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Clinical Practice Guideline

European Society for Paediatric Endocrinology (ESPE) and European Society of Endocrinology (ESE) joint clinical practice guidance for healthcare transition from paediatric to adult endocrine care

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Abstract

Background **The transition from paediatric to adult healthcare is a critical period for young individuals with endocrine conditions. Despite numerous published recommendations, Europe still lacks recent, comprehensive, evidence-based, and practically applicable guidelines for endocrine healthcare transition.**

Objective **To develop European consensus guidance for transition from paediatric to adult care in endocrine conditions through a structured, evidence-based approach.**

Methods **A systematic literature review identified 351 recommendations from 55 articles (2011-2023). Articles were included if they provided recommendations on transition from paediatric to adult care for patients with endocrine diseases or**

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general (non-disease-specific) transition guidance. The guidance was developed by a core multidisciplinary group ($n = 7$) and refined through focus groups with 18 experts from 10 European countries, representing both paediatric and adult care settings. Patient representatives have reviewed and approved it.

Results **The guidance includes recommendations across 11 domains: structure of transition service, patient empowerment, patient–professional relationship, multidisciplinary team organization, healthcare provider education, timing and planning, care coordination, management of non-attendance, psychological support, parents/caregivers role, and readiness tools. Each recommendation was rated as either "recommend" (strong) or "suggest" (conditional) based on expert consensus and available evidence.**

Conclusion **This ESE-ESPE guidance provides a comprehensive, practical framework for endocrine healthcare transition, applicable across different European healthcare settings. The recommendations emphasise structured programs, care coordination, and patient-centred approaches to optimize transition outcomes.**

Keywords healthcare transition, endocrine conditions, clinical practice guidelines, adolescent, young adult

Significance

This pan-European consensus addresses the current lack of evidence-based transition guidance for endocrine conditions, which contributes to high rates of care discontinuity in young adults. By providing validated readiness tools and coordination protocols developed through multi-stakeholder collaboration across 10 countries, it offers actionable solutions to prevent loss to follow-up during this high-risk period.

Preamble—Defining roles and responsibilities

The effectiveness of transitional care relies on a collaborative approach where each stakeholder has complementary responsibilities. The following roles and duties are applicable across various settings.

Patients (adolescents/young adults): Young individuals with chronic endocrine conditions transitioning from paediatric to adult care. They represent the central focus of the transition process, requiring personalized support to develop autonomy while maintaining optimal health outcomes.

Parents/Caregivers: The primary adult figures providing guidance and support to their adolescent or young adult child. They require education and guidance to balance support with promoting independence, facilitating smooth role evolution throughout the transition process.

Paediatric healthcare providers: Specialized professionals (medical doctor, nurses, etc.) experienced in child and adolescent care who initiate and lead the transition preparation process from early adolescence in a holistic way. Apart from their medical expertise, they focus on patient empowerment, readiness assessment, education and ensuring comprehensive medical summary documentation while maintaining patient-centred, trust-based relationships.

Adult healthcare providers: Specialists in adult care systems (medical doctors, nurses, etc.) who continue the transition process after patient transfer from paediatrics, and continue long-term chronic disease management with a holistic approach. They require expertise in both the specific medical condition and adolescent/young adult populations, with skills to build new therapeutic relationships and adapt care approaches.

Transition coordinator (or transition navigator): Dedicated professional (paediatric nurse, social worker, or paediatrician) responsible for coordinating and facilitating the transition process, ensuring continuity between paediatric and adult care systems. They foster trusting relationships with adolescents and families, coordinate communication across services, coordinate appointments, monitor attendance, address barriers to care, connect patients with resources and primary care, and promote autonomy and continuity beyond the post-transfer period. While peers may assist at specific points, the coordinator should remain a trained professional to ensure objective care coordination.

