



EURORDIS Patient Partnership Webinar Series

Transition in Healthcare: Turning recommendations into practice

A webinar series highlighting how ERN recommendations on transition from adult to paediatric care are being translated into wide practice, with a focus on patient partnership

Background and rationale

People living with rare diseases experience multiple transitions throughout their healthcare journey. These may occur between healthcare providers (e.g. specialist centres and local services), across types of care (e.g. paediatric to adult care, primary care, palliative care), or during key life stages such as adolescence, adulthood, pregnancy, and ageing.

In the absence of structured and coordinated approaches, these transitions often result in fragmented care, gaps in service delivery, and an increased burden on patients and families to coordinate their own care.

The European Patient Advisory Group (ePAG) Steering Committee has identified transition in healthcare as a key priority and expressed strong interest in advancing work in this area in the coming years.

Across the European Reference Networks (ERNs), significant efforts have been made to map barriers and challenges, particularly in the transition from paediatric to adult care. Most ERNs have established dedicated Transition Working Groups, conducted surveys of clinical practices across centres and developed recommendations.

However, translating these recommendations into practice requires adaptation at the national and centre level, including defining roles and establishing mechanisms to monitor progress. While promising practices and innovative initiatives are emerging, these often remain isolated rather than systematically implemented.

Building on the momentum of both the ERN Transversal Working Group on Transition in Healthcare (Ghent, 27-28 February 2026) and the priorities identified by the ePAG community, this webinar series aims to highlight concrete experiences and explore how to move from recommendations into practice, with a strong focus on the role of national indicators and patient partnership.



Aim

To support the implementation of effective and scalable transition practices in rare disease healthcare by translating ERN recommendations into action across ERNs and healthcare systems, with a strong emphasis on patient partnership.

Objectives

- Provide an overview of ERN-wide efforts on transition in healthcare, including the role of the ERN Transversal Working Group and Youth Panel
- Highlight the need for capacity building in adult care services for rare diseases patients with congenital or paediatric-onset conditions experience
- Explore the role of indicators in enabling the implementation of ERN recommendations at the national level
- Clarify the roles of different stakeholders involved in transition processes
- Showcase innovative initiatives and tools developed across ERNs in which patient experience and partnership contributed towards effective transition practices
- Inspire practical and transferable actions and foster collaboration between all stakeholders involved to improve transition from paediatric to adult care

Expected Outcomes for participants

- Increased awareness of existing scalable, transferable, collaborative transition practices and initiatives across ERNs.
- Showcase concrete examples that can be adapted or implemented in different healthcare settings.
- Better understanding of how patient partnership strengthens transition processes in healthcare
- Identification of opportunities for collaboration across ERNs and stakeholders.

Target audience

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|--------------------------|---------------------|
| ✓ ERN Coordinating teams | ✓ HCPs |
| ✓ ePAG advocates | ✓ Hospital managers |
| ✓ National Alliances | |

Programme

Webinar #1: Setting the scene: From evidence to implementation in transition in healthcare | Date: Tuesday, 30 June 2026 | Registration link:

<https://us02web.zoom.us/meeting/register/Zpl8L6ONQmCDLgaZ3g9LnA>

Time	Topic	Speakers
12.00 - 12.05	Welcome	Inés Hernando , EURORDIS
12.05 - 12.15	Introduction to the topic	Nora Lázaro , EURORDIS
		TBC Speaker Youth Panel Member
12.15 - 12.30	ERN Transversal Working Group on Transition in Healthcare – outcomes from Ghent and Youth Panel perspectives	Janne Suykens , Researcher, Leuven University, ERN Liver
12.30 - 12.40	Questions and answers	All
12.40 - 12.55	The use of indicators to support implementation of transition practices at national level	TBC Speaker
12.55 -13.05	Questions and answers	All
13.05 - 13.15	Wrap-up	Nora Lázaro , EURORDIS

Webinar #2: ERN innovative initiatives – Developing tools and resources for an effective transition | Date: Wednesday, 1 July 2026 | Registration link:

<https://us02web.zoom.us/meeting/register/4eBeTxQaTaCHBM4ZhF0ggQ>

Time	Topic	Speakers
12.00 - 12.05	Welcome & Introduction	Nora Lázaro , EURORDIS
12.05 - 12.25	ERN ERNICA – Building capacity of adult services to receive transition patients	Caroline Love , ePAG lead (ERN ERNICA)
12.25-12.30	Questions and answers	All
12.30 - 12.50	ERKNet – Developing a Transition Passport for Rare Kidney Diseases	Karsten Vanden Wyngaert , ePAG advocate (ERKNet) Simge Celik Stojanovic , Project Manager (ERKNet)
12.50 - 12.55	Questions and answers	All
12.55 - 13.00	Closing	Inés Hernando , EURORDIS