BSBMTCT
BRITISH SOCIETY OF BLOOD AND MARROW TRANSPLANTATION & CELLULAR THERAPY

Submission to APPG for Ethnicity Transplantation and Transfusion: Ensuring a resilient and sustainable UK stem cell supply for all

Thank you for inviting me to submit evidence to this inquiry.

I am providing evidence on behalf of the British Society for Blood and Marrow Transplantation and Cellular Therapy (BSBMTCT), in my current role as President of the Society and as a practising transplant clinician.
BSBMTCT is the national organisation for those with a professional interest in haematopoietic cell transplantation and cellular therapies. The stated purpose of the organisation is to improve patient outcomes - both survival and quality of life - by advancing the fields of blood and marrow transplantation and cellular therapy. The vision of the BSBMTCT is to strive for a world where all transplant and cellular therapy patients receive the highest-quality and most effective treatments and care they need to live well. BSBMTCT is the leading society for the blood and marrow transplantation and cellular therapy community in the UK. BSBMTCT maintains the national data registry of all stem cell transplants and cellular therapies performed in the UK & ROI and provides data and insight to inform research, commissioning, policy and clinical practice.

The BSBMTCT

- undertakes, facilitates and contributes to pioneering research and clinical trials that improve the outcomes of treatment and care.
- Provides education and training to transplantation and cellular therapy professionals and promotes the sharing of knowledge and good practice across the clinical community.
- Develops guidelines, protocols and quality standards that safeguard and enhance the interests of transplantation and cellular therapy patients and professionals.
- Provides data and insight to patients and the public, to educate and empower them as they make decisions about their treatment and care.

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Addressing the questions raised: -

1. UK stem cell supply

Areas that we would like to address are below but the APPG welcomes any other inputs relevant to our purpose.

a) Does the size, composition, or quality of UK registries, or strategies for donor recruitment mean UK donors are less likely to be chosen?

b) Have there been changes in overseas registries that increase their chances of being chosen as suppliers?

c) Does the availability of key UK support services for stem cell donation such as apheresis (there is a DHSC review being undertaken of apheresis services) affect the likelihood of UK donors being chosen?

d) Is availability and training of key staff that support the UK stem cell transplantation pathway influencing choice of donor?

e) Have there been changes in behaviour of UK adult stem cell donors on the UK Aligned Registry that make them less likely to donate?

f) The UK system for stem cell provision has evolved over decades. What are the pros and cons of the current system and what system changes could provide a more resilient and sustainable stem cell transplant system?

These questions will most appropriately be addressed by the expertise of the donor registries, however, relating to point d) I am not aware of any specific training issues in transplant centres that have changed and that would influence the choice of donor against selecting a UK donor, where appropriate.

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2. Factors influencing decisions about donor selection -clinician's and commissioners' perspective. The APPG understands that clinicians make decisions based on what is best for their patients. However, the reasons why fewer UK donors are being chosen has not been discussed publicly. This is an opportunity for organisations and individuals with insight into why this is happening to share their experiences so that factors impacting donor selection decisions can be clearly identified. We would also welcome any written evidence from stem cell patients or patient groups. Suggested areas to address are: a) Timeliness and reliability of UK stem cell donations and
   b) Quality of UK stem cell donations

Clinicians usually select donors as part of a multidisciplinary team, in conjunction with guidance from those with expertise in tissue typing (HLA matching).
The primary aim is to choose the best donor, that is, the donor who is likely to give the best outcome for the patient, regardless of country of origin.
Two main factors affect the choice of a donor for a specific patient:

1) Matching of the donor to the patient, which is primarily based on tissue type or HLA matching.
2) Donor availability to donate at a time which is clinically relevant to the patient in question.

However, in practice the specific choice of a donor is complex and multifactorial. Other factors that are considered for unrelated donors are as follows:

1) Age of the donor; there is increasing evidence of improved outcomes with younger compared with older donors.

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2) Biological sex of the donor; male donors may be preferred
3) Weight of recipient and donor; a very small donor may have a lower chance of providing sufficient stem cells by weight, for a very large recipient

4) Blood group of the donor, particularly where the recipient has high levels of antibodies against the donor's blood group, a donor with the same ABO blood group may be preferred, if available.
5) For HLA mismatched unrelated donors, selection may be based on the presence or otherwise of donor specific antibodies in the recipient that could reduce the chance of a successful outcome.
6) Virological status of the donor and recipient. CMV is the main virus considered but in our practice at my own institution we also take into consideration EBV and HSV as mismatching of these viruses can also be associated with morbidity post-transplant, in our experience.

In deciding regarding donor selection, all available donor options are reviewed; these will include potential related donors and both UK and overseas potentially matched donors listed on the unrelated donor search and where relevant, cord blood options.
In my own practice as a transplant clinician and director of a transplant and cell therapy program serving central south England (Southampton), in the absence of a suitable sibling matched donor, an unrelated UK donor would be selected by preference, if they were determined to be the best available donor for the recipient and had availability for cell collection at a time that is clinically relevant to the patient.

c) Changes to transplantation processes.

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In my experience, as the average age of patients eligible for allogeneic stem cell transplantation has increased, the percentage of patients for whom we use sibling donors has fallen, as the age of potential sibling donors also increases, to the extent that they may not be optimal donors. The fall in family size over several decades in the UK, may also impact the ability to use sibling donors, as sufficiently matched sibling donors may not be available. Thus the proportion of unrelated donors we use has increased over time.