Primary care providers: General practitioners who provide comprehensive, holistic and preventative care, general health support, and navigation guidance in healthcare services. They serve as crucial safety nets, particularly in settings where specialty adult care is unavailable, ensuring holistic healthcare management during transition. Improved education and training of primary care providers in endocrine disorders are essential to strengthening the quality and continuity of transition care, especially when these providers play a role in the transition process.

Mental health professionals: Specialized providers who address psychosocial aspects of transition, offering screening, assessment, and support for mental health and social adjustment issues. They provide professional awareness, parent education, and direct patient support through psychoeducation and targeted interventions for transition-related psychological and social challenges.

Multidisciplinary team members: Collaborative network of healthcare professionals from both paediatric and adult care settings working together with clearly defined roles. They ensure coordinated, holistic care through regular communication, shared decision-making, and a comprehensive approach to patient needs throughout the transition continuum.

Introduction

The transition from paediatric to adult healthcare represents a critical phase for adolescents and young adults with chronic endocrine conditions. This transition phase, varying across European healthcare systems, but typically spanning from early adolescence to young adulthood (ages 12-25), coincides with significant developmental, psychosocial, and medical changes.[1] Studies demonstrate that young patients with endocrine disorders face substantial risks of loss to follow-up during transition, with rates varying by condition and measurement methods: 28%-43% for type 1 diabetes (with clinic attendance declining from 94% pre-transition to 57% post-transition),[2-4] 44% for Turner syndrome,[5,6] and 22%-61% for obesity.[7,8] Poor transition management can compromise care, potentially leading to serious consequences for their long-term health outcomes and quality of life.[9-14] While there is no universally accepted definition of successful transition, we define it as a process resulting in improved self-care skills, maintained adherence to care, and seamless establishment in adult services, measured by absence of care gaps, reduced emergency utilization, high patient satisfaction, and stable or improved disease-specific outcomes.[15-17]

Endocrine conditions pose unique challenges during transition, due to their chronic nature, the need for regular monitoring, and the critical importance of treatment adherence. The complexity of care management is amplified by the diversity of endocrine conditions, ranging from pituitary disorders and thyroid diseases over adrenal disorders and diabetes mellitus to disorders/differences of sexual development, many of which directly affect pubertal development (spontaneous, delayed, or induced). This broad spectrum of disorders requires careful referral to an adult endocrinology centre equipped with the appropriate expertise to manage the specific condition alongside attention to developmental and psychosocial factors and healthcare system capabilities.

Existing guidelines on healthcare transition in endocrinology are disease-specific[18-22] and leave many rare or less-discussed disorders without tailored transition guidance.

To address this, we propose a new European guidance based on a rigorous methodology combining a systematic review of scientific literature and extensive consultation with multidisciplinary experts. This guidance positions itself as a structural reference framework applicable to all endocrine conditions, designed to be adapted and complemented by disease-specific recommendations where they exist. It is not intended to replace disease-specific guidelines, but rather to provide a common organizational architecture that can be enriched and modulated according to the specificities of each condition. By building on existing research evidence and incorporating diverse expert opinions, we have developed practical recommendations that address the real constraints of European healthcare systems while maintaining scientific rigor.

Methods

Guidance development process

This guidance was developed through a 3-step process: (1) systematic literature review to identify current evidence and practices; (2) drafting of initial guidance by the core group based on literature findings and clinical expertise; and (3) refinement and validation through expert panel focus groups representing diverse specialties and geographical regions. Patient advocacy groups reviewed and validated the final manuscript to ensure alignment with patient and family perspectives.

Core guidance group

A multidisciplinary core group ($n = 7$) was established jointly by the European Society for Paediatric Endocrinology (ESPE) and European Society of Endocrinology (ESE). The group included adult endocrinologists (S.N., K.S., and M.F.), a paediatric endocrinologist (S.C.), a public health researcher specialized in healthcare transition (E.L.), and representatives from ESPE (A.H.) and ESE (V.D.G.).

