

Enhancing Transitional Care in Digestive Health

Addressing Challenges and
Implementing Strategies
Across Europe



Contents

About UEG	2
Foreword	3
Introduction	4
Digestive Diseases and Transitional Care	6
Key Challenges	9
Late Initiation of the Transitional Care Process	10
Care Coordination Gaps	13
Recognising Life Stage Impact	16
Managing Disease Characteristics	19
Recommendations for Future Action	23
Contributors	26
References	27

About UEG

Founded in 1992, United European Gastroenterology (UEG) is the leading non-profit organisation for excellence in digestive health in Europe and beyond, with its headquarters in Vienna.

UEG's mission is to serve as the united and trusted voice of European gastroenterology and to be recognised as the leading authority for digestive health. The organisation's efforts are dedicated to improving the prevention and care of digestive diseases in Europe through the provision of top-tier education, research support and advancement of clinical standards.

As Europe's home and umbrella for multidisciplinary gastroenterology, UEG unites over 50,000 engaged professionals from national and specialist societies, individual digestive health experts and related scientists from all fields and career stages.

In alignment with UEG's commitment to fostering collaboration to enhance digestive health on a pan-European scale and to advocate for its prioritisation on both national and European political agendas, the following report reflects the diverse perspectives and invaluable contributions of a dedicated working group comprising leading experts throughout Europe, alongside UEG's specialist societies and endorsing patient organisations.

Foreword

Over 332 million people in the European region are living with digestive disorders, which often begin early in life and require lifelong management.

Transitional care is critical in the person-centred, life-course approach, ensuring continuity of care and alignment with patient preferences and needs as they shift from child-centred to adult-centred healthcare. Early and structured transition simplifies patients' adaptation and empowers them to make informed health decisions, enhancing their quality of life and improving long-term outcomes. However, the transition process presents numerous challenges for everyone involved, requiring coordinated efforts to overcome them.

This publication highlights the crucial role of prevention and clinical management in gastrointestinal healthcare. It advocates for a steadfast commitment to integrated care pathways that bridge paediatric and adult services, emphasising the importance of effective communication and collaboration among healthcare teams, patients, and families. Adequate training for healthcare providers ensures they are well-equipped to manage evolving diseases and treatments, delivering comprehensive and cohesive care. Incorporating insights from people with lived experiences enriches our understanding and enhances care practices, making healthcare systems responsive and truly aligned with patient needs.

This publication champions transitional care principles, prioritises continuity of care, and fosters a culture of collaboration within healthcare systems. By advancing these initiatives, we can transform gastrointestinal healthcare and improve the lives of countless patients. Let us move forward with determination and commitment to ensure the optimal health and well-being of all people throughout their lives.

Dr Gauden Galea

Strategic Adviser to the Regional Director
Special Initiative on NCDs and Innovation
WHO Regional Office for Europe

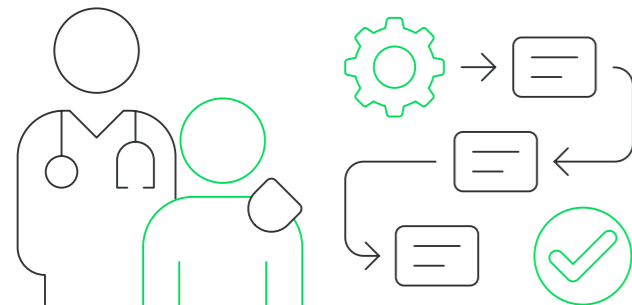
Introduction

As adolescents with digestive diseases transition into adulthood, they are faced with another significant transition – moving from paediatric to adult care.

In this context, transitional care can be defined as a:

“purposeful, planned movement of adolescents with chronic medical conditions from child-centred to adult-centred healthcare.”¹

This can be a challenging time for adolescents, parents and care providers. If these challenges are missed or not addressed, patient outcomes can be significantly impacted:^{1,2}



This report has been developed following the UEG Digestive Health Roundtable, where leading experts and patient advocates identified transitional care as a key priority. Of particular concern was the lack of transition regulations in an area where disease monitoring and management are critical to preventing complications.³

Within this report, four key transitional care challenges are presented, including late initiation, care coordination gaps, recognising life stage impact and managing disease characteristics. Importantly, recommendations are made for overcoming these challenges.

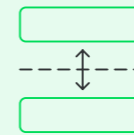
To ensure all patients benefit from improved care, regardless of their location or treatment institution, UEG appeals for the global adoption of these recommendations.

Together, we can pave the way for better transitional care and outcomes for everyone living with a digestive disease.

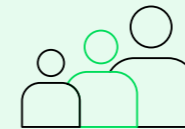
Key transitional care challenges:



Late initiation



Care coordination gaps



Life stage impact



Managing disease characteristics

Example transition challenges

Adolescents and parents might not always be prepared for the cultural shift between paediatric and adult care

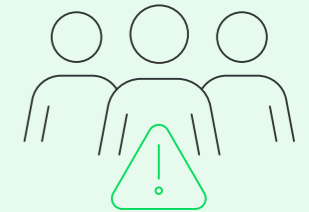
Variations in disease presentation and treatment protocols between paediatric and adult digestive disease

Determining the best time to start the transition process based on age, readiness and disease stability

Age-related adherence barriers

Coordinating transition to minimise disruption

Adult care providers might not understand the nuances of childhood digestive diseases and the needs of this population



Potential outcomes of an inefficient transition

Non-adherence to monitoring and treatment

Workflow difficulties for healthcare professionals

Loss of care continuity

Individual and parent dissatisfaction

Negative feelings and attitudes about the transition

Strained relationships between patients, parents and new care providers

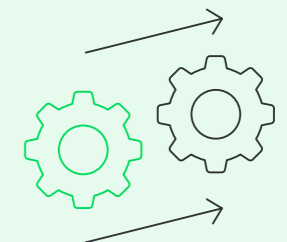
Hospitalisations

Reduced quality of life

Poor self-management

Decreased trust in healthcare systems

Financial strain on families



Digestive Diseases and Transitional Care

Patients with certain digestive diseases are more in need of transitional care due to their chronic nature and potential long-term effects.

These conditions present unique challenges during the transition process. An overview of these challenges is outlined below, some of which are not exclusive to one condition.

Coeliac Disease

A chronic, multi-organ, autoimmune disease that affects genetically-predisposed individuals.⁴



Incidence in Europe (≤19 years old)

Highest in parts of Scandinavia, Finland and Spain at >50 per 100,000 person-years.⁵

Transition challenges:^{6,7}

Pubertal development: Growth, puberty delays and emotional maturity affect readiness for adult care.

Cultural shift: Moving from family-centred to autonomous care.

Disengagement: Coeliac disease patients are not obligated to see their doctors; they are not dependent on medication and instead self-manage with diet.

