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Shishkov, S.; Iotova, V.; Pelsma, I.; Zurita, A.L.P.; Biermasz, N.; Ahmed, F.; Endo-ERN Pituitary Transition Care Study Grp

Endocrine Connections (2025) **14** e250586
https://doi.org/10.1530/EC-25-0586

Received 5 September 2025
Accepted 13 November 2025
Available online 14 November 2025
Version of Record published 2 December 2025

RESEARCH

Feasibility of transition research in pituitary disease using patient registries: a EuRREB secondary survey

Savi Shishkov[1], Violeta Iotova[2,3], Iris Pelsma[4], Ana Luisa Priego Zurita[4], Nienke Biermasz[4] on behalf of the Endo-ERN Pituitary Transition of Care Study Group and Faisal Ahmed[5,6]

[1]Department of Endocrinology, Medical University of Varna, Clinic of Endocrinology, UMHAT "Sveta Marina", Varna, Bulgaria
[2]Department of Pediatrics, Medical University of Varna, Varna, Bulgaria
[3]First Pediatric Clinic with Intensive Care, UMHAT "Sveta Marina", Varna, Bulgaria
[4]Division of Endocrinology, Department of Medicine, Leiden University Medical Center, Leiden, The Netherlands
[5]University of Glasgow, Office for Rare Conditions, Glasgow, United Kingdom
[6]Developmental Endocrinology Research Group, School of Medicine Dentistry & Nursing, University of Glasgow, Glasgow, United Kingdom

Correspondence should be addressed to S Shishkov: savirshishkov@gmail.com

(Details of the Endo-ERN Pituitary Transition of Care Study Group is given in the Acknowledgements section)

This paper forms part of the second collection of papers collated by the European Reference Network on Rare Endocrine Conditions. The Collection Editors were George Mastorakos, Marek Niedzela, Violeta Iotova and Elena Valassi.

Faisal Ahmed is Editor-in-Chief of *Endocrine Connections* and was not involved in the review or editorial process for this paper

Abstract

Aim: Rare disease registries focusing on natural history provide an opportunity to understand the transition process for rare endocrine conditions, including pituitary diseases. This study aims to assess the feasibility of using the European Registry for Rare Endocrine & Bone Conditions (EuRREB) for transition research in pituitary disease and to establish basic clinical characteristics of transition-age pituitary patients managed at reference centers (RCs) within the European Reference Network for Rare Endocrine Conditions (Endo-ERN).

Methods: Patients in the Core Registry of EuRREB aged between 14 and 24 years with a pituitary diagnosis were eligible for inclusion. Physicians were asked to fill out a secondary survey evaluating transition aspects. Descriptive statistics and non-parametric analysis (Kruskal–Wallis, Mann–Whitney) were used.

Results: Of 106 eligible patients, 98 patients had a confirmed diagnosis. Secondary survey data were available for 79 patients (74%) across 6 RCs from 5 countries. 72/79 patients (91%) remained in active care, with a single patient lost or discharged from follow-up (each $n = 1$, 1.3%). 29/79 (36.7%) were already transferred to adult care. Transfer typically occurred at age 18 years and in a few patients up to 22 years. A documented transfer plan was reported for 11 patients (13.9%). Patient-reported outcomes were collected in ten patients (13.5%). Transition challenges were either care-related or patient-related.

Conclusion: This study provides initial characterization of transition of care in rare pituitary diseases in Endo-ERN RCs, showing high follow-up but inconsistent use of plans, patient-reported outcome measures (PROMs), and documentation. Rare disease registries can act as a tool to understand the process and identify barriers.

Keywords: transition; pituitary diseases; disease registry; core registry

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https://doi.org/10.1530/EC-25-0586

Introduction

The transition from pediatric to adult healthcare is a critical period for adolescents and young adults (AYAs) with chronic diseases. It is often associated with discontinuation or interruption of care, poor treatment adherence, and overall worse health outcomes (1).

The challenges in the transition period are not unique to any illness but are shared among numerous chronic diseases (2, 3). In conditions such as diabetes mellitus type 1 (T1DM) (4, 5, 6, 7) and congenital heart defects (8), detailed programs have been developed to facilitate the proper care through the teenage years to adulthood. For T1DM, specific medical outcomes (9) have been explored, as well as generic and diseases-specific patient-reported outcome measures (PROMs) (10).

