



Inquiry into the impact of COVID-19 on blood cancer services

What is this inquiry about?

One of the groups greatest struck by the COVID-19 pandemic is people with blood cancer. Having blood cancer is a similar risk to being over 80, and vaccines are much less likely to be effective, meaning that the blood cancer community has been shielding for over a year, to their great physical and psychological detriment. It has also impacted blood cancer treatment, emotional support, and diagnosis itself. The long-term impact of this crisis on the blood cancer community, therefore, is yet to be uncovered. The APPG on Blood Cancer and the APPG on Stem Cell Transplantation are holding a joint inquiry, looking into what is required for blood cancer services to be able to recover from the issues that have been caused or exacerbated by COVID-19.

Given that health and, within that, COVID-19 policies are devolved, the inquiry's scope can only consider blood cancer services in England. Although this inquiry will be blood cancer specific, it will consider evidence about the impact of COVID-19 on cancer services more generally, in order to understand the wider context and how blood cancer relates to this. This inquiry will accept evidence from all relevant parties, including clinicians, researchers, NHS, Government, patient organisations and professional bodies. The perspectives of people directly affected by blood cancer will also be used to inform this inquiry.

If you have any questions, please get in touch by emailing public.affairs@anthynolan.org or appg@bloodcancer.org.uk

Inquiry questions

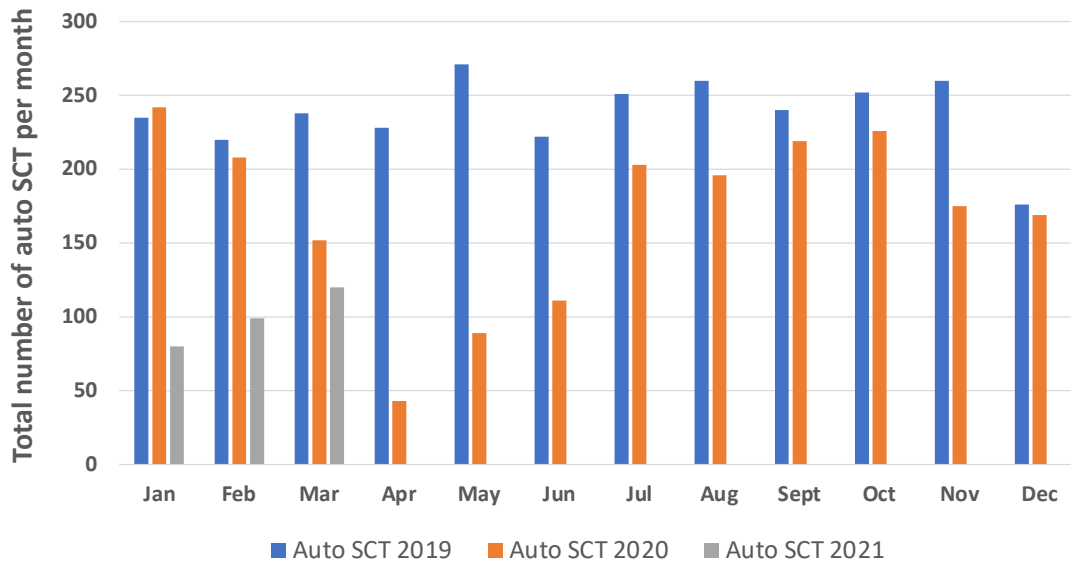
You do not need to answer all the questions, only those you feel are applicable to your experience.

1. What has the effect of the pandemic been on rates of diagnosis, length of waiting times, and types of treatment for blood cancer?

Comments from the British Society of Blood and Marrow Transplantation and Cellular Therapy:

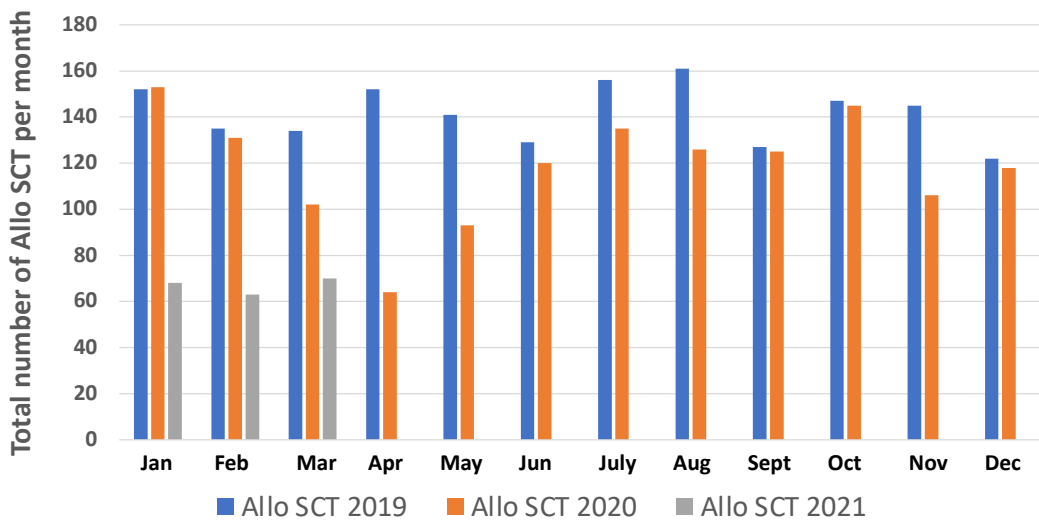
- Rapid NICE guidance was published during the pandemic which provided levels of priority for patients undergoing stem cell transplants.
- The largest delays in treatment were in patients who were undergoing autologous transplants particularly for multiple myeloma.
- There is a wide regional variation depending on pre-existing resources and program resilience.

Auto SCT activity Jan - Dec 2019 and 2020 and Jan - March 2021



Day 0 allo-HSCT activity reported to BSBMTCT registry
Source: BSBMTCT Registry data

Allo SCT activity Jan - Dec 2019 and 2020 and Jan - March 2021



Day 0 auto-HSCT activity reported to BSBMTCT registry
Source: BSBMTCT Registry data

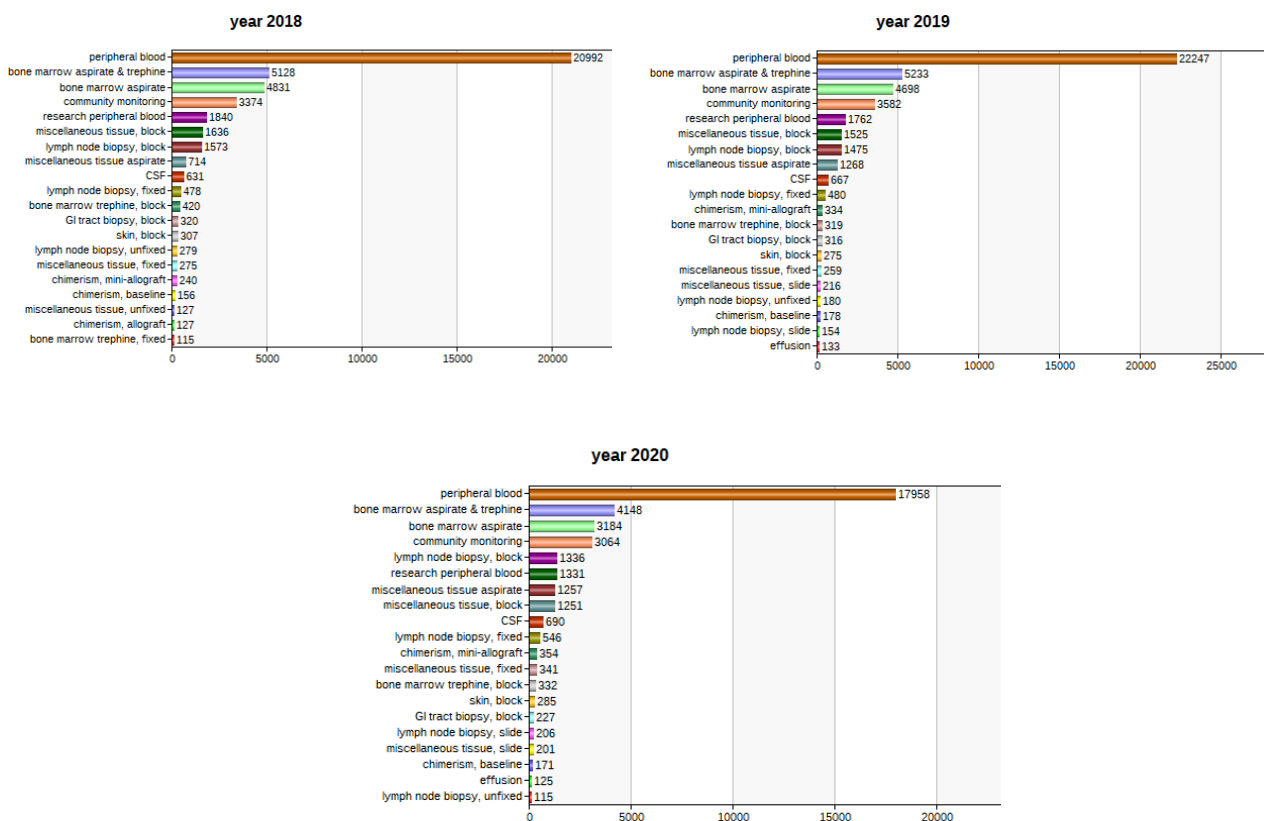
Allo SCT refers to Allogeneic Stem Cell Transplantation