Literature review

A systematic literature search was conducted through July 2023 using PubMed and Google Scholar databases using 3 complementary search strategies (Appendix 1). Strategy 1 targeted endocrine-specific transition guidance (yielding 55 articles), strategy 2 targeted general transition recommendations (yielding 190 articles), and strategy 3 used broader search terms (yielding 109 articles). After removal of duplicates, 326 unique articles were screened. Articles were included if they met at least one of the following criteria: (1) provided recommendations on transition from paediatric to adult care for patients with any endocrine disease or (2) provided general (non-disease-specific) recommendations on transition from paediatric to adult care. Articles were excluded if published in languages other than English, French, or German, did not contain explicit recommendations on transition care, or focused solely on adult-onset conditions without relevance to paediatric-to-adult transition. Eligibility analyses on abstracts and full-text were performed independently by 5 members of the core group (E.L., S.N., K.S., M.F., and S.C.). A total of 351 recommendations were extracted from 55 eligible articles.

Quality assessment

For each included article, we assessed the level of evidence supporting its recommendations using a 3-tier classification: low-quality evidence (expert consensus, case series), moderate-quality evidence (observational studies, small interventional studies, RCTs with high bias risk), and high-quality evidence (large RCTs with low bias risk, systematic reviews/meta-analyses). This informed the strength of our final recommendations, though the paucity of high-quality evidence in transition care meant most guidance relied on moderate- or low-quality sources and expert consensus.

Synthesis of recommendations

The 351 extracted recommendations were thematically classified by 5 core group members (E.L., S.N., K.S., M.S., and S.C.) working in pairs. When multiple articles provided overlapping recommendations, we synthesized them into unified statements while preserving nuanced differences and ensuring comprehensive coverage. Through virtual meetings the entire core group reviewed the statements, and divided them into 11 domains, hereby creating a draft guidance.

Expert panel selection and focus groups

The draft guidance was presented to expert focus groups for validation and refinement. Healthcare professionals with expertise in transition care, research, and/or policy development were recruited through ESE and ESPE networks. The expert panel included 18 healthcare professionals from 10 European countries (France, Italy, Lithuania, Denmark, Belgium, The Netherlands, Sweden, Ireland, Greece, and Germany), representing diverse perspectives in endocrine care transition. The panel included both paediatric ($n = 5$) and adult ($n = 8$) endocrinologists, nurses ($n = 4$), and a professor in children's nursing ($n = 1$). All participants had extensive experience in transition care, with several leading dedicated transition clinics at their institutions. Their areas of expertise covered the full range of endocrine conditions, including growth and pituitary disorders, thyroid disease, diabetes mellitus and metabolism, disorders/differences of sex development, adrenal conditions, and reproductive health. The panel included members with leadership roles in academic institutions and endocrine European reference networks. No formal evaluation of the representativeness of the expert-panel was performed.

These experts were divided into 3 balanced focus groups (4-7 participants each), ensuring diversity in terms of countries, specialties and professional roles. Each group reviewed 3-4 specific domains of the draft guidance, providing suggestions for modifications and additional references during 2.5-hour focus group sessions (facilitated either by E.L. and V.D.G. or S.N. and A.H.). Subsequently, all experts reviewed the complete document.

Patient representatives review and validation

Patient representatives from 5 advocacy groups, covering both paediatric and adult endocrine aspects, critically reviewed the completed document from the expert panels to ensure patient-centred relevance.

Grading of recommendations

Based on the available evidence and expert consensus, recommendations were classified as either "recommend" (strong) or "suggest" (conditional) by the 5 core group members. This classification reflects both the quality of evidence and the degree of consensus among experts. Although the grading system resembles that of the ESE guidelines, several notable differences exist. The recommendations are defined as follows:

- We recommend: Based on moderate-quality evidence such as expert consensus, low-quality RCTs (with high risk of bias), large cohort studies, or a synthesis of these.
- We suggest: Supported primarily by expert opinion, small cohort or case–control studies, usual clinical practice, descriptive case series, or a synthesis of these.