Non-adherence: Dietary adherence rates vary widely, impacting health outcomes.

Transition support deficiencies: In one study, 27% of physicians reported no formal transition process, leading to gaps in ongoing support.

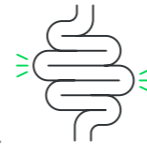
Gastrointestinal healthcare professional awareness:

Not all gastrointestinal healthcare professionals are aware of the autoimmune, multi-organic nature of coeliac disease.

Inflammatory Bowel Disease

A chronic, life-long disease that evolves in a relapsing and remitting mode and can result in progressive bowel damage and disability.

There are two types of Inflammatory Bowel Disease: Crohn's disease and ulcerative colitis.⁸



Incidence in Europe (<20 years old)

Highest in Western Europe and Northern Europe. (Scandinavia: 17.4 per 100,000 person-years) (Scotland: 23.1 per 100,000 person-years).⁹

Transition challenges:^{1,10-12}

Complexity: Complex management challenges and varying severity levels, often markedly worse than in adult Inflammatory Bowel Disease.

Patient knowledge: Adolescents may lack an understanding of their medical history, medication and how the adult healthcare system operates.

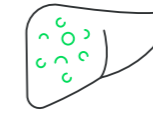
Psychological morbidity: Symptoms, treatment side-effects, body image and surgery concerns contribute to psychological distress.

Parental anxiety: Parents can become anxious about a new healthcare team.

Practical factors: Loss of insurance coverage and limited treatment options.

Chronic Liver Disease (CLD)

A chronic, life-long disease that in some cases can progress to deterioration of liver function, which includes synthesis of clotting factors, other proteins, detoxification of harmful products of metabolism and excretion of bile.¹³

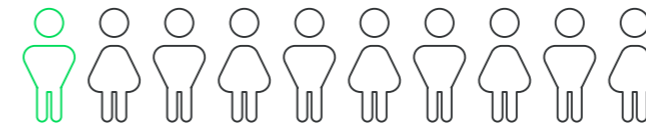


Global incidence for cirrhosis (≤19 years old):

There were 241,364 cases in 2019, an increase of 18% from 1990.¹⁴

18% increase in incidence from 1990

Incidence in Europe for metabolic dysfunction-associated steatotic liver disease (MASLD): 1 in 10 children.¹⁵



Transition challenges:^{16,17}

Complex management: CLD and cirrhosis require multifaceted management.

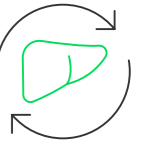
Care needs: Needs vary across the treatment journey, particularly around prompt referral, nutritional support and medication regimes.

Emotional health: Patients may require psychosocial support and management of psychiatric illnesses or substance-use disorders.

Mortality risks: Risks persist after transitioning to adult care.

Liver Transplantation (LT) at Paediatric Age

LT is an effective therapeutic option for many acute and chronic liver diseases occurring in paediatric patients, such as biliary atresia, Alagille syndrome and Wilson's disease.



Data on paediatric liver transplants

From June 1968 to December 2017, 16,641 paediatric LTs were performed on 14,515 children by 133 centres in Europe. Patient survival at five years is currently 86% overall and 97% in children who survive the first year after LT.¹⁸

16,641 paediatric LTs from 1968 to 2017

Transition challenges:^{2,19}

Nutrition: Patients awaiting LT require a customised nutritional care pathway and, ideally, regular counselling to ensure nutritional adherence.

Complex management: The risk of graft rejection (both acute and chronic) must be balanced against the side-effects of immunosuppressants. There is also a risk of post-transplant disease recurrence for certain conditions. Proper management of extrahepatic conditions is essential.

Readiness to transition: A patient-centred approach should be planned through a multidisciplinary team.

Global health and quality of life: Needs vary throughout the treatment journey and depend on age. For example, issues such as schooling, employment and pregnancy should be addressed. Quality of life warrants thorough investigation.

Emotional health: Patients may require psychosocial support during and after transition.

Other digestive diseases face similar transitional challenges, but with additional obstacles related to their rarity and limited disease expertise within the healthcare setting:

Digestive cancers

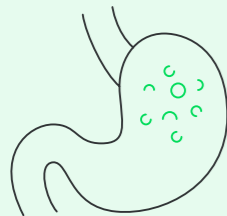
Cancer that develops along the digestive tract, e.g.:

Stomach cancer

Incidence per 100,000 (15–19 years old): 0.06 (Western Europe); 0.09 (Central Europe); 0.26 (Eastern Europe)²⁰

Pancreatic cancer

Incidence in Europe (≤19 years old): 0.2 per 100,000²¹



Rare digestive diseases

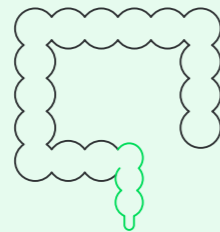
Inherited and congenital digestive and gastrointestinal anomalies, e.g.:

Hirschsprung's disease

Incidence in Europe: 1 in 10,000 births²²

Biliary atresia

Incidence in Europe: 1 in 20,000²³

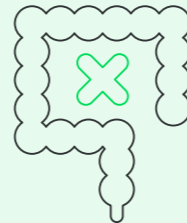


Intestinal failure and other nutritional-related conditions

The inability of the gut to absorb sufficient macronutrients, micronutrients or water, resulting in the need for intravenous supplementation

Intestinal failure

Prevalence rates range from 3.2 to 66 individuals on home parenteral nutrition per million population (children and adults)²⁴



Childhood obesity and gastrointestinal diseases

An added complication across all of these diseases is surging rates of obesity in Europe. The World Health Organization (WHO) European Regional Obesity Report 2022 revealed that approximately one in three children are overweight or obese – a figure that is set to rise further.²⁵ Childhood obesity is associated with gastrointestinal diseases such as irritable bowel syndrome, functional constipation, Inflammatory Bowel Disease, coeliac disease and liver diseases.²⁶

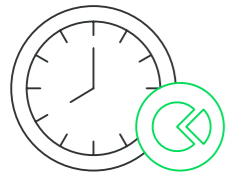
Given the rising incidence of many paediatric digestive diseases^{5,9,27} and obesity,²⁵ there has never been a more critical time to build structured transitional care programmes that help streamline the process for patients, parents and healthcare professionals.

Key Challenges

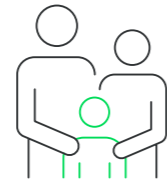
Late Initiation of the Transitional Care Process

Late initiation of the transitional care process can have numerous negative consequences for patients, parents and healthcare professionals.