In rare diseases, transition challenges are compounded by the complexity of disease management, requiring multiple specialists and limited availability of disease-specific transition programs, of which childhood-onset chronic pituitary diseases are an example (11, 12). Despite long-term treatment needs and potential morbidity for individuals with pituitary disorders, transition-related data such as adherence, disease knowledge, and self-sufficiency in decision making in the context of transition readiness are missing, limiting our understanding of care continuity and outcomes post-transfer to adult services.

In other chronic conditions, several key performance indicators (KPIs) for transition have been repeatedly studied, like loss to follow-up (13), therapy adherence (14), and emergency admissions (7). Considering common psychological issues in each chronic condition, these KPIs are applicable outcomes for individuals with pituitary diseases as well.

Rare disease patient registries have proven to be valuable resources for longitudinal data collection, for clinician-reported outcome measures (CROMs), patient-reported outcome measures (PROMs), and care pathway analysis. Notably, registries have supported transition research in conditions such as cystic fibrosis (via the CF Foundation Patient Registry) (15) and juvenile idiopathic arthritis (through the CARRA Registry) (16).

The European Registries for Rare Endocrine and Bone Conditions (EuRREB) is a joint platform developed to support healthcare providers, patients, and researchers within Endo-ERN, ERN BOND, and beyond. It includes two registries, e-REC and the Core Registry, both covering nine main thematic groups: eight endocrine domains and one on bone dysplasia. E-REC is a light-touch platform used to map new patient encounters at participating centers, while the Core Registry collects a set of common data elements recommended by the European Rare Disease Platform (https://eu-rd-platform.jrc.ec.europa.eu/set-of-common-data-elements_en), as well as condition-specific outcomes and PROMs. As the platform is accessible to patients, outcomes can be completed by both patients and healthcare professionals. EuRREB thus provides a valuable resource for studying rare diseases, including pituitary disorders (17).

The potential of registries to facilitate structured transition studies is evident yet remains underutilized in pituitary disease. Therefore, the first aim of this study is to assess the feasibility of using existing patient registries to conduct transition research in pituitary disease. By evaluating registry structure, data completeness, and key outcome availability, we seek to determine whether such registries can support future studies focused on transition-related care and outcomes. Moreover, the second aim is to identify the number and basic characteristics of patients with rare pituitary diseases managed at Endo-ERN reference centers (RCs) whose data are entered in EuRREB and who are in the transition age (14–24 years).

Methods

Design and ethics

The present study employed a mixed-methods design: multicenter registry study (both e-REC and Core Registry) with a secondary survey within the Core Registry. All participating RCs obtained review board approval for entering data into the EuRREB registries. Written informed consent was obtained from all patients before data entry.

Patient selection

Patients aged 14–24 years with a documented diagnosis under the hypothalamic and pituitary group of conditions within the Core Registry at the time of inquiry were included (n = 106). This group accounted for 12.1% of all pituitary patients in the registry (106/1,286) (https://eurreb.eu/reports/). In comparison, as of 26 August 2025, e-REC had registered 1,639 pediatric and 16,895 adult pituitary cases. Among the included 106 patients, 98 had a specific diagnosis, and 79 had a secondary survey completed and were further subject to detailed analysis (Fig. 1). Those outside this age range or lacking a diagnosis were excluded.

Core Registry data collection

For patients with a specific diagnosis, further data were acquired. Data were extracted from the Core Registry based on a standardized data dictionary (https://eurreb.eu/data-dictionaries/). The dataset included: number of registered patients aged 14–24 at the time of inquiry, gender distribution, primary condition and specific diagnosis, current age, age at diagnosis, date of first clinical manifestations, date of first contact with RC,

