



THE ALL-PARTY PARLIAMENTARY GROUP ON STEM CELL TRANSPLANTATION

INQUIRY INTO BARRIERS TO ACCESSING TREATMENT AND CARE FOR STEM CELL TRANSPLANT PATIENTS

Background

This inquiry will be run through the All-Party Parliamentary Group (APPG) on Stem Cell Transplantation and will seek to understand how a patient's background can lead to barriers in accessing treatment and care.

We have learnt from conversations with patients and clinicians that patients can experience varying quality of care and access to treatment. The inquiry aims to understand how a patient's background can lead to barriers in accessing treatment and care and will explore options for addressing the identified barriers. We would like to hear from a range of groups including patients and their families, clinicians and healthcare professionals, researchers, policymakers and charities.

Exploring barriers to accessing treatment and care is more relevant than ever. The COVID-19 pandemic has exposed and amplified existing health inequalities. A [recent report published by Public Health England \(PHE\)](#) showed that the risk of dying among those diagnosed with Covid-19 is higher in people of a black, Asian and ethnic minority background than in white ethnic groups. Additionally, mortality rates in the most deprived areas were twice those in the least deprived areas.

The purpose of the APPG inquiry is to gain a richer picture of the variations to treatment and care and explore recommendations to address the inequalities highlighted.

Scope

This inquiry will be made up of qualitative responses and produce experiential evidence. The inquiry will accept evidence from patients, their families, policymakers, clinicians, researchers and others involved in the provision of treatment and care for people with blood cancers and blood disorders who may require a stem cell transplant. We are also interested to hear from those with experience in other disease or healthcare areas who may have interesting insights into health inequalities.

This inquiry will not use quantitative data in its presentation of evidence within the final report. Whilst we understand the importance of data covering large numbers of the population, this inquiry lends itself better to experiential evidence and will act a foundational piece of work to better understand barriers a patient may face.

Patients, families and carers will be asked questions about personal background in order to help determine connections between specific backgrounds and barriers to accessing treatment and care. Questions will be asked on age, gender identity, ethnicity and geographic location. We are also interested in finding out more about whether income, health literacy levels or living in an urban or rural setting can impact on experiences of treatment and care. There will be a free text box to explain any other background characteristics respondents feel might impact access to treatment and care.

The inquiry is UK wide and we welcome responses from representatives in Scotland, Northern Ireland and Wales. The inquiry will recognise the difference in healthcare structures

in the final report and make clear where issues are specific to certain UK nations and where it is applicable UK wide.

Anticipated timelines

Response to the current pandemic may mean that timelines are altered, and some sections may have to be delayed. However, we anticipate that the following dates will correspond with key milestones of the inquiry.

- Call for written evidence – August 2020
- Close of written evidence – Friday 27 November 2020
- Oral evidence session – January/ February 2020
- Publication of final report – February/March 2020

Written Evidence questions

To submit written evidence, [please follow this link](#) if you are a patient, family member or carer to the online survey. For any other respondents, [please follow this survey link](#). Alternatively, if you would like a paper copy sent to you please get in touch on public.affairs@anthonyolan.org.

Although wording will be slightly altered to suit the respondent answering, the questions will be on the topics below and follow the same format. For patients and families, the questions will require you to answer questions about your background, this is to ensure that we can understand what specific barriers different groups in the population face.

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

- 1. What barriers might patients with blood cancers and blood disorders face in accessing stem cell transplantation and post-transplant clinical care?** This question is specifically about the medical treatment. Are some patients less likely to be referred to transplant, to find a match, or to progress to transplantation for other reasons? This question also refers to complications such as GvHD that might be experienced as a result of a stem cell transplant.
- 2. What barriers might stem cell transplantation patients face in accessing the care and support they need?** This question is about the holistic care associated with a stem cell transplant: this could be related to the Clinical Nurse Specialist you were assigned or the support you received from your clinical team once you were sent home. Are there barriers for specific patients associated with travel to appointments or how well patients can understand their treatment and what steps they need to take to stay well.
- 3. What are the experiences of people and their families who have struggled to access treatment, care and support that meets the full range of their physical, psychological and practical needs?** This question is directed at patients and their families but is also open to others who feel they can add valuable insight.
- 4. What barriers might stem cell transplantation patients face when accessing clinical trials and related research programmes?** Clinical trials are crucial in forming the evidence base for new approaches to treatment. Improved patient outcomes are found through research and access to trials. This question asks

whether you were aware of clinical trials being available, how they were discussed with you and whether you felt able to participate in a trial.

- 5. What national, regional and local levers would support improving access to the care and support stem cell transplant patients need? Do you have any examples of best practice in other areas of healthcare?** This question is mainly directed at policymakers, healthcare professionals and commissioners but other insights are welcome. Are there changes that could be made at a local Cancer Alliance level, do you think it is more valuable to have national direction, do you find that no matter what the level patient involvement is key or is it all of the above?

Further information

Thank you for your interest in the APPG on Stem Cell Transplantations inquiry into barriers to accessing treatment and care. If you have any further questions please do not hesitate to get in touch with Anthony Nolan, who provide the Secretariat to the APPG on Stem Cell Transplantation on public.affairs@anthohnolan.org.