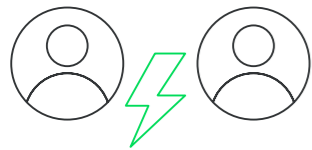
Key Challenges¹



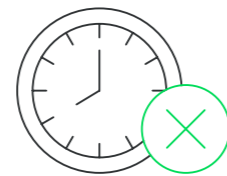
Delays in transition can contribute to fragmented care delivery



Responsibilities may have largely been with parents up to this point, and healthcare professionals who don't address this during the transition process reinforce a passive patient attitude



Abrupt transitions at 18 years old can lead to dissatisfaction and frustration for patients, parents and healthcare professionals



Delays in transition can compromise patient outcomes

Time for Action!^{1,2,6,11}

Early and structured transition processes are critical to mitigating potential challenges and ensuring seamless continuity of care.

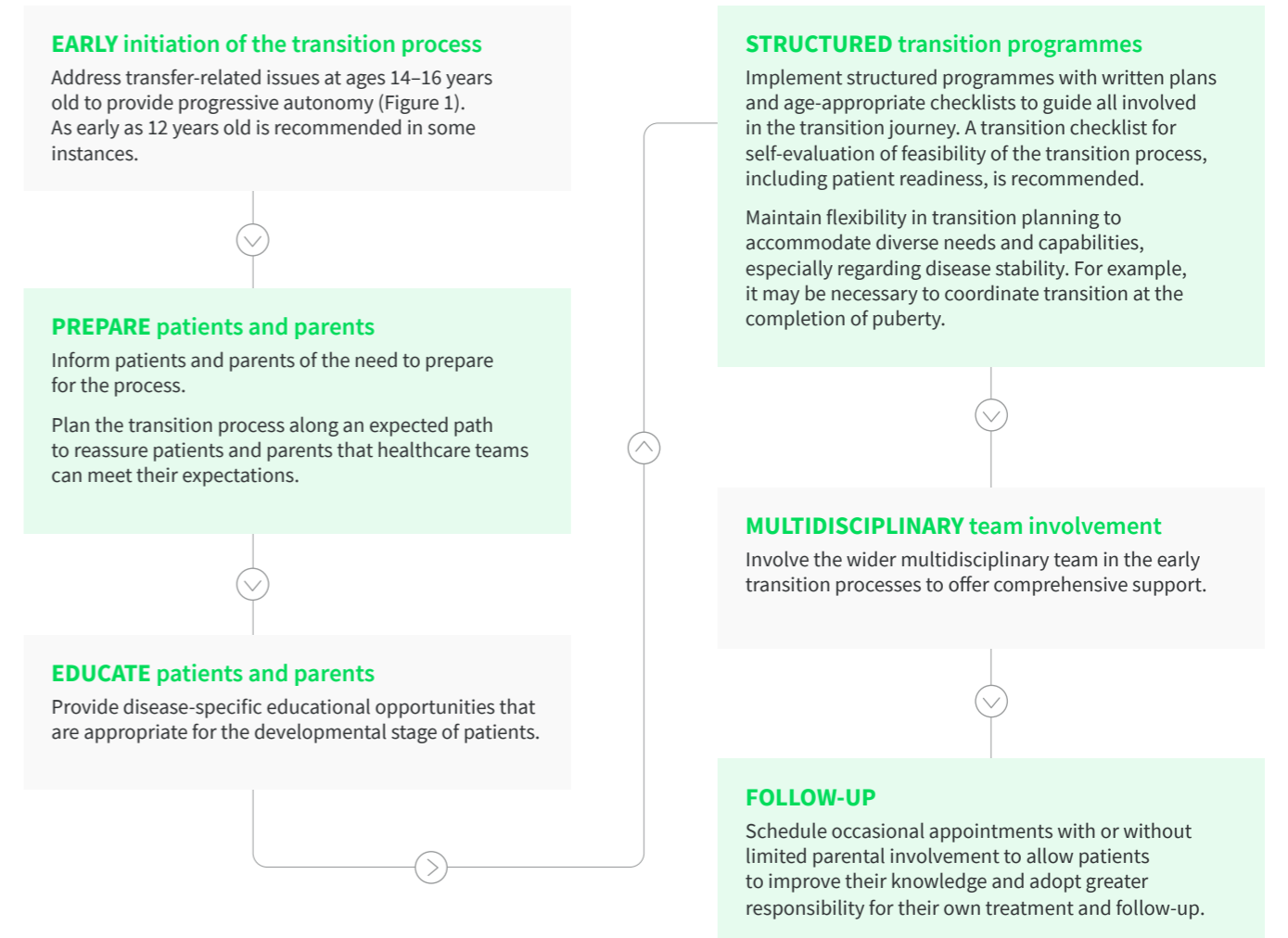
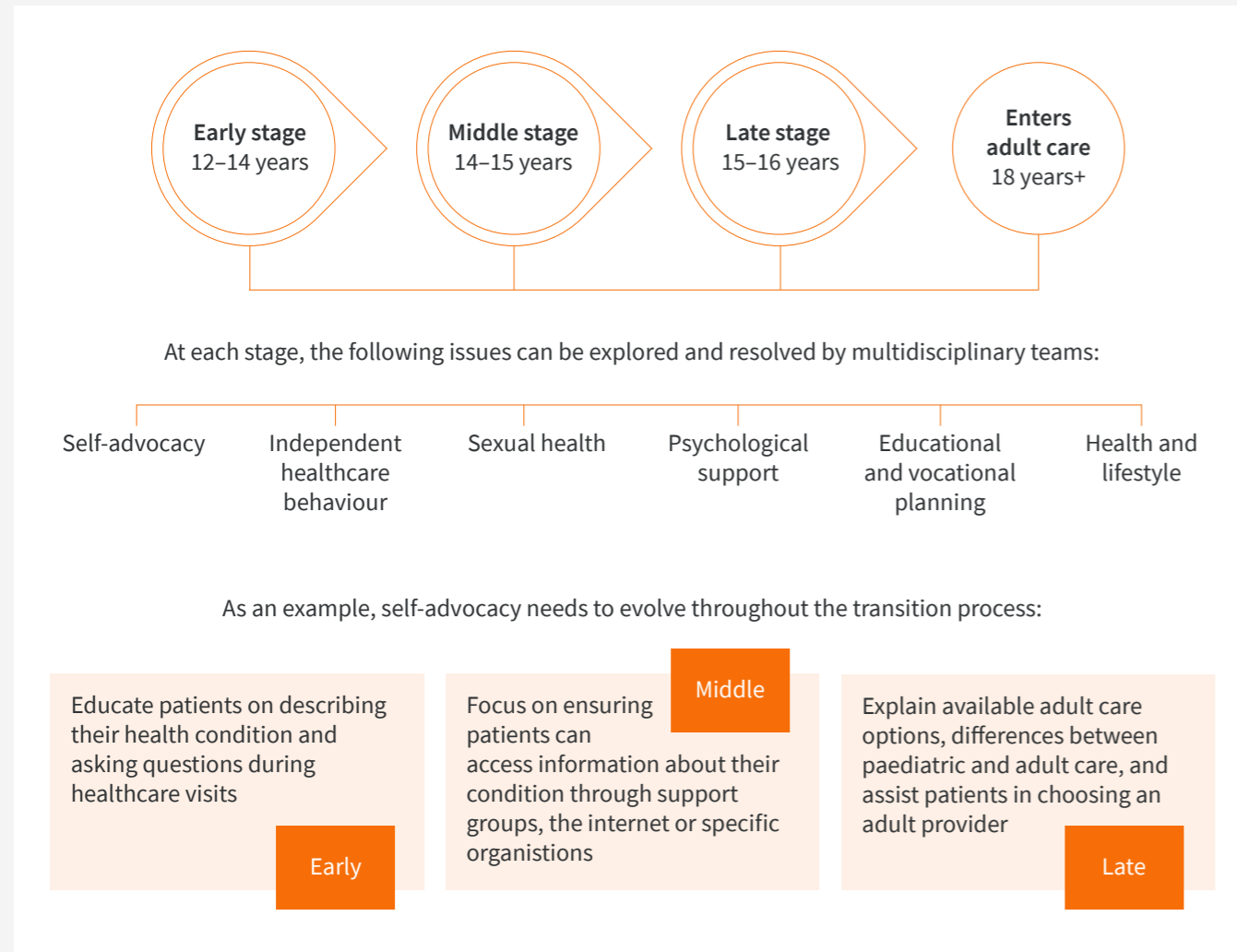


