

22 May 2020

Attention Dr David Girdwood
HPC Policy and Programs
Department of Health
HPCPolicy&Programs@health.gov.au

Dear Dr Girdwood

Re: Leukaemia Foundation comments on HPC Consultation Paper

The Leukaemia Foundation is writing in response to the Department of Health's National Haemopoietic Progenitor Cell (HPC) Future Framework Consultation Paper.

Blood cancers are a complex group of diseases that can affect anyone, at any stage of life. Despite the seriousness of a blood cancer diagnosis, we know that there are things we can do to improve people's chances of survival and help them live well.

As the only patient organisation representing the needs of all people living with a blood cancer in Australia, we appreciate this opportunity to comment on the Consultation Paper, particularly around security of supply of stem cells and the ability of the sector to meet the needs of patients requiring an allogenic stem cell transplant.

The Leukaemia Foundation's priority is to ensure that all Australians living with blood cancer have timely access to the best therapies and treatments available, which improve time spent in remission, survival and quality of life.

If we can provide any further assistance, please contact Emily Forrest, Head of Policy and Advocacy on eforrest@leukaemia.org.au or mobile 0407 898 958.

Yours sincerely,



Tim Murphy

General Manager, Blood Cancer Partnerships
Leukaemia Foundation

About us

The Leukaemia Foundation is a charitable organisation that has been supporting and caring for people affected by leukaemia, lymphoma, myeloma and related blood disorders since our organisation was established in 1975.

We provide services to people living with blood cancer and their families across the whole country – from practical and emotional support, accommodation services, through to investing in research and advocating to government on behalf of the blood cancer community. We have a physical presence and community connections in every state and territory, covering all capital cities and a significant number of regional centres.

Our vision is zero lives lost to blood cancer by 2035.

To help us achieve this vision, in September 2019 we delivered a [*State of the Nation: Blood Cancer in Australia*](#) report. Soon after, we secured a commitment from the Federal Government to establish the Blood Cancer Taskforce and deliver Australia's first National Strategic Action Plan for Blood Cancer.

We are delighted by the Federal Government's support and have been working with the blood cancer community and the Department of Health over the past 12 months to deliver the National Action Plan in June 2020. This will be the first national consensus, from the blood cancer community, on the blood cancer agenda.

The HPC sector and needs of people living with blood cancer

With respect to the HPC Consultation Paper and draft Framework, the sector clearly involves numerous stakeholders, governance, legislative requirements and funding considerations at various points along the supply of stem cells and care continuum for donors and patients.

As a patient organisation, our mission is to meet the needs of blood cancer patients and their families. With that in mind, our comments are focussed on security of supply of stem cells and the ability of the sector to meet the needs of patients requiring an allogenic stem cell transplant.

Bone marrow and blood stem cell transplants are used to treat a range of diseases, the majority of which are haematological diseases such as leukaemia, lymphoma, myeloma, amyloidosis and aplastic anaemia.

An autologous transplant uses the patient's own stem cells, collected in advance and returned to them after they receive high doses of chemotherapy.

In allogeneic transplants, stem cells are donated to the patient from another person who is a genetically matched stem cell donor. This may be a sibling or family member with the same tissue type as the patient. However, where no related donor is available, a search is conducted of Australian and overseas registries to find a suitably matched unrelated stem cell donor. Sometimes there may be a slight mismatch, but it may still be the best (and only) possible match for that patient.

Around 2000 transplants are carried out in Australia every year (1,884 in 2018). The majority of these are autologous transplants (1,253 in 2018), compared to allogeneic transplants (631 in 2018). For more than half of the patients needing an allogeneic transplant, the cells came from an unrelated donor and the vast majority of these (around 85%) are from an overseas donor.

Allogeneic transplants can offer the best chance of curing a number of blood and bone marrow cancers. However, they are also complex procedures that carry significant risks. The complexities and risks may be increased even more with a mismatched or volunteer unrelated donor transplant.

Patients have better outcomes with closely human leukocyte antigen (HLA) matched donors (at least 8 out of 10). In some instances, patients who cannot find a suitable stem cell donor may opt for a haploidentical (half HLA-matched) transplant (exactly 5 out of 10) from their parent or child. The more compatible the donor patient match, the less likely there will be rejection or severe Graft versus Host Disease (GvHD). GvHD is triggered when the transplanted donor immune cells begin attacking the recipient's organ tissues. It has detrimental effects on a person's health and quality of life (with associated costs to the health system) and can be fatal in up to 40 per cent of cases.