Results

The joint ESE-ESPE guidance provides evidence-based recommendations across 11 domains for transitioning adolescents and young adults with endocrine conditions from paediatric to adult care. Throughout this guidance, we use "transition" to describe the comprehensive, gradual process of preparing young people for adult healthcare but also supports their medical, psychosocial, and educational needs as they move towards greater independence and integration into adult life while "transfer" refers specifically to the single point in time when care responsibility shifts from paediatric to adult providers.[1] The guidance emphasises a structured, comprehensive approach to transition. These recommendations were developed to be applicable across different healthcare settings while maintaining high standards of care. While all domains should be considered, we recognise that support needs vary considerably among patients and healthcare resources must be allocated efficiently. Healthcare providers should engage patients and their families in collaborative discussions to identify individual needs and priorities, tailoring the transition plan accordingly rather than applying all recommendations uniformly, thereby optimizing both individual outcomes and resource utilization. Certain risk factors for unsuccessful transition have been identified: unstable or complex disease courses, younger age, male gender, limited self-management skills, low health literacy, lower levels of cognitive or developmental maturity, public insurance coverage, reduced family socioeconomic status, poor parent–adolescent communication, and excessive parental dependence.[23-27] Patients presenting with multiple risk factors may therefore benefit from enhanced support.

Appendix 2 presents a comprehensive overview of the recommended transition timeline and tools. Appendix 3 offers an implementation checklist to serve as a practical tool to support adoption. Each item in the checklist serves as a process indicator to evaluate the integration of the guidance into routine practice.

The 11 domains of the guidance encompass structured transition, patient empowerment, the patient–professional relationship, multidisciplinary team organization, transition coordination, healthcare provider education, timing and planning, management of non-attendance, psychological assessment, the parents/caregivers preparation and involvement, and readiness assessment (Figure 1). For each domain, recommendations are provided based on the available evidence.

Guidance

Structure of transition services

We recommend implementing a structured, comprehensive yet flexible transition programme that adapts to an individual patient's needs and aligns with available national and local resources of various centres. Preparation of the individual transition programme should be initiated in early adolescence, its deployment should occur in mid/late adolescence, and completion of the transition, with follow-up, in young adulthood. Paediatric and adult care professionals both should be aligned towards shared transition objectives.