Figure 1.
Spotlight on Best Practice in Liver Disease

Multidisciplinary teams can facilitate the transition from paediatric to adult care via a three-stage process that personalises support along the journey to adulthood:²



Care Coordination Gaps

The transition phase from paediatric to adult care can be associated with loss of follow-up, interrupted treatment and monitoring, and increased risk of unnecessary complications or relapse.¹ A significant proportion of this could be prevented with enhanced care coordination.

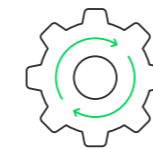
Key Challenges^{1,8}



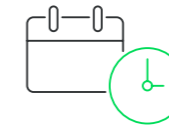
Gaps in communication and information transfer between paediatric and adult services



Discrepancies between paediatric and adult healthcare professionals



Lack of continuity of treatment plans and care, resulting in disjointed management



Paediatric settings are often more tolerant of unplanned contacts



Physicians may primarily focus on clinical aspects of disease management, overlooking other important aspects of the process



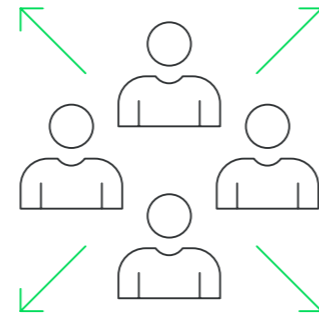
Paediatricians discussing disease evolution and treatment plans with parents and failing to involve patients can hinder patient understanding of their own condition and its management

In an Inflammatory Bowel Disease study, more paediatric gastroenterologists viewed a structured transition service as very important (80%) than adult gastroenterologists (47%), while more adult gastroenterologists (79%) identified inadequacies in preparing adolescents for transfer than paediatric gastroenterologists (42%).²⁸ This demonstrates the distinct approaches, experiences and priorities of those providers the patient is moving between, and the potential implications of this for coordinated care.

80%
of paediatric gastroenterologists viewed a structured transition process as very important

Time for Action!

Effective communication and collaboration with Transitional Care Coordinators at the centre can facilitate a seamless transition process (Figure 2). Transitional Care Coordinators, often nurses or allied professionals, play a crucial role in building confidence among patients, families and healthcare professionals as they prepare for the shift from paediatric to adult care. They manage advanced knowledge transfer and bonding with the new healthcare team, while gently and progressively shifting the dialogue to the patient during joint appointments with the multidisciplinary team.^{1,11,29}



Transitional Care Coordinators are vital in addressing the evolving needs of patients and parents throughout the transition, helping them navigate the challenges and organisational differences between paediatric and adult care.

One of their key responsibilities is to conduct individual assessments to evaluate transition readiness and maturity for the final handover to adult services, thereby enhancing treatment adherence. In one study, a transition coordinator-led intervention improved transition readiness and the development of self-management skills in adolescents with Inflammatory Bowel Disease. Additionally, rates of remission significantly increased from pre- to post-intervention, demonstrating the effectiveness of having a dedicated coordinator to guide the transition process.³⁰

Critically, the first meeting with the new adult healthcare professional should not be seen as the end of paediatric care. Continuity of care with the same healthcare professional before and after transitioning to adult care is crucial for a successful transition process.²⁹