As described above, the key factor in selecting a suitable donor is the degree of HLA matching, with a "full match" (10/10 or 12/12 HLA-matched) judged as ideal. More recently, both internationally and in the UK, there has been an increasing use of mismatched unrelated donors and related partly mismatched (haplo-identical) donors. This has occurred due to advances in strategies to prevent one of the most common and potentially life-threatening complications of transplantation, graft versus host disease (GVHD). This mainly relates to the increasing experience with and use of post-transplant cyclophosphamide (PTCy). The UK transplant community will be meeting shortly, in October, to agree a consensus approach to the use of PTCy. This is particularly relevant for those patients for whom a well-matched donor cannot be found in a clinically relevant time, including those from mixed and minority ethnic genetic backgrounds.

d) Any other factors relevant to this inquiry I have no further comments to make at this time.

I hope that the inquiry finds these comments helpful in addressing an important question and case of need for the patients that we serve. It is essential that we develop and support services which can provide equity of access for all of those in need of this life-changing and saving procedure. Thank you for your support and interest in this issue.

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Submission to APPG for Ethnicity Transplantation and Transfusion: Ensuring a resilient and sustainable UK stem cell supply for all

Many thanks for inviting me to submit evidence to this inquiry. I am providing evidence on behalf of the British Society for Blood and Marrow Transplantation and Cellular Therapy (BSBMTCT). BSBMTCT is the organisation for those with a professional interest in haematopoietic cell transplantation and cellular therapies. The purpose of the organisation is to improve patient outcomes – both survival and quality of life – by advancing the fields of blood and marrow transplantation and cellular therapy. BSBMCT is the leading society and data registry for the blood and marrow transplantation and cellular therapy community in the UK. BSBMTCT maintains a registry of all stem cell transplants and cellular therapies performed in the UK and promotes collaboration between healthcare professionals working in this field. The organisation provides a platform for clinical research, education, guidelines and quality improvement to advance the practice of stem cell transplantation and cellular therapy.

I note that the first part of the inquiry relates to UK stem cell supply:

1. UK stem cell supply

Areas that we would like to address are below but the APPG welcomes any other inputs relevant to our purpose.

a) Does the size, composition, or quality of UK registries, or strategies for donor recruitment mean UK donors are less likely to be chosen?

b) Have there been changes in overseas registries that increase their chances of being chosen as suppliers?

c) Does the availability of key UK support services for stem cell donation such as apheresis (there is a DHSC review being undertaken of apheresis services) affect the likelihood of UK donors being chosen?

d) Is availability and training of key staff that support the UK stem cell transplantation pathway influencing choice of donor? e) Have there been changes in behaviour of UK adult stem cell donors on the UK Aligned Registry that make them less likely to donate?

f) The UK system for stem cell provision has evolved over decades. What are the pros

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and cons of the current system and what system changes could provide a more resilient and sustainable stem cell transplant system?

These questions will largely be addressed by the donor registries. In the response to question 2, I have outlined the process that the clinicians use to select donors.

I note that the second part of the inquiry relates to factors influencing decisions about donor selection:

2. Factors influencing decisions about donor selection -clinician's and commissioners' perspective. The APPG understands that clinicians make decisions based on what is best for their patients. However, the reasons why fewer UK donors are being chosen has not been discussed publicly. This is an opportunity for organisations and individuals with insight into why this is happening to share their experiences so that factors impacting donor selection decisions can be clearly identified. We would also welcome any written evidence from stem cell patients or patient groups. Suggested areas to address are:

a) Timeliness and reliability of UK stem cell donations and
b) Quality of UK stem cell donations

In response to questions 2a and 2b, there are several factors which clinicians consider when selecting a suitable donor for a person needing a stem cell transplant. These include the quality of the donation. For example, a younger male donor may be preferred over an older donor. The reason for this decision making is that studies have shown that these donors tend to provide more numerous cells which can translate into better outcomes for patients.

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Other factors that will be considered by clinicians include the HLA matching status of the donor, the CMV status of the donor and recipient and the blood group of the donor and recipient. In making that decision, all donor options are reviewed, and these are likely to include both UK and overseas donors as the search for donors includes options on all the global registries. In my experience as a transplant clinician, a UK donor is usually selected if they were the best

donor for the patient and the donor was available at the time that the patient needed to receive the stem cells.

c) Changes to transplantation processes.

There are 3 main stem cell sources available for people needing a stem cell transplant. These include related donors (usually a sibling, parent or child), unrelated donors or umbilical cord blood. If an unrelated donor is required, a search is carried out of the global registries. These registries include more than 40 million donors worldwide. The key factor in selecting a suitable donor is the degree of HLA matching (usually 10/10 or 12/12). More recently, there has been an increase in the number of haploidentical transplants which use a greater degree of mismatch (e.g. a related donor with a 5/10 match). This increase is occurring globally and within the UK.

One reason why it is possible to undertake transplants with a greater degree of mismatch is the advent of a new strategy to reduce the risk of graft versus host disease. This includes the use of post-transplant cyclophosphamide as a form of GVHD prophylaxis. The UK is rapidly gaining experience in the use of posttransplant cyclophosphamide due to a

national clinical trial called Methods of T cell depletion. Work is currently underway to try and agree a consensus approach for the use of post-transplant cyclophosphamide. It is possible that this approach may be of particular importance in improving outcomes and access to donors for patients from mixed and minority ethnic backgrounds where there is difficulty in finding an unrelated donor.

d) Any other factors relevant to this inquiry

The BSBMTCT has no further comments to make at this stage

I hope that this response is helpful to the inquiry

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