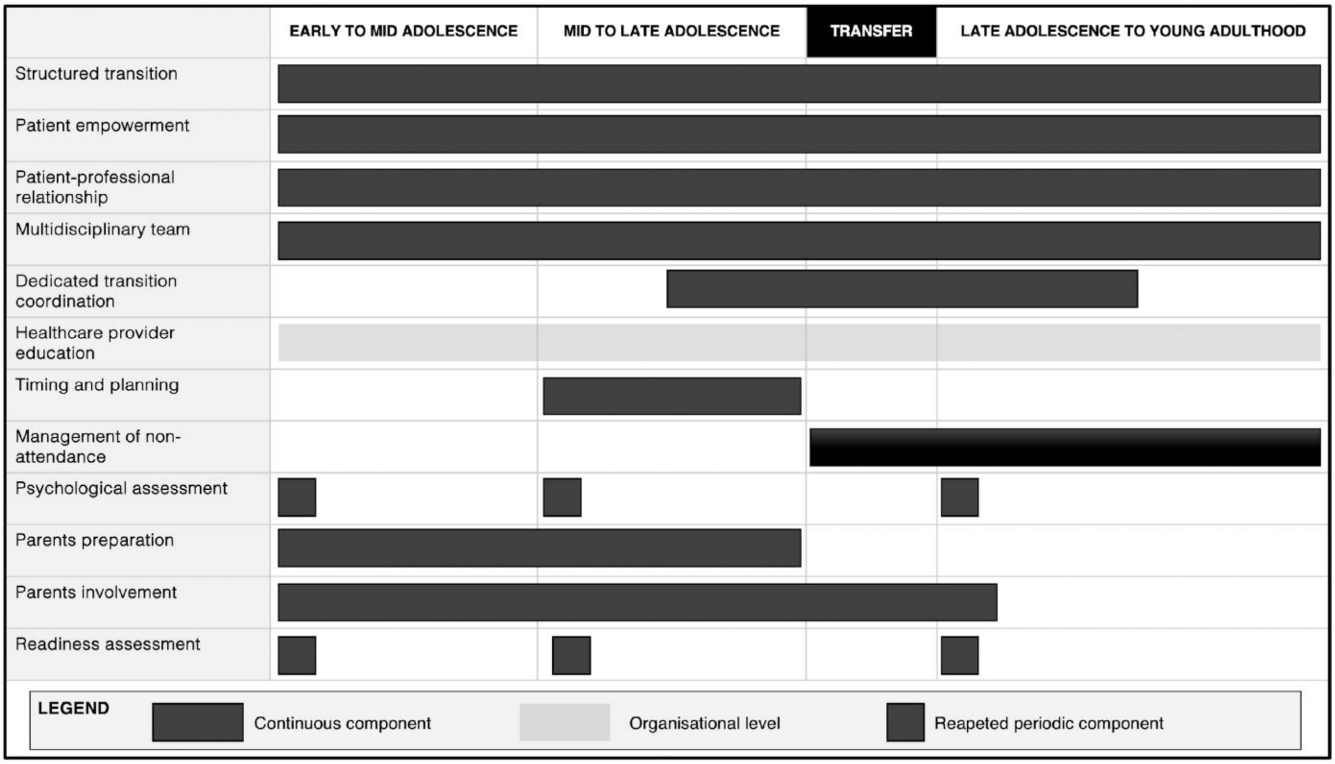

Figure 1 Timeline of the eleven domains of the guidance.

We recommend that the transition programme, encompassing paediatric and adult care, include core components: creation of a medical summary document (such as a paediatric provider's letter) with a synthesis of the patient's medical history along with clinical record sharing; a tailored plan of care coordination and emergency management strategies for patients and families; readiness tools (pre-transfer and post-transfer checklists); holistic psychosocial assessment using standardized tools, such as HEADSS[28] or SSHADESS;[29] inter-service communication and coordination (collaborative exchanges between paediatric and adult care providers); a referral to the adult physician; patient empowerment initiatives; and developmentally appropriate educational resources emphasizing autonomous health management both before and after transfer.

We suggest that healthcare professionals engage in specialized training in adolescent and young adult care, create welcoming care environments, identify a transition coordinator for each patient, establish accessible communication channels with patients, and implement digital health solutions including patient communication apps and telemedicine platforms. Additionally, programmes should incorporate feedback mechanisms from patients and families.

Patient empowerment

We recommend transition programmes to (re)inform adolescents about their chronic condition and treatment and to address health literacy, communication, decision-making, and self-management skills, developed in collaboration with the patients, their families and healthcare providers starting in paediatrics and continuing to be offered after the transfer. We suggest including accurate and understandable information on the transition process to encourage active informed participation.

We suggest a gradual transfer of responsibility from the parent(s) to the patient, ensuring development of comprehensive chronic illness management. This transfer of responsibility should be personalized for all individuals, taking into account their readiness—maturity, cognitive abilities, preparation and abilities (tools are presented in Table 1).

We suggest actively developing medical self-management skills, including medication adherence and emergency management. We also recommend fostering broader life skills such as independence, driving, substance use awareness, and knowledge of birth control. We suggest providing developmentally appropriate counselling about risk behaviours (such as alcohol use, recreational drugs, and other activities) that may interfere with disease management or medication adherence, offering practical strategies to support safe decision-making while respecting the adolescent's need for autonomy and exploration. This includes progressively introducing age-appropriate discussions about puberty, fertility and reproductive health, initial basic information should be provided during paediatric care, recognizing that many adolescents may not be emotionally ready to fully engage with these topics, and more detailed counselling continuing during the transition phase in adult care, adapting to the patient's developmental stage and readiness.