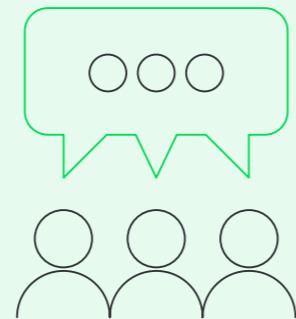
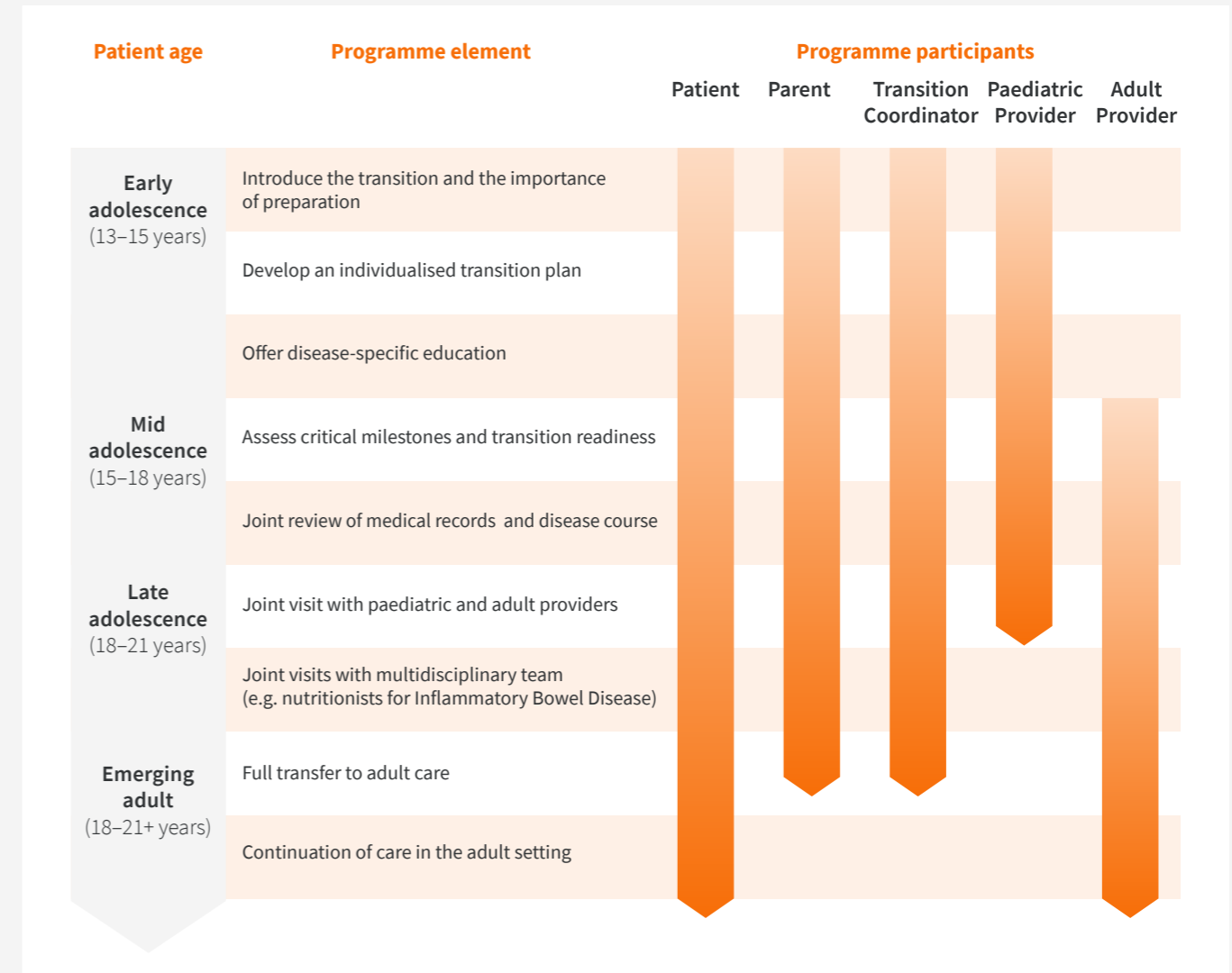


Figure 2.

Spotlight on Best Practice in Inflammatory Bowel Disease



A collaborative approach to ensuring the success of the Inflammatory Bowel Disease transition process (Adapted from Amil-Dias, et al. 2023)¹

Recognising Life Stage Impact

Adolescence is a time of physical, mental and psychosocial development, which will impact the transition from paediatric to adult care. In particular, both medical and non-medical age-related factors introduce a host of barriers to adherence if missed by healthcare professionals, which can also dramatically impact the health and quality of life of the young person.¹

Key Challenges^{1,10,11,29-33}

Medical challenges

Delayed puberty in certain conditions

Crohn's disease can affect pubertal development, emotional maturity, sexual health and menstrual regularity.

Disease management

Adolescents may lack knowledge of their condition and experience with self-management. For example, patients with Eosinophilic Esophagitis (EoE) transitioning to adult care struggle with meal planning, food shopping, cooking, finding foods that don't exacerbate their condition and understanding insurance coverage.

Psychological morbidity

Depression and anxiety can result from illness and treatment beliefs, body image difficulties and disease uncertainty.

Gut-brain confusion

Difficulties differentiating physiological symptoms from those related to stress can be emotionally challenging.

Healthcare professional training

Adult care providers can have suboptimal training in adolescent medicine. In one study, 73% of gastroenterologists felt competent regarding medical aspects of adolescent care, while only 46% felt competent with adolescent developmental and mental health.

Non-medical challenges

Developmental differences

Adolescents have varying levels of autonomy and self-esteem, both of which can impact transition readiness.

Transition to adulthood

Many adolescents haven't completed their psychological transition to adulthood by the time they transfer to adult services. Some may feel a sense of abandonment.

Multiple transitions

Adolescents are juggling multiple transitions that may overshadow their healthcare transition, including study, work, travel, moving away, and encounters with drugs and alcohol.

Non-adherence risk factors

Poor adherence due to education failure, substance abuse or other factors can lead to complications. For example, in liver disease, non-adherence related to alcohol consumption was reported in 25% of cases of transplant recipients who had transitioned from paediatric to adult healthcare.

Outdated communication methods

Old ways of communicating, such as letters and telephone calls, are not fit for adolescents and may lead to loss of follow-up.

Time for Action!^{1,2,11,29,34}

Medical and non-medical age-related barriers to a smooth transition process require a concerted effort to ensure individual needs are incorporated into the transition journey. This means adopting a skills-based approach that ensures patients are empowered to enter both adulthood and the adult healthcare system. This also requires consideration of growth-related patient needs, not just age: chronological age doesn't encapsulate the diverse and complex needs of a young person with a digestive disease.

SKILLS-BASED transition

- Implement a stepwise training programme to equip patients with essential skills, including self-efficacy, medication management, independent decision-making and healthcare navigation.
- Provide comprehensive patient education to ensure patients have an understanding of their medical history.



Provide GROWTH-APPROPRIATE support

- The transition should occur after evaluating mental health stability and when the individual has stable emotional and physical functioning.
- Paediatric healthcare professionals should share developmental and puberty-related information with adult providers.
- Tailor education to emotional and cognitive maturity, considering factors like delayed sexual development.
- Ensure the multidisciplinary team is aware of individual patient issues affecting autonomy and disease control.



Leverage MODERN COMMUNICATION tools

- Harness technology-based communication, like smartphone apps, web-based solutions and telehealth, for quick contact with healthcare professionals and to enhance adherence.
- Utilise tools like MyHealth Passport to build independence and facilitate communication between past and future healthcare professionals (Figure 3).

MONITOR closely

- To identify and address factors impacting treatment adherence and successful transition, including psychosocial challenges that may necessitate relevant support groups and the inclusion of psychological professionals in the multidisciplinary team.



Build SUPPORT NETWORKS

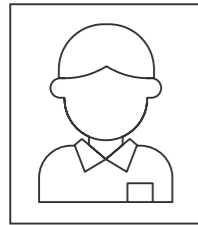
- Integrate patients into networking groups with similar conditions to help them develop an optimistic view of life with their condition.
- Utilise patient organisations and social media for social integration and community support.



TRAIN healthcare professionals

- Train adult and paediatric healthcare professionals on issues specific to adolescents and how to effectively support them during the transition.
- Train adult healthcare professionals on how to foster a comfortable environment that encourages open discussions on future plans and sensitive topics such as substance abuse and unplanned pregnancies.
- Include psychosocial and psychological professionals in multidisciplinary teams to provide tailored support. Improvement in psychological well-being in Inflammatory Bowel Disease patients has been reported with the involvement of psychological professionals.

