



February 6, 2020

Dear EBMT Center Director

Re: Discontinuation of AGNIS data transfer from EBMT to CIBMTR

In the spirit of facilitating data registration for centers, the EBMT entered into an agreement with the CIBMTR (then IBMTR) in 2004 by which the EBMT would forward Med-A/TED data to the CIBMTR if requested by an EBMT center. This data flow continued for many years until the implementation of the General Data Protection Regulation (GDPR) in the European Union in May 2018. Based on the requirements of this new regulation, all aspects of data sharing and transfer between the EU and other nations needed to be carefully addressed.

Data transfer via AGNIS from EBMT to CIBMTR was therefore formally halted in May 2018. Since this time both organizations have been actively working towards signing a Data Sharing Agreement, however we also took the opportunity to fully review our current systems. Besides the privacy issues raised by GDPR, there are several reasons which contributed to the decision by both organizations to discontinue the routine AGNIS connection:

- Migration of the EBMT data from *ProMISe* to MACRO will require remapping of all Med-A/TED elements in the new system to AGNIS which represents a significant cost and logistic burden
- Current electronic data sharing via AGNIS is one directional and expanding to bidirectional sharing using AGNIS is not a timely or practical solution
- AGNIS requires modernization and a more up to date technological solution may be better for future data sharing between EBMT and CIBMTR

While CIBMTR and EBMT agree to continuing to explore the potential for a new solution for bidirectional electronic data sharing, this is unlikely to occur in the near term. However, both EBMT and CIBMTR are committed to continuing to perform joint studies and to sharing datasets once the appropriate GDPR-compliant Data Sharing Agreement has been signed. We are committed to continue the longstanding efforts of both organizations to harmonized data collection for hematopoietic and cellular immunotherapy (both data elements and timing), in order to facilitate data sharing in the long term.



If you have questions about providing data to the CIBMTR, please submit a ticket via CIBMTR Center Support (<https://nmdp.service-now.com/csm>) and select 'CPI' under *What is your question regarding?*

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