

# ERN-TRANSPLANTCHILD, a European strategy to attend “the secondary rare disease” induced by Paediatric Transplantation

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## Background:

Pediatric transplantation (PT), including both solid organ (SOT) and hematopoietic stem cell (HCST), are highly complex procedures that have greatly improved survival of children over the last decades. A wide variety of rare diseases are benefited by these procedures making multidisciplinary approach mandatory.

## Methods:

As established in the Strategic approach of the network, the strategic areas have been approved in order to ensure the achievement of the mission and vision of the Network:

## ERN-TRANSPLANTCHILD

integrates 18 Healthcare providers from 11 Members States (Figure 2) with acknowledge expertise in PT.

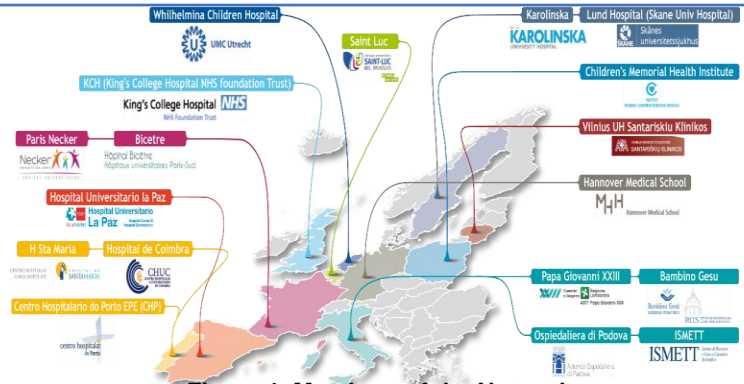


Figure 1. Members of the Network

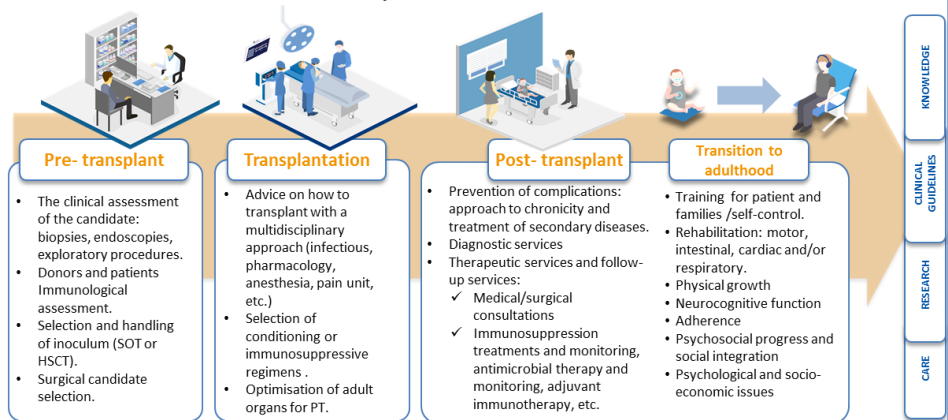
**ERN-TRANSPLANTCHILD** aims to increase life expectancy and quality of life of pediatric patients and their families, providing added value by:

- (1) Ensuring patients access through the network to the best knowledge and healthcare practices in PT.
- (2) Integrating “real” patient’s needs as the cornerstone of the ERN
- (3) Promoting best practices, training, research, and knowledge sharing.
- (4) Integrating stakeholders in the transplantation process and making available the knowledge and information.

## Results:

The crosscutting approach of **ERN-TRANSPLANTCHILD** allowed the identification of common topics to all transplanted children such as clinical, personal and socio-economic issues, personalized patient handling, life expectancy and long-term quality of life of children and their family.

These common issues were addressed by: (1) developing of specific clinical practical guidelines for children (2) mapping healthcare providers structural and human resources (3) prioritizing research bearing in mind personalized medicine (4) Improving quality and safety indicators (5) identifying critical knowledge within the ERN (6) promoting networking within and outside the ERN.



To promote patients and families involvement and empowerment, ERN-TRANSPLANTCHILD has integrated the patients subcommittee in which currently 19 patient’s associations from 10 countries participate to ensure consistency in the development of the Network.



**Conclusion:** ERN-TRANSPLANTCHILD changed the paradigm of disease/organ approach by a more holistic process approach. This vision allowed the development of an integrative model of healthcare, focused on patient’s needs, and conceived to promote best practices, knowledge sharing and translational research.