Lucas' Health Passport



Name Lucas Andersson

Date of Birth 24th April, 2006

Diagnosis Crohn's disease

Location	Small intestine (the terminal ileum)	Chickenpox	Chickenpox in 2011
Perianal (around the anus) Issues	Fistulae (tunnel near the anus, creating connection between the inside of the anus and the skin around the anus)	Tuberculosis	Negative, 2014
Complications	Arthritis	Height	152.4cm (5ft) - linear height delay
Family History	No family history of Inflammatory Bowel Disease or arthritis	Weight	60kg
Admission Date	3rd January, 2016	Scopes	Upper endoscopy, January 2016
Medication	Methotrexate	Imaging	Small bowel follow-through, January 2016
Vitamins	Multivitamins, Calcium, Vitamin D	Bloodwork	Once every two months
Warning	Lucas is on immunosuppressant medication. If he presents with fever, please call his doctor (details below)	Coverage	None
Special Requirements	I sometimes struggle to understand doctors' instructions and may need it written down so I can remember and discuss with my support network	Paediatrician	Dr Lindström +46 766 111
Drug Allergies	Penicillin	Family Doctor	Dr Pettersson +46 766 112
Immunisations	Routine immunisations up to date	Paediatric Gastroenterologist	Dr Eklund +46 766 113
		Pharmacy	Apotek Care +46 766 114
		Emergency Contact	Mrs Andersson (Mother) +46 766 256
		Date Created	3rd February, 2016

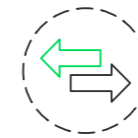
Figure 3. Example of a MyHealth passport, which can be used to communicate relevant patient data with the adult healthcare team (Adapted from Amil-Dias, et al. 2023)¹

Managing Disease Characteristics

Advancements in medical treatments have increased the life expectancy of patients with certain diseases that traditionally did not reach adulthood.^{1,35}

Therefore, healthcare professionals are faced with diseases they are unfamiliar with, many of which have multiple complexities and variations in disease characteristics between adolescence and adulthood. Such factors need careful consideration when making treatment decisions.

Key Challenges^{1,35}



Some diseases are more frequent or behave differently in adolescents vs adults, with differing demands on multidisciplinary teams



In some diseases, like Inflammatory Bowel Disease, patients might reach adult life after several treatment adaptations or surgery, limiting future treatment options



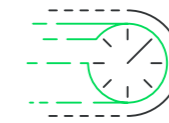
Treatment guidelines can differ in paediatric and adult healthcare due to different disease severity and different pharmacodynamics of recommended treatments



With more paediatric diseases reaching adulthood, such as liver and metabolic diseases, many physicians have not been exposed to these 'new diseases'



Sudden changes in treatment by adult healthcare professionals with different approaches to paediatric providers may raise concerns in patients and parents



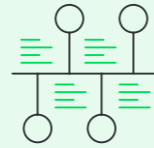
Optimal transition timing. For example, if the patient is experiencing a flare and requires an immediate treatment change, this is not the ideal time to change doctors

Time for Action!¹

Managing a diverse range of disease characteristics requires a personalised, collaborative approach where paediatric and adult care teams effectively negotiate around the evolving needs of patients.

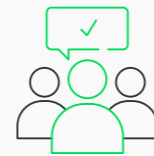
ORCHESTRATE transition timing

It is crucial to carefully orchestrate the timing of transitioning between healthcare professionals, ensuring it aligns with the patient's disease stability and best interests. The ideal scenario is to achieve remission before the final transition.



Treatment REGIMEN COLLABORATION

- Paediatric and adult healthcare professionals should strive for consensus on treatment regimens before initiating new protocols.
- In instances where differences in approach arise, changes should be approached thoughtfully, with clear explanations provided to mitigate any mistrust that may emerge due to shifts in care guidelines after years of adherence to previous protocols.



Ongoing HEALTHCARE PROFESSIONAL TRAINING

- Continuous education and training initiatives are essential to ensure healthcare professionals remain adept in managing evolving diseases and treatment modalities.
- Facilitating knowledge transfer between paediatric and adult healthcare professionals can be achieved by involving adult practitioners in paediatric outpatient clinics to help preserve continuity of care.
- Adult healthcare professionals assuming responsibility for patients with paediatric-onset conditions must be well-versed in the specific nuances of these diseases and equipped with knowledge of available options as patients transition into young adulthood.

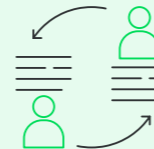
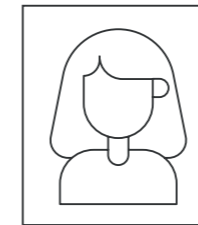


Figure 4.

Spotlight on Intestinal Failure

Case Study: Transitioning Paediatric Patients with Intestinal Failure to Adult Care

Meet Maria, a 17-year-old who has been living with intestinal failure since early childhood, a condition stemming from extensive gut surgery during her formative years.

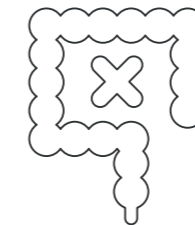


Name Maria Rodriguez

Date of Birth 2 October, 2007

Diagnosis Intestinal failure

Maria faces a unique set of challenges as she prepares to transition from paediatric to adult care. Unlike adult-onset intestinal failure, which often arises from acute events like trauma or disease, Maria's condition is rooted in congenital issues and prolonged reliance on parenteral nutrition. This reliance presents impending hurdles as she navigates the complexities of transitioning to adult care, balancing her medical needs with her educational and personal growth.



For Maria's transition to be successful, several key components are essential:

A specialised multidisciplinary team comprising both paediatric and adult specialists, including gastroenterologists, dietitians, nurses, radiologists, surgeons, stomal therapists and pharmacists.

Comprehensive familiarisation of all multidisciplinary team members with Maria's unique medical history and needs.

Education for all multidisciplinary team members on the nuanced differences between adolescent and adult care for intestinal failure.

Careful planning and seamless coordination among the multidisciplinary team, Maria and her parents, ensuring a smooth transition.

Provision of ongoing support and education for Maria, empowering her to navigate the complexities of her condition as she steps into adulthood.

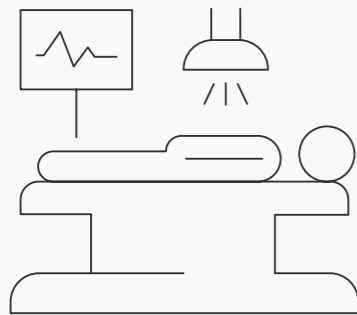
By implementing these strategies and fostering a supportive environment, Maria can confidently transition to adult care, equipped with the resources and knowledge necessary to thrive despite the challenges posed by her condition.