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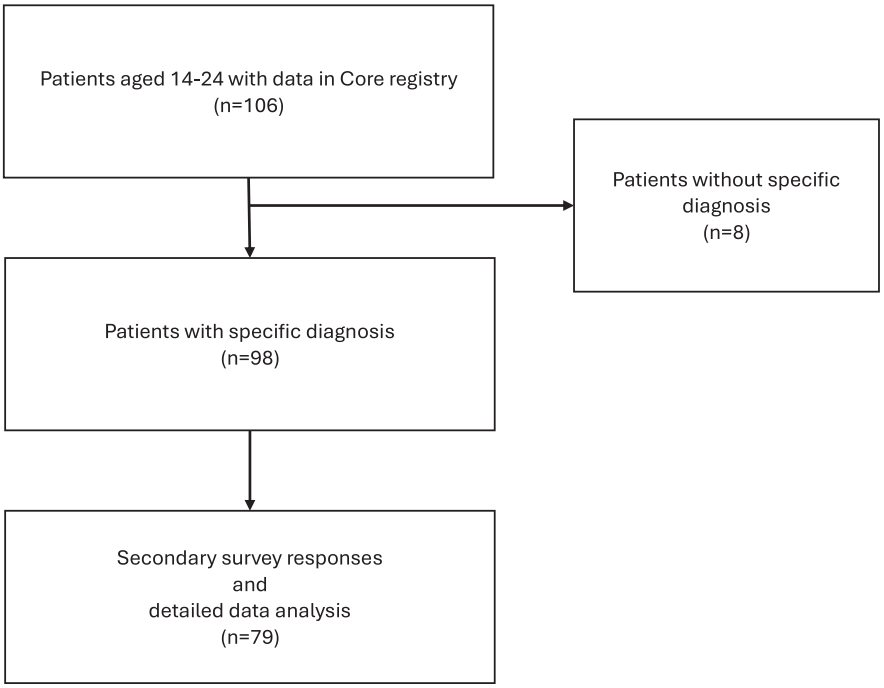

Figure 1

Patient selection flow chart.

time in care, patient follow-up status (defined as active, inactive, care suspended, care terminated, deceased, or unknown), and completion status of patient-reported outcome measures (PROMs).

Survey-based data collection

A specifically designed survey to follow up the individual patients' developments was distributed via email to RC leads and responsible clinicians from institutions that had entered patient data. Survey questions are available as supplementary material (Supplement 1 (see section on Supplementary materials given at the end of the article)). Patient IDs were provided to facilitate linking registry data with additional patient-specific responses from the RCs. Nonresponders received two reminders in the following 30 days. The survey questions were included as a separate questionnaire in the generic outcomes sections of the Core Registry and included: current patient care status, type of managing specialist (pediatric/adult/transition/other), presence of a transfer plan, use of PROMs for transition readiness, age at or planned age of transfer, special interventions to support transition, reporting of transition-related outcomes, challenges encountered during transition, and parental involvement in decision making. Questions were designed for minimal respondent burden, utilizing categorical and short free-text formats.

Statistical analysis

Data from both sources were integrated and analyzed to evaluate patterns and gaps in care transitions among adolescents and young adults with rare endocrine conditions. Descriptive statistics were used, nominal variables being presented as numbers (*n*) with percentages calculated from the total number of cases or secondary survey responses. The number of missing values is indicated for each parameter. Non-parametric tests were used for the between-group comparisons (Kruskal–Wallis, Mann–Whitney U tests with Bonferroni correction).

Results

Patient characteristics

At the time of the study, 106 patients in the Core Registry currently fit the age criterion (14–24 years). Eight patients were excluded based on lacking a diagnosis, resulting in the final inclusion of 98 patients. Eight RCs from the following seven countries reported the included patients: Austria (1 RC), Bulgaria (1 RC), Czech Republic (1 RC), France (1 RC), Germany (1 RC), Italy (1 RC), and the Netherlands (2 RCs).

The average age at the time of the study was 18.6 ± 3.3 years (median – 19, IQR – 6), with 45/98 patients being <18 years (45.9%), and 53/98 patients were ≥18 years (54.1%), 44 out of 98 patients (44.9%) were female. The average age at diagnosis was 13.0 years (median 14, IQR 9), and the average time in care was 5.89 years (median 4, IQR 7). Age distribution is presented in Fig. 2.

The distribution of the diseases revealed that the most common diagnoses are congenital

