

Challenges in Transitioning Adolescents with Rare and Complex Epilepsies from Paediatric to Adult Care: A Health System Policy Assessment

Natalia Wierzbicka¹, Viorel Constantin Vacaru², Isabella Brambilla^{3,4}, Myriam Cheddadi⁵, Dr. Burçak Aydın⁵

1. UCB, Warsaw, Poland,
2. UCB, Bucharest, Romania,
3. Fondazione Dravet ETS, Veneto, Italy,
4. E+A CREA ALLIANCE, Brussels, Belgium,
5. Deloitte, Brussels, Belgium.

OVERVIEW

QUESTION

What are the key improvement areas in transition care pathways for adolescents with rare and complex epilepsies (R&CE) in Europe and the United States, and what policy actions could enhance patient and caregivers outcomes?

RESULTS

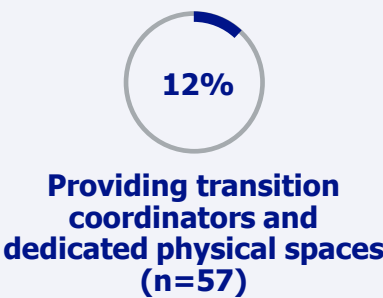
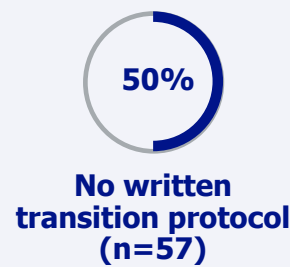
Challenges of Transitioning Adolescents with R&CE

- The 24 included publications indicated that R&CE transition remained fragmented across studied countries, with limited and/or inconsistent transition.
- Identified literature suggested that multidisciplinary support decreased in most adult clinics.
- Communication between paediatric and adult teams was mostly informal.
- Unsuitable waiting environments for sensory, cognitive, and behavioural impairments, and limited adult neurologists’ knowledge in R&CE management and recent therapeutic advances, could potentially increase the risk of suboptimal care (e.g., lack of holistic care provision).

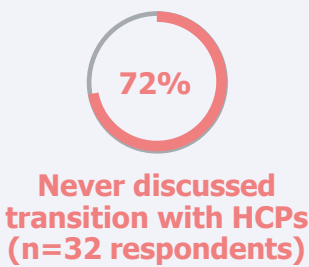
INVESTIGATION

Literature review was undertaken to describe transition care pathways for adolescents with rare and complex epilepsies (R&CE) to adult care in Europe and the United States, identify improvement areas, and propose potential policy opportunities to enhance patient outcomes.

- For example, EpiCARE Reference Network conducted a survey (April-July 2024), providing data from 42 healthcare providers (HCPs) in 21 EU countries (total sample size n=57) ²:



- In a North American survey of 12–17-year-olds with epilepsy (published in 2024, data from 2019), reflective of R&CE (74% reported intellectual disability), according to their caregivers⁷:



CONCLUSIONS

The analysis revealed critical gaps in transition care for adolescents with R&CE, highlighting opportunities for targeted health policy intervention around structured transition programmes starting from age 12–16 with dedicated coordinators, specialised transition clinics, sustained multidisciplinary teams with ring-fenced funding, adapted adult facilities for adolescent needs, and R&CE-specific medical education.

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Objective

- To describe the transition care pathway for adolescents with rare and complex epilepsies (R&CE) to adult care in Europe and the United States and identify improvement areas for policy actions to enhance patient outcomes.

Methods

TARGETED LITERATURE REVIEW

- Targeted literature review on transition challenges in the UK, France, Spain, Italy, Germany and the United States was conducted.
- PubMed/MEDLINE searches (01.2010–12.2024, refreshed 03.2025) used MeSH terms.
- Only English-language literature was retrieved.
- Of 297 records, 273 were excluded based on title and abstract screening for transition related keywords (exclusion criteria were: case reports, clinical trials, non-rare and non-complex epilepsies, other geographies and not transition-specific).
- 24 publications underwent full-text review.
- Additionally, grey literature (including white papers, patient organisation websites, and health policy documents) was identified through desktop research.

LIMITATIONS

- This targeted literature review was restricted to English-language publications in 6 European countries and the United States with most included articles were from the US; relevant non-English studies and other healthcare systems may have been missed, potentially limiting generalizability.
- The included studies predominantly employed observational or cross-sectional designs with limited sample sizes, which may limit the certainty of evidence and the ability to establish causal relationships.
- The analysis lacks quantitative synthesis and comprehensive stakeholder perspectives; further research is needed to evaluate the impact of transition care gaps on patient outcomes and identify priority policy interventions.

CONCLUSIONS

- Structured, publicly funded transition pathways ensuring continuity of care, multidisciplinary support with integrated rehabilitative, therapeutic, and social services, an enhanced professional training are critical to close care gaps, prevent clinical deterioration, support caregiver, and preserve dignity and quality of life for patients with R&CE and those who support them.