Comments from the UK Myeloma Forum:

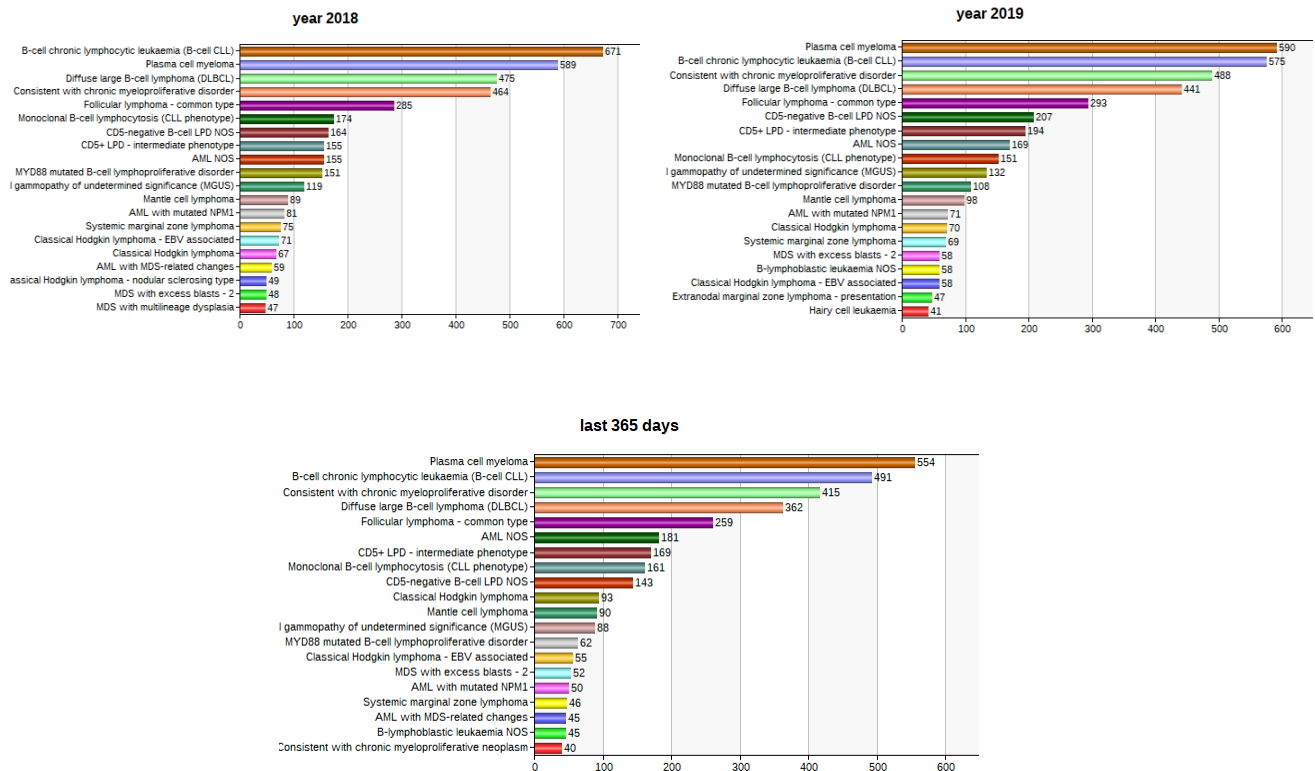
Through the pandemic diagnostic rates for haematological cancers dropped (outlined graphically below) due to multiple factors including reluctance of patients to present, perceived risks of hospital attendances, changes in priorities within the NHS and workforce absences. The data suggesting missed/lower blood cancer diagnosis and delays is reinforced by the recent NHSE Systemic Anti-Cancer Therapy (SACT) uptake report published in Lancet Haematology alongside an ongoing audits of myeloma diagnosis before and through the pandemic which is again highlighting delays. Late presentations will lead to greater morbidity and early mortality alongside a likely surge in presentations evolving as the pandemic eases with potentially more seriously unwell patients in a service under strain with an already exhausted and overstretched workforce.