We propose peer mentorship as an adjunctive transition intervention for adolescents and young adults. Evidence from diabetes care demonstrates that peer-based models can enhance self-efficacy, provide developmentally appropriate and

Table 1 Comprehensive table of transition readiness assessment generic tools (applicable to all chronic disease).

Tool Name	Number of Items	Domains	Main References
TRAQ (Transition Readiness Assessment Questionnaire)	20 items (revised version)	Medication management; Appointment keeping; Tracking health issues; Talking with providers; Managing daily activities	Sawicki et al. 2011[30]; Wood et al. 2014[31]
STARx (Self-Management and Transition to Adulthood with Rx)	18 items	Self-management; Disease knowledge; Provider communication	Ferris et al. 2015[32]; Cohen et al. 2015[33]
UNC TRxANSITION Scale/Index[a]	33 items (revised version)	Type of illness; Medication; Adherence; Nutrition; Self-management; Reproduction; Trade/school; Insurance; Ongoing support; New providers	Ferris et al. 2012[34]; Cantú-Quintanilla et al. 2015[35]
Good2Go	20 items	Health self-advocacy; Knowledge about chronic conditions; Self-management skills	Mellerio et al. 2020[36]
Am I ON TRAC for Adult Care	32 items (revised version)	Knowledge; Behaviour	Moynihan et al. 2015[37]
Self-Management Skills Assessment Guide	21 items	Self-management; Advocacy skills	Williams et al. 2010[38]
TRANSITION-Q	14 items	Self-management skills	Klassen et al. 2015[39]

[a] Clinician-administered.

experiential support, and improve continuity and engagement with adult services.[40]

We suggest that preparing for transition readiness should include evaluation of health-care navigation, appointment management, practical medication management (including independently obtaining prescriptions and collecting medications from the pharmacy), knowledge related to the disease, self-management and communication skills. We acknowledge that not all patients are able to reach the same level of achievement of these objectives.

For patients with intellectual disability (ID), including conditions such as Prader-Willi syndrome, the objectives and assessment of autonomy should be commonly defined and adapted to the cognitive level, as well as the degree of parental involvement.

We suggest discussing future needs early in the paediatric setting and continuing discussions throughout the adult care setting.

We suggest that paediatric units lead the patient empowerment process and, at the time of transfer, facilitate the identification of appropriate adult healthcare providers by sharing information with patients and engaging in a discussion that balances treatment recommendations with the patient's priorities.

Patient–professional relationship

We recommend building a patient-centred and trust-based relationship between the patient and the healthcare providers, to improve better patient self-management outcomes. The patient rather than the disease should be the focus of both paediatric and adult care.

We suggest encouraging healthcare professionals and caregivers to guide the patient in learning how to manage their condition as much as possible, according to their abilities. We suggest including shared decision-making during consultations to ensure patient engagement and understanding.

We suggest facilitating at least one introductory meeting with adult healthcare professionals before the transfer. This helps to establish a personal relationship, to build patient confidence, and foster rapport within the adult care system.

Multidisciplinary team organization

We recommend adopting a comprehensive, holistic, coordinated, and team-based approach to patient care. This approach should establish clearly defined roles for all providers and ensure regular communication and collaboration both within and between paediatric and adult care providers.

We recommend assigning a dedicated transition coordinator (such as a paediatric nurse, social worker, or paediatrician) who mediates organization and communication among stakeholders, and maintains a mutually trusting relationship with the patient. At the relevant time, this multidisciplinary team should ideally include fertility specialists (gynaecologists and/or andrologists) and, for patients with genetic endocrine disorders, clinical geneticists who can provide early counselling about reproductive options and risks. If a monogenic aetiology is considered likely but has not been identified, re-evaluation with genetic testing may be considered, particularly in the presence of evolving clinical features and/or the availability of additional or more advanced genetic methodologies (eg, whole-genome sequencing or RNA sequencing). However, in routine clinical practice this approach may be limited by logistical constraints, as biological samples are frequently not retained beyond a defined storage period.