Figure 5.

Spotlight on Surgical Interventions¹¹

There are distinct groups of patients who may benefit from transitioning from paediatric to adult surgical care, including those who have undergone surgery in a paediatric unit and require long-term follow-up, those receiving ongoing paediatric medical treatment necessitating surgical intervention, and those newly diagnosed with conditions requiring surgery at an age where transition is indicated.

While adolescents and young people in these surgical groups could potentially be seen in regular adult surgical outpatient settings, unfamiliarity of the adult clinic environment may be daunting for both patients and parents. A transitional clinic, where paediatric surgeons can hand over cases to adult surgeons, offers a more seamless and reassuring transition process.



Key components of an effective surgical transition clinic include:

Appointing a dedicated Transitional Care Coordinator to oversee the transition process, coordinate appointments and provide ongoing support.

Involving a multidisciplinary team of surgeons, nurses and other healthcare professionals to support transitioning patients.

Detailed communication between paediatric and adult surgeons regarding past procedures, family dynamics and the psychological needs of patients.

Consideration of joint operations between paediatric and adult surgeons in cases where patients are not yet ready for full transition.

Assignment of a named adult surgeon to patients requiring surgical intervention during transition. This surgeon is involved in the patient's care preoperatively, perioperatively and postoperatively as part of the multidisciplinary team.

Implementing processes for ongoing evaluation and quality improvement to monitor the effectiveness of treatment.

Recommendations for Future Action

This report contains actionable recommendations to facilitate the transition from paediatric to adult care for people with digestive diseases, with the aim of benefitting everyone involved in this process.

Below is a summary of these recommendations, which should be considered under the overarching recommendation for their global implementation. Through global structured transitional programmes, we can ensure seamless care for patients regardless of their decisions to relocate for academic and occupational pursuits, or other life events.

Challenge

Late initiation of the transitional care process

Recommendation

Initiate the transition process early, ideally by age 12 and no later than 14 years.

Prepare patients and parents, ensuring they know what to expect.

Provide disease-specific education to patients and parents.

— Implement structured transition programmes with written plans and age-appropriate checklists, allowing flexibility for diverse needs.

Engage the multidisciplinary team throughout the process to offer comprehensive support.

Schedule follow-up appointments that encourage patients to progressively take responsibility.

Challenge

Care coordination gaps

Recommendation

Appoint a Transitional Care Coordinator early in the process, preferably a nurse or allied health professional.

Foster collaborative care between paediatric and adult teams, including joint appointments.

Address evolving needs of patients and parents encountering transition challenges.

Assess patient readiness.

Engage patients in discussions about their disease.

→
 →
 → Guide patients and parents to adult healthcare services.

Challenge

Recognising life stage impact

Recommendation



Implement a stepwise, skills-based training programme for patients.



Provide growth-appropriate emotional and cognitive support.



Utilise modern communication tools (e.g. telehealth, web-based solutions, MyHealth Passport).



Monitor closely for factors affecting treatment adherence.



Establish support networks for patients.



Train both adult and paediatric healthcare professionals on issues specific to young adults and effective transition support.

Challenge

Managing disease characteristics

Recommendation



Coordinate transition timing based on disease stability and the patient's best interests.



Aim for treatment regimen consensus among paediatric and adult healthcare professionals.



Create education and training initiatives to keep healthcare professionals adept in managing evolving diseases and treatments.

“

Despite a growing body of evidence and consensus on its critical role in supporting continuity of care and treatment adherence for patients affected by digestive diseases, transitional care has often been overlooked by both the medical community and broader society.

In light of the challenges and recommendations outlined in this report, we are calling for a united effort among policy makers and healthcare professionals to prioritise transitional care and advocate for measures that support the inclusion of best practice protocols and principles within healthcare systems. By doing so, we can empower patients to confidently navigate their healthcare journey, ensuring they receive the best possible care at every stage.

”

Patrizia Burra
UEG Public Affairs Group Chair

Working group within the UEG Public Affairs Group
Maria Buti, Jorge Amil Dias, Pierluigi Fracasso, Daniel Hartmann,
Joana Torres, Hans Törnblom

UEG Specialist (Ordinary) Member Societies

European Association for Endoscopic Surgery and other interventional techniques (EAES) – member of European Society for Surgery of the Alimentary Tract (ESSAT)

European Association for Gastroenterology, Endoscopy and Nutrition (EAGEN)

European Association for the Study of the Liver (EASL)

European Crohn's and Colitis Organisation (ECCO)

European Digestive Surgery (EDS) – member of ESSAT

International Society of Digestive Surgery (European Federation) (EFISDS) – member of ESSAT

European Helicobacter and Microbiota Study Group (EHMSG)

European Pancreatic Club (EPC)

European Society of Coloproctology (ESCP) – member of ESSAT

European Society of Digestive Oncology (ESDO)

European Society of Gastrointestinal and Abdominal Radiology (ESGAR)

European Society of Gastrointestinal Endoscopy (ESGE)

European Society of Neurogastroenterology and Motility (ESNM)

European Society of Pathology (ESP)

European Society for Primary Care Gastroenterology (ESPCG)

The European Society for Clinical Nutrition and Metabolism (ESPEN)

European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN)

European Societies and Patients' Associations

Association of European Coeliac Societies (AOECS)

Digestive Cancers Europe (DiCE)

European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)

European Liver Patients' Association (ELPA)

European Reference Network RARE LIVER (ERN RARE-LIVER)

European Reference Network Transplantation in Children (ERN Transplant - Child)

European Reference Network for rare Inherited and Congenital (digestive and gastrointestinal) Anomalies (ERN ERNICA)