The falls in both diagnostic rates and reductions in the numbers of samples received by the Haematological Diagnostic Service in Leeds over the last year give some impression of the overall impact of the last 18 months on blood cancer diagnosis.

Haematological Diagnostic service (HMDS), Leeds Specimens received by year



Haematological Diagnostic service (HMDS), Leeds New Diagnosis by year



Waiting times have lengthened and the pausing of Stem cell transplantation programmes, which is of specific relevance to patients with myeloma, has increased uncertainty and risk of early relapse. Due to rapid guidance allowing utilisation of ‘bridging’ treatments in multiple myeloma care must be taken to ensure patients future treatment options are not adversely affected in what is an already complex treatment algorithm. The pausing /stopping of some, particularly supportive treatments (e.g. Bone disease treatments) are also likely to have longer term consequences for patient outcomes.

Changes in working practices have had both negative and positive effects. Positive effects include the embracing of technologies for remote consultation which will have longer term benefits but should be balanced against the increased consultation time they can cause and the risk of missing clinically relevant detail.

The reduction in research activity and greater isolation of patients both in and out of hospital will have had negative impacts on both the individual patient and their family

2. How can NHS England ensure that people with blood cancer, diagnosed before or during the COVID-19 pandemic, receive high quality care and treatment?

Comments from the British Society of Blood and Marrow Transplantation and Cellular Therapy:

- Ensure preservation of workforce i.e. avoid redeployment to other areas
- Ensure preservation of capacity e.g. ward space, clinic space, ambulatory areas
- Ensure pathways are in place to minimise the risk of exposure to covid
- Ensure access to rapid testing for patients
- Ensure access to rapid PCR testing for staff

- Ensure that centres adhere to JACIE accreditation standards and checklist
- Ensure that cluster working arrangements are in place so that mutual aid is possible if required.

Comments from the UK Myeloma Forum:

Ensure clinical trial activity is efficiently restarted, supported, and developed. Specifically increase the ability of patients to transfer between centres for trials and treatment. The former could potentially be assisted by the development of clinician directed ‘apps’ through the National Institute for Health Research allowing the identification of suitable trials in real time across units. This would increase recruitment and reduce inequity of access.

Any changes to post pandemic treatment pathways need direct input from clinical experts. This joint working is of particular relevance in the complex myeloma algorithm.

3. How can we address the decline in referral rates created by the pandemic, and further build upon pre-COVID-19 rates of early diagnoses? Are there potential improvements which could make the process more efficient?

Comments from the UK Myeloma Forum:

National education campaigns raising awareness of blood cancers and improve access to rapid diagnosis / straight to test pathways to support the present 2 week wait system.

Further develop and fund regional haematopathology provision this will increase rapid accurate diagnosis and direct MDT input for all patients.

The roll out of the community diagnostic hub model will provide an invaluable resource however these centres should remain within the NHS structure to maintain national standards and avoid fragmentation of health provision. The Royal College of Pathologists welcomes the move to introduce easier access to diagnostic services centred around patients. Quicker, easier access through a ‘one stop shop’ will lead to earlier diagnoses which leads to better outcomes for patients and can save lives. These new diagnostic hubs need to be introduced with sufficient resources, in terms of staffing, IT provision and connectivity with other systems (such as GP practices).

4. What will the long-term outcome (physical and psychological) be for people with blood cancer whose care was delayed or changed due to COVID-19?