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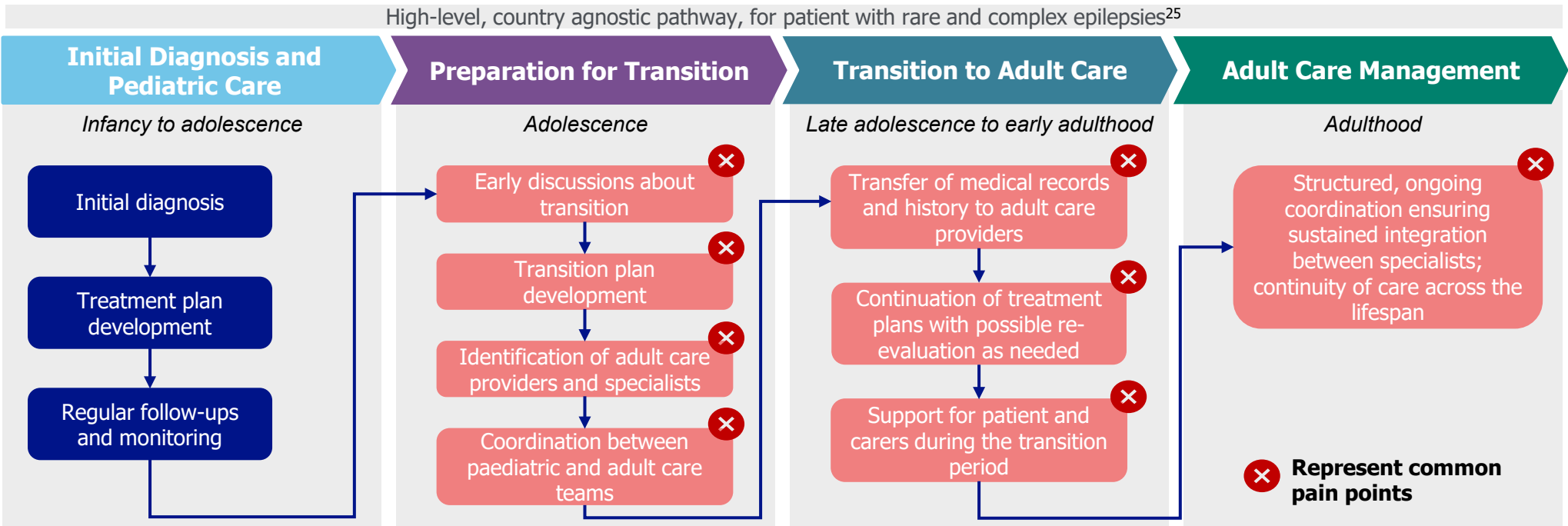
25. Author-developed transition care pathway based on evidence synthesis from literature review and qualitative thematic analysis of transition care challenges

Results

CHALLENGES OF TRANSITIONING CATEGORIZED IN 6 THEMES

	Poor Communication and Coordination Insufficient connection and communication between paediatric and adult care specialists^{2,3}, coupled with inconsistent transition guidelines across countries, impede effective transitions and lead to inadequate preparation and management¹⁻⁶.		Inadequate Adult Care Setting - Adult care systems, including infrastructure, are poorly adapted for severe epilepsy, intellectual disabilities, and behavioural comorbidities^{6,15,16}. - Only 12% (7/57) of European centres provide dedicated transition coordinators or physical spaces². Innovative treatment continuation/start can be challenging¹⁷.
	Inadequate Patient Preparation Many patients are unaware of transition plans with ~50% (28/57) report no written transition procedures in European centers², continue relying on paediatric neurologists, and receive mostly none or limited transition discussions (especially those aged 12–17) or clear instructions after age 18⁷⁻¹¹.		Carer/family Concerns - Carers fear uncertainties in adult services perceived as more fragmented with multiple providers, and are attached to paediatric-led model of care, facing a challenging shift from coordinated family-centred paediatric care to patient-centred adult care^{6,11,13,18,19}. - Mostly no specific funding or reimbursement mechanisms exist for transitional activities^{10,14,20}.
	Lack of Specialized Expertise Adult neurologists often lack knowledge about rare and complex epilepsies, making it difficult for patients and caregivers to find qualified specialists^{6,11-14,18}.		Reduced Multidisciplinary Support Access to multidisciplinary teams, essential for R&CE patients with multiple comorbidities, significantly decreases during transition and remains a sustained gap in adult care settings (e.g., social support, physiotherapy, speech therapy, psychological–psychiatric care)^{2,7,11,21-24}.

MAPPED TRANSITION CARE PATHWAY FROM PAEDIATRIC TO ADULT CARE



OPPORTUNITIES FOR POLICY ACTION

	Advocate mandatory transition programs for R&CEs from age 12-16 years to increase awareness and preparedness for transition. Collaborate with epilepsy organizations and health ministries for national integration.		Fund epilepsy-specific Transition Coordinators to support R&CE patients six months before and after transition.
	Partner with hospitals to create epilepsy transition clinics that are disease-specific multidisciplinary model, offering joint consultations between paediatric and adult neurology/epileptologist experts for R&CE needs, including seizure monitoring, behavioural and psychosocial assessments and coordinated referral to specialists for cognitive/educational/social needs; with accessible virtual options for rural patients.		Enhance adult epilepsy facilities with sensory-friendly settings and R&CE-trained staff, actively involving caregivers/legal representative and establishing supported care pathways for adults with intellectual disabilities.
	Promote integrated multidisciplinary teams to manage R&CE complexities (seizure and non-seizure challenges), ensure continuity of care and, provide therapeutic and rehabilitative support tailored to evolving patient needs.		Close the diagnostic and treatment gap by mandating rare epilepsy training for adult care neurologists through medical curricula and ongoing education, while raising awareness about the benefits of proper diagnosis regardless of patient age.
			Advocate expanded adult epilepsy services and reimbursement for specialized diagnostics (genetic testing), innovative treatments, and monitoring, matching paediatric care standards.

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