Given the seriousness of the allogeneic transplant process for these consumers – both the risks involved and the potential for what might be a curative therapy – all Australians have a vested interest in ensuring that Australia's HPC sector is functioning to the highest possible standard.

Central to this is ensuring Australian patients have access to the best possible matched stem cell donors, both in Australia and from overseas.

The chances of finding the best possible match depends on the characteristics of the patient and the donor. Patients need donors from an ethnic background similar to their own. While some Australians will find a matching donor in countries like the UK or USA, for others, a matching donor will only be found in Australia.

This is particularly true for Aboriginal and Torres Strait Islander people, but also for people from ethnic groups that are not well represented on the current Australian Registry nor any

overseas registries. For these individuals, unfortunately, without a suitable matched donor they will not have access to what may be a life-saving treatment.

Security of supply

The risks of relying so heavily on overseas stem cell donors has been highlighted by the COVID-19 pandemic and restrictions this has placed on the international movement of live cells. It means that patients relying on overseas stem cells are highly susceptible to the risks involved when collection, movement and transport of medical tissue is restricted, thus delaying what may be a life-saving treatment.

The COVID-19 situation has thrown into sharp relief the urgent need to expand and diversify the current donor pool to better serve the needs of patients in Australia and around the world. Our over-reliance on international donors poses both an unacceptable risk to Australian patients and is also counter to our mutual obligations with international registries to maintain a registry that is able to meet the needs of patients, all around the world, needing a donor.

As the HPC Consultation Paper notes, based on PwC's review of the sector in 2018, "the current recruitment approach is mismatched to clinical needs in respect of donor demographics, age and sex, and mostly relies on blood donors who may not fit the profile of donors preferred by clinicians."

The Leukaemia Foundation agrees that the current recruitment approach is mismatched to clinical needs. Furthermore, relying on recruitment through the blood service is also a significant barrier to having a wide pool of donors that are representative of the Australian population, including that it may prevent donors on the basis of their particular religious and/or cultural beliefs, sexual orientation, or past history with drug use.

Given the different requirements for collecting blood products versus bone marrow or stem cell products, careful consideration must be given to how these different processes are managed, including resource allocation, prioritisation and clarity around collection purposes. We would suggest that stem cell donor recruitment, retention and administration should be distinct from the blood service and that collection methods must be expanded, as a matter of urgency, including through an expansion of the cheek swab program.

It is not acceptable that the pool of Australian registered stem cell donors does not meet the needs of patients requiring an allogeneic stem cell transplant, including people with ethnic backgrounds that are not well represented on the current Registry, particularly Aboriginal and Torres Strait Islander people and other culturally and linguistically diverse communities.

The development of a framework for the HPC sector must, as a priority, contribute to the sector working more cohesively and effectively to address this issue.

Strength to Give program

We believe that increasing the Australian donor pool through additional cheek swabs, along with clear and ongoing communication with potential donors, will go a long way towards addressing these serious issues.

The capacity of Australia's pool of registered donors to meet the needs of patients has been diminishing for some time. While this issue has been amplified in recent months due to the crisis of the COVID-19 pandemic and the stark realisation of the risks inherent in Australia's over-reliance on overseas donors, this is not a new finding. Government, non-government and community partners have been aware of these issues for some time.

We must act quickly and decisively to address these issues – both by increasing the size and diversity of the current pool of donors on the Australian Registry and by implementing common sense recruitment and retention strategies to ensure the model is sustainable into the future and continues to attract suitable donors.

That is why the Leukaemia Foundation is one of the community partners involved in the *Strength to Give* program, which was established by the Australian Bone Marrow Donor Registry in 2019. This partnership with the donor and blood cancer community seeks to increase the size and suitability of Australia's pool of registered stem cell donors.

The *Strength to Give* program has the Leukaemia Foundation's full support. While we are delighted that the program achieved its initial aim of 5,000 new registered stem cell donors on the Australian Registry, we are very disappointed that the program has been paused.

We want commitments to support the recommencement of the *Strength to Give* program, with appropriate funding allocated to the program so that it continues and remains sustainable.

We note that the HPC Consultation Paper's proposed National Policy Statement no. 6 describes the HPC sector as "costly", with annual spending to maintain donation, registry, tissue typing and overseas sourcing services of approximately \$26 million per year, not including the cost of hospital transplantation services, and further than "it is proposed that no additional investment will be provided to support HPC donation services beyond the total level of funding provided under current agreements."