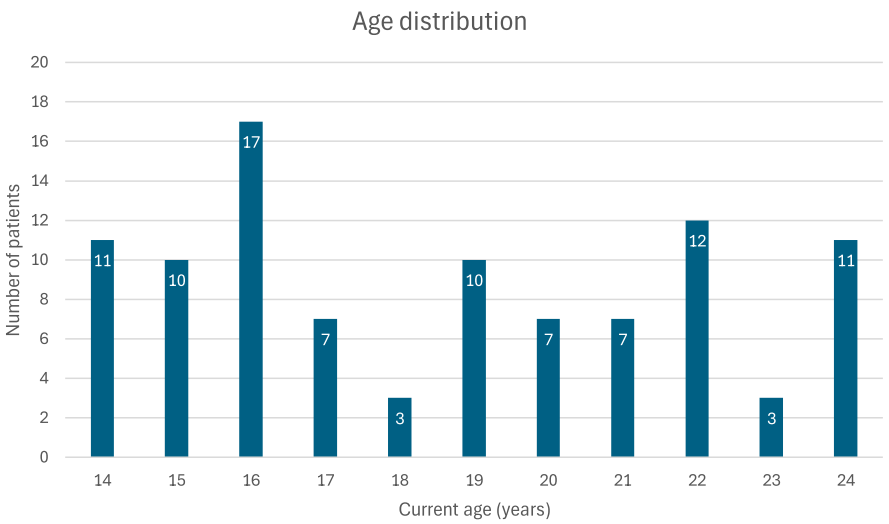

Figure 2

Current age distribution.

hypopituitarism (n = 47), pituitary adenoma (n = 31), followed by acquired hypopituitarism (n = 13), sellar and parasellar tumors (n = 2), and craniopharyngioma (n = 5), as represented in Supplementary Table 1.

In total, the secondary survey was filled out for 79/98 patients by six RCs from five countries. These 79 patients with a completed secondary survey were further grouped into three categories based on their condition: congenital hypopituitarism (n = 43), acquired hypopituitarism (n = 9), and tumor-related disease (n = 27). Detailed data on the current age, time in care, and age of diagnosis for these three patient groups are presented in Supplementary Table 2.

Secondary survey data

Current treating physician and follow-up status

Detailed distribution of specific diagnoses according to the main specialist or disease status is presented in Supplementary Table 3. The leading physician at the time of the survey was the pediatrician for 37/79 patients (46.8%, three of them older than 18 years), the adult endocrinologist for 43.0%, and a psychiatrist for one patient. Notably, one 17-year-old patient was managed in a combined pediatric–adult transition clinic. For the patients under adult care, older than 18 years, only seven patients (8.9%) were discussed at transition meetings. In 32 patients still under pediatric care (40.5%), two of whom were older than 18 years, the transition process was reported as currently ongoing.

Current follow-up status

According to the secondary survey, 72/79 cases (91.1%) were actively followed at the RC at the time of the survey, while 4/79 cases (5.1%) were discharged from follow-up (one before the transfer and two after the transfer, one presented as adult), and 2/79 cases (2.5%) were lost from active medical care. For one individual, no data were provided (1/79; 1.3%).

A total of 29/79 cases (36.7%) were transferred to adult care at the time of the survey. On the other hand, 49/79 cases (62.0%) had not yet undergone transfer. For one case, no data were provided on whether he/she was transferred. Ten cases (12.8%) presented as adults and did not need to be transferred. One patient was lost to follow-up, and one patient was discharged from the RC before the age of 18. For the last patient, information on why transfer was not accomplished was missing.

For those 36 patients for whom transfer was upcoming, the average planned age for transfer was 18.06 years with a range between 18 and 19 years (Fig. 3B). For most of the patients for whom the transfer had already occurred, it occurred at the age of 18 (Fig. 3A).

Age at diagnosis and transfer

Patients could be divided into two groups: patients currently aged <18 years (37/79 (46.8%), average age 15.6 years (median 16, range 14–17, IQR 1)) and patients currently aged ≥18 years (42/79, 53.2%, average age 21.4 years (median 21, range 18–24, IQR 3)), with these ages significantly different ($\chi^2(2) = 27.62$, $P < 0.001$). Moreover, the average age at diagnosis was significantly lower in the younger group (average age of diagnosis 9.17 years (median 6, range 1–14 5)) compared to the older group (average age 16.42 years, median 16, (3–22); $\chi^2(2) = 21.21$, $P < 0.001$). By contrast, the average time in care did not differ between the two age groups (younger: average 6.41 years (median 6, range 1–14, IQR 6); older: 6.79, median 4, (0–19); $\chi^2(2) = 3.54$, $P = 0.171$). Detailed data are presented in Supplementary Table 4.

