pathways among GPs should also be increased. These changes would be beneficial for both blood cancer patients and solid tumour patients.

Do you have any suggestions for how to get more people diagnosed quicker? (500 words)

Delayed diagnosis limits treatment options for patients and negatively impacts quality of life and survival for many blood cancer patients. For example, Myeloma UK's recent report "A Life Worth Living" reports new survey findings showing that 49% of myeloma patients who had a delayed diagnosis experienced a high negative impact on their quality of life, compared to 30% of myeloma patients who had a timely diagnosis. The Blood Cancer Alliance's own research on the unmet needs of people with blood cancer highlights that people with blood cancer are much more likely than other cancer patients to have to see their GP multiple times before receiving an urgent referral, and around 30% of blood cancers are diagnosed via emergency routes, which is much higher than for other types of cancer.

It is therefore imperative that the Government deliver earlier diagnoses for blood cancer patients, which is known to be a longstanding challenge and warrants specific attention and action. The Alliance would like to see specific action on improving blood cancer diagnosis throughout the strategy, distinct from but with equal prominence to solid tumour cancers.

There are several ways that the Government could take firmer action on blood cancer diagnosis, including:

- Implementing early diagnosis targets that include non-stageable cancers, for example introducing a specific target to reduce the proportion of blood cancer diagnoses made in emergency care. Currently, around 30% of blood cancer diagnoses in England are made through emergency routes (such as presentation in A&E) according to the Blood Cancer Alliance's research on unmet needs in blood cancer
- Improving best practice guidelines for diagnosis
- Increasing resources available for, and awareness of, those best practice guidelines,
- Improving referral pathways for non-specific symptoms, for blood cancers and solid tumour cancers. This should include piloting self-referral in NSS pathways/Rapid Diagnostic Centres
- Investing in improving and growing haematology diagnostic infrastructure, which must include additional funding for haematology consultants, nurses, pathologists, pathway navigators and other personnel; and diagnostic technology such as imaging and pathology services
- Investing additional resource into the faster diagnosis framework, especially in order to expand NSS pathways while avoiding attrition in other parts of the system

- Consistently evaluating the performance of NSS pathways/Rapid Diagnostic Centres for blood cancers, with best practice learnings and proven approaches shared nationally and embedded into national standards
- Improved screening for secondary cancers. Provision of routine secondary cancer screening after a primary cancer diagnosis is at present highly variable across geographies. We recommend implementation of a new guideline and KPIs to ensure all patients known to be at higher risk of a secondary cancer are being regularly monitored
- Additional funding for haematology pathology services to ensure there is capacity to support the volume of diagnostic activity required in the wake of the pandemic as well as to maintain capacity for translational research into blood cancer diagnostic tools and processes

Do you have any suggestions for how to improve access to and experiences of cancer treatment? (500 words)

It is crucial that blood cancer patients have equal access to clinical trials, equitable to solid tumour patients. There is also extensive work to be done to remedy the impact of COVID-19 on clinical trials. For example, during the pandemic, patient enrolment for three out of four of Blood Cancer UK's funded advanced clinical trials was suspended, setting these trials back significantly. As part of the implementation of the Clinical Research Delivery Framework, the Government should provide regular reporting on the number of clinical trials underway in the NHS, identified by condition, phase, and location, and these should be benchmarked to pre-pandemic levels. This information should be provided to all NHS Trusts, as well as to all blood cancer patients, to deliver greater awareness of, and access to, trial participation.

It is also imperative that the 10 Year Cancer Strategy prioritises stopping blood cancer patients from being diagnosed as emergency presentations – as outlined in the previous answer this has a deeply negative impact on patient's experience and can be rectified with proper processes. Whilst additional funding to tackle the overall NHS backlog is welcome, targeted action is needed to ensure more blood cancer patients are diagnosed sooner, and to tackle long waiting lists for blood cancer treatments.

We also want to see patients be more involved in decision making about their care, including through the co-production of treatment pathways for blood cancer patients, ensuring that people's lived experiences are considered when designing those pathways. Engaging marginalised communities to develop targeted information campaigns should also be a priority, to ensure harder to reach groups have the proper access to resources and are considered in planning treatment pathways. All patient groups should have access to peer support, as well as access to relevant, up to date information to support informed decision making.

Supportive medical measures put in place during the pandemic should remain, such as providing treatment closer to patients homes, covid-safe centres, access to newer medicines, community testing, and flexibility to access care either in person or remotely.

Access and experience of care would be improved by assigning all blood cancer patients a named CNS for the duration of treatment and for long-term support. Although this is already a target in the NHS Long Term Plan, there is currently no clear tracking of the implementation of this among blood cancer patients. We are calling for improved transparency, with regular reporting on progress broken down by specialty.

The Blood Cancer Alliance's Unmet Needs report revealed that blood cancer patients experience disproportionately negative financial impacts compared with other cancer patients.. The median impact on a blood cancer patients' finances is £181 per month, compared with £120 in breast cancer and £52 in prostate cancer. The current economic climate is likely to exacerbate the negative financial impact of living with cancer. Wholesale review of the financial support available to cancer patients and their families, with a focus on those from more disadvantaged groups is urgently required.

Do you have any suggestions for how to improve after-care and support services for cancer patients and their families? (500 words)

The needs of blood cancer patients are distinct from solid tumour cancer patients, and so unique and tailored care is required. This must be developed in partnership with blood cancer patients and the patient advocacy community, to ensure that those lived experiences and issues are fully integrated into plans.

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%). A recent UK study also demonstrated that 50% of blood cancer patients reported concerns related to their psychological wellbeing.

The Alliance is calling for a number of actions to improve the psychological and other support available to blood cancer patients:

- Better access to written or multimedia information about the impact of coping with diagnosis and treatment
- Improved awareness of support or peer support groups
- Offering continued access to information and informal/formal support for patients on 'Watch and Wait' – these are patients who have received a blood cancer diagnosis and do not need immediate treatment, but are aware their condition will require treatment at an unspecified point in the future
- Improved links between specialist haematology and community services to ensure after care and support is seamless and patient centred
- More consistent provision of palliative care and end of life support, including advance planning and bereavement support for families
- After-care services available equitably across the country

Do you have any suggestions for how can we maximise the impact of research and data regarding cancer and cancer services in England, including how we can translate research and data into practice sooner?

The Alliance wants the Government to support NHSE in regularly updating and reporting data on blood cancer, which is particularly important for blood cancers as some are

operating using datasets which are out of date, for example the NCIN/NCRAS routes to diagnosis which have not been updated since 2017.

Ensuring data collected can be shared in a timely, efficient way would also contribute to better understanding of blood cancer, and so the Alliance would like to see the Government invest in development systems which can share that data efficiently by making it as public as possible. We'd like to see the Government invest in putting those systems in place without delay, incorporating new technology, personnel, and processes. The fact that some blood cancers cannot be staged must be considered when developing these new data systems. The Alliance would like to see this incorporated by ensuring that early diagnosis targets which focus on staging data include data specific to blood cancers, or, have separate blood cancer measures created.

Finally, we want to see the Government standardise the data collected on blood cancer across the NHS, delivering a clear definition of 'blood cancer' which is consistent across all data sets. This should be in consultation with the blood cancer patient and clinical community. From here, we would like to see this data be aggregated by stage and type, and broken down by demographics including age, gender, ethnicity and location. This improved data collection and reporting must then be used to inform development of new, innovative treatments.