
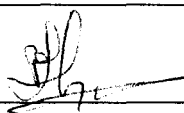


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<i>Author name</i>	<i>Signature</i>	<i>Date</i>
P. Westveer		09-Feb-2011
<i>Approver name</i>	<i>Signature</i>	<i>Date</i>
P C Huijgens		09 02 2011

Dutch Hematopoietic Stem Cell Transplantation Registry

Dutch centers licensed to perform autologous and/or allogeneic hematopoietic stem cell transplantations (HSCT) (and accredited for that activity by JACIE) are obliged to report their transplant activities to the international registry of the European Group for Blood and Marrow transplantation (EBMT). The HOVON and SKION foundations facilitate the management of the Dutch data that are reported to the Registry of the EBMT. The HOVON Transplantation Working Group serves as a reference address for EBMT with respect to national transplantation issues and policies.

Data entered by each individual center in the European registry database are owned by the respective hospital department that has entered the data. Informed consent from the patient to enter his/her data in the registry and permission to use these data for scientific research and reporting to authorities and health care institutions has been obtained by the hospital department.

Data entered by the centers undergo a regular check by the associated HOVON data manager and statistician. That part of the registry, relating to the transplant activities in the Netherlands may be used by HOVON and SKION to provide reports to government agencies, health care authorities and health care institutions (e.g. insurance companies) for the purpose of management, planning and regulatory oversight of transplant activities for adults and children respectively.

The registry of adult patients (aged 18 or over at primary diagnosis) may be used by HOVON to provide reports to the Dutch transplant centers, the chairman of the HOVON Transplantation Working Group and the HOVON board for the purpose of management and planning of transplant activities.

The registry of pediatric patients (aged 17 or under at primary diagnosis) may be used by SKION to provide reports to the Dutch transplant centers and the SKION board for the purpose of management and planning of transplant activities.

The registry may also be used as a source for retrospective studies under the auspices of the HOVON Transplantation Working Group, but only if permission from the hospital department that has entered the data is obtained. Requests to perform studies are directed to the chairs of that Working Group and subsequently discussed in the bi-annual meetings by the group as a whole.

If data from the registry are collected for use in an observational or clinical trial for which HOVON or SKION is the primary sponsor, the HOVON or SKION foundation is the owner of the data that are collected according to the trial protocol.