Post hoc pairwise Mann–Whitney U tests with Bonferroni correction (α = 0.017) revealed that participants with acquired conditions were significantly older than those

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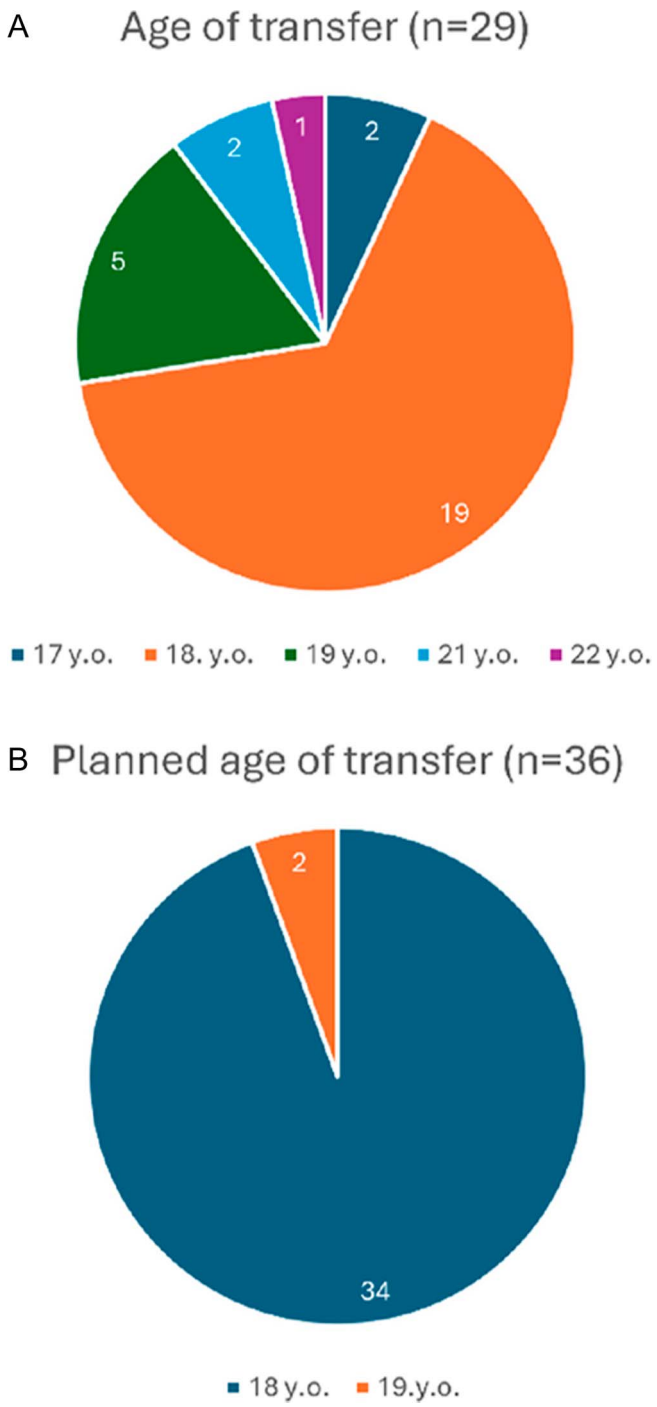

Figure 3

Age distribution for (A) age of transfer for patients already referred to adult care, (B) planned age of transfer for pediatric patients.

with congenital conditions (20.63 vs 16.68), U = 39.00, P < 0.001, and participants with tumors were significantly older than those with congenital conditions (21.11, vs 16.68), U = 169.50, P < 0.001. For age at diagnosis, only the comparison between congenital and tumor groups reached significance, with the tumor group diagnosed at an older age (9.35 vs 15.96), U = 132.50, P < 0.001. No significant group differences were observed for time in care across any pairwise comparisons (all P > 0.05 after correction).

Documented transition plans

A documented transfer plan was implemented for 13 young adults (17.3%) in 4/6 RCs. Only one of these 13 patients was younger than 18 years and under pediatric care. Ten among them were under adult endocrinologist care; one was managed in a transition clinic, and one by a psychiatrist. In some cases, details on the plan were elaborated. Consultation between pediatric and adult endocrinologists had taken place separately with each specialist depending on their expertise and specific issues. In addition, a referral letter from the pediatric center and discussion with the patient were part of the transition planning.

PROMs use for transition

According to the responses from the survey, PROMs were collected for only 10/79 patients (13.5%), all older than 18 years, in three RCs. In one of the RCs, the Transition Readiness Assessment Questionnaire (TRAQ) was used, in one RC the name of the instrument was not mentioned, and in the third RC a local, non-standardized questionnaire was used.