We recognise that healthcare settings vary considerably in available resources. We encourage a pragmatic, tiered approach to implementation, where each centre adapts recommendations according to local resources and constraints.

In the absence of specialized adult hospital care, we suggest communicating relevant information to the general practitioner responsible for the patient's ongoing management, and the patient should be prepared for this scenario through appropriate education and support resources. The general practitioner may actively search for specialized adult endocrine care in the nearest reference centre through European Reference Networks (ERN), e-health resources, or regional/national networks. However, in many European countries, it is not realistic that the general practitioner can manage complex endocrine conditions during transition independently. In these situations, the paediatric team should support the general practitioner in identifying appropriate adult specialists and facilitate this connection. Evidence demonstrates superior clinical outcomes when patients with endocrine conditions receive specialist care compared to generalist management. For example, in type 1 diabetes, specialist care is associated with significantly lower HbA1c levels, greater engagement in diabetes self-care practices, more frequent monitoring, and reduced incidence of nephropathy during long-term follow-up.[41,42]

For patients with intellectual disability, an enhanced collaboration with social, educational, and medico-social services should be consider as well as transition to specialized adult structures (reference centres, medico-social facilities).

Healthcare provider education

We suggest that paediatric and adult health care providers involved in transition should regularly engage in exchanging information, practices, knowledge and skills regarding treatment methods, transition goals and programmes, and timelines, to improve the overall process.

We suggest that the implementation and facilitation of this information and knowledge transfer can be achieved through clinical lectures and staff exchange programmes. We suggest learning from, and collaborating with, providers of successful transition programmes in other chronic disease areas and adapting their strategies, where relevant.

Timing and planning

We recommend considering transition as part of a continuous process that must be planned and discussed during early adolescence, integrating flexible timelines tailored to patient readiness rather than a fixed age.

We acknowledge that some healthcare systems have mandatory age limits (typically 18 or 21 years) beyond which paediatric services cannot continue. In such contexts, we suggest that transition planning must proactively account for these constraints, and that patients and families should be informed well in advance to ensure adequate preparation within the available timeframe.

Globally, there is no recommended age for transfer; we suggest that the appropriate time should be determined based on the patient's readiness to integrate into adult care, their parents'/caregivers' readiness, and country regulations.

We suggest that target transfer ages between 16 and 24 years are appropriate, with most patients transferring around 18-19 years. This flexible approach accommodates diverse circumstances, maturity, cognitive functioning, psychosocial functioning, ability to make informed health decisions independently, patient decision/choice and individual developmental needs.

We suggest using planning tools such as personalized action plans with clear goals and milestones, and regularly reviewing these plans with the patient to adjust the timing of transfer.

Care coordination

We recommend that the transition preparation and process is led by a transition coordinator.

We suggest that the transition coordinator, at the time of the last meeting in paediatrics, makes the first appointment with adult care, and that this appointment is planned within 3-6 months post transfer. We suggest that the transition coordinator uses digital reminders and follow-up with the patient after transfer to confirm attendance at adult clinics and to identify any barriers.

We suggest ensuring clear and consistent communication between paediatric and adult teams, formal transition policies, and transparent leadership (eg, from the transition coordinator) during the different stages of the transition process to avoid gaps in care.

We suggest organizing joint clinics involving paediatric and adult providers (and primary care providers if possible and relevant) during the transition to improve the patient's comfort, facilitate smooth introductions, and ensure adequate transfer of responsibility of care and continuity.

Based on available evidence, the transition coordinator should ideally be present at key transition milestones including initial transition discussions, joint paediatric-adult clinics (or alternatively, the last paediatric visit and first adult care visit), and should maintain contact for several months after transfer. However, no data exist to define the optimal intensity and duration of this involvement, which should be tailored according to individual patient needs and local resources.