Comments from the British Society of Blood and Marrow Transplantation and Cellular Therapy:

- Survival outcomes are measured by BSBMTCT and likely to be helpful to providing information on long-term outcome for allogeneic transplants. They are likely to be less helpful in conditions where autologous transplants have been delayed e.g. myeloma.
- Informal feedback suggests that the psychological impact for patients has been massive for patients with blood cancer. Psychology support is required in every unit to help overcome this challenge.

Comments from the UK Myeloma Forum:

There will be ongoing psychological effects regarding poor vaccination responses and increased covid risk with a likely reluctance to return entirely to normal life activities for those with blood cancers.

Late presentations during the pandemic and over the coming months will give rise to poor outcomes (patients diagnosed through admission rather than outpatient referral carry a significantly reduced survivorship likelihood) whilst presentation with advanced stage disease will give rise to both greater use of healthcare resource utilisation and psychological burden for those affected.

The rapid evolution of new ways of working especially the use of technology and non-face to face review is difficult for some patient groups to embrace. This can lead to detachment between the patient and specialist healthcare service teams leading to unwillingness to contact their specialist early with disease related issues.

5. How can we best enable patient access to specialised therapies (such as stem cell transplants) alongside post-COVID recovery?

Comments from the British Society of Blood and Marrow Transplantation and Cellular Therapy:

- See answer to question 2
- Funding needs to be available for Covid recovery for blood cancer patients undergoing stem cell transplants.
- The biggest challenge is workforce. Covid has had a significant psychological impact on staff and it is more difficult than previously to recruit and retain staff. Staff are also having to provide cover for those who are isolating due to Covid-related issues. The funding constraints imposed by NHSE have meant that it is more difficult to backfill posts which is putting increased pressure on teams.

Comments from the UK Myeloma Forum:

Encourage and incentivise the spreading of workloads across accredited centres within reasonable distances to encourage cluster working.

6. What effect will COVID-19 and the efficacy of the vaccines for people with blood cancer have on their treatment and their outcomes. What measures are needed to ensure that treatment can be received safely while COVID-19 is still in circulation?

Comments from the British Society of Blood and Marrow Transplantation and Cellular Therapy:

- Maintain Covid safe pathways
- Maintain staff and patient screening for Covid
- Support for research into efficacy of vaccines in patients with blood cancer including the efficacy of booster vaccines.

Comments from the UK Myeloma Forum:

Communicate clearly and early regarding potential reduction in vaccine efficacy, need for boosters and ongoing precautions that are necessary for this group.

Presently available data will reduce the confidence of patients in both vaccination and their personal safety. Patients receiving intensive cancer treatments or those on continuous therapy (as are many multiple myeloma patients) are likely to retain a higher ongoing Covid risk if our good longer term disease outcomes are to be maintained. Targeted programmes and research into the best interventions to reduce the risk of these vulnerable groups are needed urgently.

7. Is there a sufficient and adequately equipped workforce in place to ensure all of the above?

Comments from the British Society of Blood and Marrow Transplantation and Cellular Therapy:

- No.
- This is the biggest challenge. Retention of staff is difficult as many have chosen to move overseas or retire early or reduce their hours. The remainder are covering for staff who have left and also those who are isolating due to Covid-related problems (e.g. childcare issues).
- Replacement of staff is difficult due to funding restrictions and workforce shortages.
- A Covid recovery funding package would help to support these staffing problems.

Comments from the UK Myeloma Forum:

- This is a major challenge. As reported in the [British Society For Haematology workforce report](#), vacant posts are an issue, exacerbated by the need for service expansion to accommodate new therapies and increasing complexity of the clinical workload in an ageing population with longer survival. The BSH workforce/member research has also highlighted the increasing prevalence of stress and concern about the wellbeing of those in the haematology profession (>75% respondents)
- There is a high proportion of consultants approaching retirement, 48% of haematologists will be retiring in the next 10 years, this will be compounded by difficulties in recruitment to both substantive and trainee posts and represents a higher proportion of the workforce than in many other specialities <https://www.rcplondon.ac.uk/projects/outputs/focus-physicians-2018-19-census-uk-consultants-and-higher-specialty-trainees>
- There are areas of haematology training and career development that need specific attention including development of improved pathways for career progression for healthcare scientists, acknowledgement of the role of consultant scientists and clarity on career structure in other areas including paediatric haematology.

8. Do you have any further comments? Please state them below:

Thank you for taking the time to respond to this inquiry.