The Leukaemia Foundation would argue that in the context of the overall health budget, and considering the immense benefits to Australian patients in maintaining a broad local registry

which reduces reliance on overseas sourcing, this cost is appropriate and the *Strength to Give* program even more so.

We also note that the Consultation Paper suggests broadening the current scope for the use of the cord blood export revenues held by the Australian Bone Marrow Donor Registry. We support this proposal and recommend these funds are urgently directed towards donor pool renewal. From a patient perspective, we believe the proposed Framework can and should ultimately prioritise the funding and maintenance of the Australian Bone Marrow Donor Registry to provide sustainable and self-sufficient HPC services to Australian patients.

Stakeholders

The Leukaemia Foundation agrees that ongoing engagement between all relevant stakeholders is vital to the viability of the HPC sector. This includes governments, regulators and registries, but also and perhaps most importantly, the Australian community, including donors, recipients and their families, as well as other *Strength to Give* partners and patient representative groups. As well as the Leukaemia Foundation, patient organisations that may wish to be involved in ongoing consultation on the future of the sector include the Cancer Council of Australia, Rare Cancers Australia and all community partners involved in the *Strength to Give* program.

We hope to continue working directly with the Australian Bone Marrow Donor Registry to ensure people living with blood cancer can access the treatment they need, in a timely manner, from the best possible donor, from Australia or from overseas.

The Leukaemia Foundation has also been a member of the COVID-19 Australia BMT Group (CABG), which involves clinicians, government representatives, Lifeblood, the Leukaemia Foundation, the Bone Marrow Transplant Society of Australia and New Zealand and the Australian Bone Marrow Donor Registry. The group was established as a COVID-19 crisis management team and has shown itself to be a highly effective way of coordinating information across the sector and involving key stakeholders in decision-making. We recommend that this model is continued in some form beyond the pandemic, to help oversee sector recovery and the re-design of arrangements in the HPC sector, under the joint leadership of the Australian Bone Marrow Donor Registry and the Bone Marrow Transplant Society of Australia and New Zealand.

These relationships have been critically important, particularly during the COVID-19 crisis, in working to maintain safe and secure transplant services for Australian patients – whatever and however it takes. These learnings, including flexibility and agility of delivery, should be incorporated into any consideration of the future of the HPC sector. Careful consideration must

be given in taking into account those existing arrangements and their respective stakeholder relationships when designing future arrangements.

Concluding remarks

The Leukaemia Foundation appreciates the opportunity to comment on the Consultation Paper. As previously stated, our aim is to represent the needs of patients.

As far as we understand, the PwC report outlining five options for future improvements to the HPC sector upon which the proposed National HPC Framework is based is not public, nor is the data on which the report itself is based. It is therefore it is difficult for the Leukaemia Foundation to assess the veracity of solutions to identified challenges.

Further, the draft Framework itself is drafted to be high-level, which may not necessarily accurately reflect the complexity of the multitudes of touch points in the HPC system – not all of which are directly relevant to a patient group like the Leukaemia Foundation, which may limit the relevance of our comments.

Nevertheless, we trust that our comments have provided some useful context on the current situation for patients in need of or awaiting life-saving transplants, and that our recommendations are taken into account when determining next steps.

From: Emily Forrest

Sent: Wednesday, 27 May 2020 3:52 PM

To: HPC Policy & Programs <HPCPolicy&Programs@health.gov.au>

Cc: Tim Murphy <tmurphy@leukaemia.org.au>

Subject: RE: Deferral of the deadline for comments on the HPC consultation paper [SEC=OFFICIAL]

Dear David

In addition to the Leukaemia Foundation's response to the HPC Consultation Paper emailed on Monday, we would like to make two additional points as an addendum to our submission.

1. The Bone Marrow Transplant Society of Australian and New Zealand (BMTSANZ) is a key stakeholder that needs to be included (as per stakeholders listed on page 7).
2. The framework must consider how to continue to improve outcomes for patients in the sector and a key part of this is monitoring the outcomes of procedures. The framework should include a coordinated and national commitment to clinical quality systems and mandatory reporting of outcomes to the Australian Bone Marrow Transplant Recipient Registry (ABMTRR).

If you could please confirm receipt of this addendum that would be much appreciated.

Kind regards

Emily

Emily Forrest

Head of Policy and Advocacy

Leukaemia Foundation

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