Documentation related to the transition was available in the medical records of 11/79 patients (13.9%) and involved focus on compliance (three patients), communication between pediatricians and adult endocrinologists (two cases), and transition readiness (three cases). In 63/79 cases (79.8%), there were no transition-related medical records. In 5/79 cases (6.3%), no answer was given.

Decision making for, and assessment of, transition readiness

Interventions aimed at supporting the transition process were implemented in 16 persons living with chronic pituitary disease (20.3%). No further inquiry was made into the details of those interventions. Caregiver involvement in decision-making was substantial, reported in 76% of patients (n = 60). In nine individuals (9.3%), parents or guardians were not involved in the decision making process, while in five participants (6.3%) no documentation regarding caregiver involvement was available, and in another five patients (6.3%) no answer was given by the respondent.

Challenges to transition

The final question of the survey addressed challenges during transition. In 30/79 cases, no data were provided. For 19/79 young adults, physicians explicitly

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Table 1 Quotes from open answers given by respondents regarding challenges during the transition of patients.

Quotes
"Good collaboration with pediatric endocrinologist care was key"
"Obstruction of education because of disease including after 18 years. Lack of social support"
"Side effects of dopamine agonist interfering with adolescence"
"Can adult endocrinologists deal with issues of adolescence?"
"Stepwise transition (multiple medical specialties were involved), patient has been referred to multiple adult centers for the different specialties"

reported no issues, while 22/79 experienced various difficulties. For 8/79, the question was not applicable either because the patient had presented and started care as an adult or had been discharged from follow-up at transition. The problems shared by the respondents were variable but could be encompassed in two broad categories: transition care related (organizational) and patient related (e.g., cognitive, psychosocial, disease related). Some of the answers are represented as quotes in Table 1.

Organizational issues

Among the healthcare-related difficulties, the most common were those related to the need for pediatric/adult endocrinologist collaboration (10 responses), followed by need for expertise on adolescence issues, delay of the transfer and the need to transfer, to multiple specialists in multiple centers (one response each).

Patient-related issues

Patient-related problems were most frequently reported, with cognitive (n = 4) and psychosocial problems (n = 4) being the most common. Other issues included the burden of comorbidities (n = 2), lack of follow-up and therapy adherence (n = 2 each), difficulties in decision making (n = 1), and problems related to the parent (n = 1). In two instances, challenges were present but no further information was provided by the respondent.

Discussion

This study identified 106 patients in the Core Registry with pituitary conditions in transition age (defined as 14–24 years), among them 79 had a secondary survey completed. The major finding of this study is that the Core Registry provides sufficient data to identify transition-aged patients and capture basic clinical characteristics, while underscoring the need for a dedicated transition module to address existing information gaps. This study highlights the potential of prospective registries to support structured, multicenter transition studies in rare diseases. Despite the high retention of patients after transfer, formal plans and interventions remain scarce. Important challenges were identified and can serve as a basis for a transition module to investigate potential issues.

The present study indicates that most patients remain actively followed up by RCs, with relatively few patients being lost to follow-up or formally discharged. Similarly, Aouchiche *et al.* recently demonstrated a 96% retention rate for rare endocrine patients (18). These results represent a higher proportion of continuously followed patients compared to other prospective cohorts involving chronic diseases. Congenital adrenal hyperplasia (CAH), as a rare endocrine disorder, illustrates these discrepancies: in some research a little over 50% of CAH patients continue to adult care (19), in other research 67% are retained for a 2-year period, and only 28% for a 10-year period (20). Other researchers share a dropout rate for CAH patients of 4.3% and a total lost-to-follow-up rate for endocrine patients of 17.5% (21).

Most patients are managed by a single specialist (adult or pediatric), but in a large percentage of cases (n = 39) the transition process is either ongoing or patients are discussed in transition meetings. There is one instance where no single physician manages the patient but a dedicated transition team. This indicates that the multidisciplinary care pathway is a practice among RCs, except that very few patients with robust transition data were identified. It can be assumed that the presence of multidisciplinary care itself, despite not being formally declared as an intervention, is a major factor contributing to better transition outcomes.

Unsurprising and consistent with previous studies (22), PROMs were utilized in only three centers. Reported are either nonstandardized or general-purpose tools that are widely used and, in some cases, provide evidence for the usefulness of interventions to enhance transition success (23, 24, 25). Given the similarities in patient experiences and psychological challenges across chronic diseases, it is reasonable to expect that a generic questionnaire could be useful for assessing transition readiness in pituitary disorders. Examples of transition readiness questionnaires specific for rare diseases are scarce, with some investigators using modified generic tools adapted for certain rare endocrine diseases. Such examples are general use for endocrinopathies (26) and congenital adrenal hyperplasia (27). A self-efficacy questionnaire in diabetes, for example (28), shows that it is associated with better disease control.

