

Transplantation (SOT & HSCT) in Children – TRANSCHILD

Allocation of/ and access to organs for the purpose of organ transplants is not included in the network scope as established in the Directive 2011/24/E



Network Scope

ERN TRANSCHILD is focused on a cross-cutting approach of paediatric transplantation of both solid organ & hematopoietic stem cell transplantations including, therefore, a set of highly specialised procedures:

Not included are: allocation and access to organs for the purpose of organ transplant (Clearly stated at the Directive 2011/24/EU).

Proposal of requirements to join the ERN TRANSCHILD

Specific condition	Number / year
Pediatric heart transplantation	2 - 5
Pediatric liver transplantation	8 - 10
Pediatric kidney transplantation	8 - 10
Pediatric allogeneic hematopoietic stem cell transplantation	8 - 10
Pediatric intestinal transplantation	2 - 4
Pediatric lung transplantation	1 - 3
Multiorgan transplantation	TBC

Why is the ERN TRANSCHILD focused on this cross-cutting approach based on highly specialised procedures:

There is evidence that paediatric transplantation is the only curative therapeutic procedure targeted to the children population that has the highest mortality rates in their age group. The current approach is performed focused on a specific disease or organ. However, there are many common complications due to the need to suppress the immunological incompatibility between individuals regardless the transplanted organ.

And this is the point where ERN is focusing on: A cross-cutting transplantation ERN is needed to share the knowledge of every type of transplantations in order to enhance the outcome.

There are challenges associated with common complications and optimising the effects of these interventions, such as those associated to:

- Mechanisms of graft rejection and the occurrence of complications.
- Innovations in surgical procedures applied to these transplantations.
- The approach to chronicity and the treatment of secondary to diseases paediatric transplantation.
- Socio-economic impact of these interventions in patients, families and health systems.

A cross-cutting approach allows:

- The collection of sound findings due to the higher amount of transplantation cases. This view is specially needed in paediatric transplantation as compared to adult transplantation in which the number of patients is higher.
- The establishment of synergies from the knowledge and results from different types of transplants (e.g. knowledge in HSCT is being applied in SOT).
- The improvement of the transplant patient handling and outcomes achieved.
- The identification of common topics to all types of transplants such as clinical, personal and socio-economic issues.
- The integration and share of knowledge and clinical expertise among all clinical teams and support departments.
- The increase of opportunities for clinical innovation towards the improvement of life expectancy and long-term quality of life of children and their families.
- The decrease of personal burden of transplantation as a chronic long-life condition.
- The provision of psycho-social support in different phases of patients' lives.
- The provision of grounds for patients' empowerment.

Innovative efforts in transplantation can impact on all transplanted children, regardless the transplanted organ, in clinical areas such as surgical procedures, pharmacological toxicity, immunosuppression and its long-term consequences, tolerance and rejection, GVHD, infections, innovative biological and cellular therapies, monitoring for personalised-precision medicine, etc

Main Aims of the Network

The Network will direct its coordinated activities towards the achievement of five five objectives:

- Improve expectancy and long-term quality of life of children and their families as well as patients' empowerment.
- Facilitate improvements in prevention, surgical interventions, patients' follow-up and health care for transplanted patients.
- Foster harmonized research and innovation.
- Promote social and economic changes.
- Spread knowledge.

Expected Outcomes:

The activities developed by the Network will provide added value, fundamentally from three perspectives:

1. The patients, families and organisations representing them, considering the following aspects among other :
 - The quality of life of the transplanted paediatric patient.
 - The humanisation of the attention.
 - Psycho-social support in different phases of their lives.
 - Social awareness.
2. The HCPs and multi-disciplinary teams involved in the attention of the transplanted patients.
 - Clinical excellence.
 - To provide training to the professionals that belong to the different health care levels.
 - Clinical practises.
 - Treatments homogenisation.
3. The health systems involved, through:
 - Harmonisation of clinical best practises.
 - Results improvement.
 - Reduction of costs related to transplantations, re-transplantations and pharmacological treatments.
 - Transference of knowledge from professionals and specialised centres.
 - Preventive practises to anticipate and minimise the risks in the patients' health.

Required Documentation and Deadlines

1. Obtain an endorsement letter provided by the national authority of the Member State – **June 13th**
2. Self-assessment checklist for Healthcare providers and all the information and supporting documentation available as requested by the Appendix B (two stage process):
 1. Documents as requested by the Appendix B (English summaries) – **May 23th**
 2. Self-Assessment Form and related comments – **May 30th**
3. Application Form – **June 6th**

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