We suggest coordinating specialized endocrine care with primary care, ensuring the patient receives preventative care, (ideally) mental health support, and guidance in navigating adult healthcare services.

Management of non-attendance

Transition is a high-risk period for non-attendance in care. To prevent patients dropping out, we recommend educating both patients and their parents within paediatric care, on the significance of ongoing care and the risks of care discontinuation.

We suggest that paediatric professionals and/or the transition coordinator should facilitate this continuity by scheduling and confirming attendance at the first appointment in adult care. Subsequently, adult care providers and/or the transition coordinator should monitor attendance at the following appointments until the transition process is fully completed.

We suggest that paediatric and adult health care providers include in their transition programme methods to secure information on follow-up in adult care, such as interviews, questionnaires, and automated appointment reminders to enhance attendance and to identify any barrier.

While we recommend these core tracking methods, the specific tools and protocols may be adapted locally based on available resources and healthcare system infrastructure.

Psychological support

We recommend the inclusion of psychosocial support and the proactive management of mental health issues in adolescents and young adults during patient consultations. When available and appropriate, we suggest involving mental health professionals in the transition process to provide information and support patients and/or their parents in the transition process if needed. Healthcare professionals should be aware of this option and able to recognize when such involvement is necessary.

We suggest using screening tools to evaluate patients' psychosocial support needs, with tool selection based on the specific risks associated with each condition, such as eating or affective disorders.

For systematic psychological screening, validated tools are well established for adolescents with type 1 diabetes such as PHQ-9 (depression),[43] GAD-7 (anxiety),[44] PAID (diabetes-specific distress),[26] and the DEPS-R (eating disorders).[45]

For other endocrine conditions, evidence for condition-specific screening tools is limited. Generic adolescent mental health screeners (PHQ-9, GAD-7) for depression/anxiety, the Strengths and Difficulties Questionnaire (SDQ)[46] for behavioural/emotional problems, and generic eating disorder screeners such as SCOFF[47] may be used, combined with clinical judgment.

On an individual basis, we recommend psychoeducation for patients.

Parents/caregivers preparation and involvement

We suggest educating and empowering parents/caregivers to support the patient's transition while promoting independence and understanding of their role in the transition process. We suggest asking parents and patients separately to evaluate the appropriateness of their level of involvement and readiness during transition.

We suggest encouraging parental presence at the first appointment with the adult health care team, with the patient's agreement, to foster alliance, trust, and a smooth evaluation of everyone's roles.

Readiness assessment

We recommend the evaluation of transition readiness to allow identification of gaps in knowledge and to provide tailored training before transfer. This evaluation should begin well in advance, with a suggested timeline of at least 2 years before the transfer, and should be repeated periodically.

We suggest that these evaluations be based on validated transition readiness assessment tools, generic or disease-specific. We suggest using language-specific and validated tools to ensure their relevance and reliability across various patient populations.

There are numerous measures of readiness to transition. For instance, the Endocrine Society has developed a disease specific Transition Readiness Assessment tool for patients with diabetes and Turner syndrome, available at https://support.endocrine.org/improving-practice/transitions. A table is provided with the main generic measurement tools (Table 1).

Conclusion

This joint ESE-ESPE guidance provides a comprehensive framework for endocrine healthcare transition, developed through a rigorous process combining systematic literature review and expert consensus. The guidance aims to provide a clear roadmap for achieving an effective and well-structured transition from paediatric to adult healthcare across Europe. We recognize that in many clinical settings, the proposed comprehensive approach—and the availability of key roles such as a care coordinator/navigator, or dedicated psychologist—may be limited. Nevertheless, we are confident that by applying this guidance, the transition of the majority of patients with childhood-onset chronic endocrine disorders will become easier and more successful. Future efforts should focus on monitoring the integration of this guidance into routine practice, while exploring implementation patterns, barriers, and outcomes across different European healthcare systems.

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Authors' contributions

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Supplementary material

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