The low rates of PROMs and transition documentation also hinder comprehensive evaluation of outcomes and quality improvement. In this context, the integration of PROMs specific to transition (e.g., self-efficacy, health literacy, patient satisfaction) is particularly relevant. The observed limited use signals the need for better implementation of such tools in routine endocrine care. No pituitary-specific transition readiness tool was identified during the literature review.

According to our data, transfer occurs at or around age 18 for most patients. This formal age threshold does not always reflect developmental readiness or the presence of an organized process, as evidenced by delayed transitions and ongoing pediatric involvement in some adult patients.

One of the strengths of this study is the possibility to acquire qualitative data and identify barriers to transition using a survey. It revealed that although care for most patients continued uninterrupted, significant challenges persist, some of them related to the pituitary disease itself. Examples of that are prolactinoma-associated treatment effects confounding patients' psychological state and autonomy. System-level barriers, while less frequently reported, highlight the fragmentation that can occur when transfers involve different institutions. These observations are aligned with the transition literature in other rare conditions (13, 14). Despite parent involvement being high (over 80%), a small proportion of patients had no documented caregiver, or roles were unclear. This highlights potential gaps in social support and shared decision making and may be critical barriers to a successful transition.

Several limitations should be acknowledged. The cross-sectional nature of the registry and survey data restricts longitudinal interpretation of outcomes in the post-transfer period. Response bias may have influenced survey results, particularly regarding subjective reporting of transition quality and challenges. Selection bias is a likely factor in this research since more active patients are more likely to be included in prospective registers. Despite the number of patients, they represent only six centers from five countries. Apart from that, the number of cases included in the current study is remarkably small compared to all new cases in the e-REC platform and only a fraction of all Core Registry pituitary cases. This discrepancy implies significant underreporting in the Core Registry.

Despite the large percentage of consistently treated patients, only 17% had a documented transition plan. This is in clear discrepancy with previous findings that more than half of Endo-ERN RCs use formal plans to organize transition (22). According to our data, less than a quarter received targeted interventions to support the process. Whether this lack of written plan and dedicated interventions affects transition success is another question requiring further study.

Recommendations for a transition-specific module

The current research provides evidence that transition study in rare endocrine disorders, pituitary disease in particular, is feasible by the means of prospective registries. Therefore, we suggest a simple pilot module to facilitate the collection of basic transition-related data. Based on our results and the major success indicators, we recommend recording the following parameters:

(i) Transition readiness, including use of PROMs focusing on self-management, adherence, and disease knowledge.
(ii) Documented transfer plans – whether a structured plan exists and has been implemented.
(iii) Transition-facilitating interventions, such as multidisciplinary care or other targeted strategies.
(iv) Challenges encountered, categorized by patient-related, disease-specific, and systemic barriers.
(v) Age at transfer.
(vi) Lost to follow-up, defined as the time elapsed since the last documented clinical appointment, to identify gaps in care continuity.
(vii) Parental/caregiver involvement – to capture the extent and role of family support during transition.

All proposed elements should be designed in a generic and adaptable format to ensure applicability across the wide range of rare endocrine conditions represented in the Core Registry. Furthermore, standardization of these measurable parameters is particularly valuable for capturing patient-centered outcomes and enabling cross-disease and cross-center comparisons.

Conclusion

The transition from pediatric to adult healthcare is a vulnerable period for adolescents and young adults with chronic endocrine conditions, particularly those with rare diseases. This study provides an important initial step in characterizing the transition landscape for AYAs with rare pituitary diseases across Europe. It confirms that while follow-up rates remain high, formal transition frameworks, use of PROMs, and documentation of transition-related care are inconsistently applied. Psychological, developmental, and system-related factors continue to pose substantial barriers. There is a clear opportunity and need for the development of condition group–specific transition protocols for rare endocrine disorders, supported by standardized outcome tracking through existing registries. Future research, by means of using prospective registers, should focus on longitudinal outcome tracking and establishing a way to evaluate the effect of structured interventions with a combination of PROMs and clinical parameters.

Supplementary materials

This is linked to the online version of the paper at https://doi.org/10.1530/EC-25-0586.

Declaration of interest

The authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of the work reported.

Faisal Ahmed is Editor-in-Chief of *Endocrine Connections*. Faisal Ahmed was not involved in the review or editorial process for this paper, on which he is listed as an author.

Funding

This work did not receive any specific grant from any funding agency in the public, commercial, or not-for-profit sector.

Author contribution statement

All authors listed have made substantial, direct, intellectual contributions to the work and approved it for publication. The Endo-ERN respondents of reference centers for MTG6, which are part of the Endo-ERN Pituitary Transition of Care Study Group. All authors evaluated the paper.

Acknowledgements

Nienke Biermasz is Adult Chair of the Endo-ERN Main Thematic Group, MTG6: Hypothalamic and Pituitary Conditions.

The authors would like to thank Dr Mariya Cherenko, Leiden University Medical Center, Leiden, The Netherlands, for her assistance with data management.

Endo-ERN pituitary transition of care study group: A Pereira – Amsterdam-UMC. A Peet, Tartu University Hospital. A Raimann – Medical University of Vienna. A van de Ven, Radboud University Nijmegen Medical Center – including Amalia's Children's Hospital. B Biagetti, Hospital Universitari Vall d'Hebron. B Donadille, Assistance Publique – Consortium Cochin, Robert Debré, Necker, St Antoine, La Pitié Salpétrière, Trousseau University Hospitals. B Fibbi, University Hospital Florence. B Zilaitiene, Hospital of Lithuanian University of Health Sciences Kauno Klinikos. C Andreescu, UZ Brussels. C Brachet, liniques universitaires de Bruxelles – Hôpital Erasme. C Grasemann – Bochum-RU. C Gravholt, Aarhus University Hospital. C Höybye, Karolinska University Hospital. C Regis – CHU Angers. D Maiter, Cliniques universitaires Saint-Luc. E Charmandari, Aghia Sophia Children's Hospital. F Albarel, Assistance Publique – Hôpitaux de Marseille. F Ceccato, Azienda Ospedaliera di Padova (AOP). F Gatto, IRCCS Ospedale Policlinico San Martino – Genova – Italy. Fl Haufler – Medical University of Vienna. G Haeausler – Medical University of Vienna, Center for Rare Endocrinologic Diseases/Dpt. of Internal Medicine III. G Hartmann – Vienna-BGC. G Russo, Ospedale San Raffaele. G Vila, Medical University of Vienna, Center for Rare Endocrinologic Diseases/Dpt. of Internal Medicine III. H Vlaardingerbroek, Leiden University Medical Center. I Rica, Hospital Universitario Cruces. J Lebl, University Hospital Motol. J Leger, Assistance Publique – Consortium Cochin, Robert Debré, Necker, St Antoine, La Pitié Salpétrière, Trousseau University Hospitals. K Stochholm, Aarhus University Hospital. L Bakker – Leiden-LUMC. L van der Hoeven – Amsterdam-UMC. L Persani, Istituto Auxologico Italiano – Istituto di Ricovero e Cura a Carattere Scientifico. L de Sanctis, Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino. M Bonomi, Istituto Auxologico Italiano – Istituto di Ricovero e Cura a Carattere Scientifico. M Avbelj Stefanija, University Medical Centre Ljubljana. M Fassnacht, University Hospital Würzburg. M van der Klauw, University of Groningen, University Medical Center Groningen. M Maříková – Prague-UHM. M Toumba, Cyprus Institute of Neurology and Genetics, Department of Molecular Genetics, Function and Therapy. N Birkebæk, Aarhus University Hospital. N Krasteva – Varna-UMHAT. N Unger, University Hospital Essen – Center for Rare Endocrine Diseases. P Maffei, Azienda Ospedaliera di Padova (AOP). P Matarazzo, Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino. S Christin-Maitre, Assistance Publique – Consortium Cochin, Robert Debré, Necker, St Antoine, La Pitié Salpétrière, Trousseau University Hospitals. S Frara, Ospedale San Raffaele. S Grottoli, Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino. T Brue, Assistance Publique – Hôpitaux de Marseille. T Kocjan, University Medical Centre Ljubljana. V Volke, Tartu University Hospital. W Bonfig, Klinikum Wels-Grieskirchen, Center for Pediatric Endocrinology/Dpt. of Pediatrics. W Staels, UZ Brussels.

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