UEG Public Affairs Team

Livia Alimena

Andreea Botos

Anna Carboni

References

- Amil-Dias, J., Törnblom, H., Mustapha, M., & Burra, P. (2023). Mistakes in transitional care for children and young adults and how to avoid them. *United European Gastroenterology*. <https://ueg.eu/a/334>
- Vajro, P., Fischler, B., Burra, P., Debray, D., Dezafofi, A., Guercio Nuzio, S., Hadzic, N., Hierro, L., Jahnel, J., Lamireau, T., McKiernan, P., McLin, V., Nobili, V., Socha, P., Smets, F., Baumann, U., & Verkade, H. J. (2018). The Health Care Transition of Youth with Liver Disease into the Adult Health System: Position Paper from ESPGHAN and EASL. *Journal of pediatric gastroenterology and nutrition*, 66(6), 976–990.
- Burra, P., Amil-Dias, J., Torres, J., Botos, A., Acedo, P., Bertelsen, B., Bretthauer, M., Carboni, A., Dugic, A., Fracasso, P., Koltai, T., Leone, S., Maravic, Z., Matysiak-Budnik, T., McColaugh, L., Mishkovic, M., Wickramasinghe, K., & van Leerdam, M. (2024). Advancing patient-centered care: Recent developments in UEG's patient relations. *UEG Journal*. <https://doi.org/10.1002/ueg2.12607>
- Association of European Coeliac Societies. (2023). *AOECS Scientific Book 2023* [Brioseur]. https://www.aoeecs.org/media/3gvlqm5p/aoecs_scientific_book_v3-2_2023_small2.pdf
- Roberts, S., Morrison-Rees, S., Thapar, N., Benninga, M. A., Borrelli, O., Broekaert, I., Dolinsek, J., Martín-De-Carpi, J., Mas, E., Miele, E., Pienar, C., Ribes-Koninckx, C., Thomassen, R. A., Thomson, M., Tzivnikos, C., Thorne, K., John, A., & Williams, J. (2021). Systematic review and meta-analysis: the incidence and prevalence of paediatric coeliac disease across Europe. *Alimentary Pharmacology & Therapeutics*, 54(2), 109–128.
- Ludvigsson, J. F., Agreus, L., Ciacci, C., Crowe, S. E., Geller, M. G., Green, P. H., Hill, I., Hungin, A. P., Koletzko, S., Koltai, T., Lundin, K. E., Mearin, M. L., Murray, J. A., Reilly, N., Walker, M. M., Sanders, D. S., Shamir, R., Troncone, R., & Husby, S. (2016). Transition from childhood to adulthood in coeliac disease: the Prague consensus report. *Gut*, 65(8), 1242–1251.
- Wessels, M., Dolinsek, J., Castillejo, G., Donat, E., Riznik, P., Roca, M., Valitutti, F., Veenliet, A., & Mearin, M. L. (2022). Follow-up practices for children and adolescents with celiac disease: Results of an international survey. *European Journal of Pediatrics*, 181(3), 1213–1220.
- Torres, J. (2023). Improve patients' lives with inflammatory bowel disease. *Open Access Government*. <https://www.openaccessgovernment.org/improve-patients-lives-inflammatory-bowel-disease/154188/>
- Ashton, J. J., & Beattie, R. M. (2024). Inflammatory bowel disease: recent developments. *Archives of Disease in Childhood*, 109(5), 370–376.
- Leung, Y., Heyman, M. B., & Mahadevan, U. (2011). Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist. *Inflammatory bowel diseases*, 17(10), 2169–2173.
- Brooks, A. J., Smith, P. J., Cohen, R., Collins, P., Douds, A., Forbes, V., Gaya, D. R., Johnston, B. T., McKiernan, P. J., Murray, C. D., Sebastian, S., Smith, M., Whitley, L., Williams, L., Russell, R. K., McCartney, S. A., & Lindsay, J. O. (2017). UK guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care. *Gut*, 66(6), 988–1000.
- Goodhand, J., Hedin, C. R., Croft, N. M., & Lindsay, J. O. (2011). Adolescents with IBD: the importance of structured transition care. *Journal of Crohn's & colitis*, 5(6), 509–519.
- Sharma, A., & Nagalli, S. (2023). *Chronic Liver Disease*. In StatPearls. StatPearls Publishing.
- Zhang, C., Liu, Y., Zhao, H., & Wang, G. (2023). Global, regional, and national burdens of cirrhosis in children and adolescents aged under 19 years from 1990 to 2019. *Hepatology International*, 18(1), 238–253.
- Hadzic, N. (2017). Paediatric and adolescent liver disease. *The Lancet Gastroenterology & Hepatology*. <https://www.thelancet.com/series/paediatric-liver-disease>.
- Burra, P., Giannini, E. G., Caraceni, P., Corradini, S. G., Rendina, M., Volpes, R., & Toniutto, P. (2018). Specific issues concerning the management of patients on the waiting list and after liver transplantation. *Liver International*, 38(8), 1338–1362.
- Stevens, J. P., Hall, L., & Gupta, N. (2021). TRANSITION of Pediatric Liver Transplant Patients to Adult Care: a Review. *Current Gastroenterology Reports*, 23(3).
- Baumann, U., Karam, V., Adam, R., Fondevila, C., Dhawan, A., Sokal, E., Jacquemin, E., Kelly, D. A., Grabhorn, E., Pawlowska, J., D'Antiga, L., Jara Vega, P., Debray, D., Polak, W. G., de Ville de Goyet, J., Verkade, H. J., & European Liver and Intestine Transplant Association (ELITA) and all ELTR contributing centers. (2022). Prognosis of children undergoing liver transplantation: A 30-year European study. *Pediatrics*, 150(4), e2022057424.
- Ferrarese, A., Germani, G., Lázaro, S., Cananzi, M., Russo, F. P., Senzolo, M., Gambato, M., Zanetto, A., Cillo, U., Gringeri, E., Perilongo, G., & Burra, P. (2018). Short-term outcomes of paediatric liver transplant recipients after transition to Adult Healthcare Service. *Liver International*, 38(7), 1316–1321.
- Zhang, Z., Wang, J., Song, N., Li-Ming, S., & Du, J. (2023). The global, regional, and national burden of stomach cancer among adolescents and young adults in 204 countries and territories, 1990–2019: A population-based study. *Frontiers in Public Health*, 11.
- European Cancer Information System. (2024). Incidence and mortality for pancreatic childhood cancer. <https://ecis.jrc.ec.europa.eu/explorer.php?S0-0>
- Trinidad, S., Kayima, P., Kotecha, V., Massenga, A., Rymeski, B., Frischer, J. S., Situma, M., & Kotagal, M. (2022). Hirschsprung's disease in low- and middle-income countries. *Seminars in Pediatric Surgery*, 31(2), 151163.
- Schreiber, R. A., Harpavat, S., Hulscher, J. B. F., & Wildhaber, B. E. (2022). Biliary Atresia in 2021: Epidemiology, screening and Public Policy. *Journal of Clinical Medicine*, 11(4) 999.
- Avitzur, Y., Pahl, E., & Venick, R. (2024). The Development of the International Intestinal Failure Registry and an Overview of its Results. *European Journal of Pediatric Surgery*, 34(2), 172–181.
- World Health Organization. (2022). WHO European Regional Obesity Report 2022. *Regional Office for Europe*. <https://iris.who.int/handle/10665/353747>
- Emerenziani, S., Guarino, M. P. L., Asensio, L., Altomare, A., Ribolsi, M., Balestrieri, P., & Cicala, M. (2019). Role of overweight and obesity in gastrointestinal disease. *Nutrients*, 12(1), 111.
- Green, Z., Ashton, J. J., Rodrigues, A., Spray, C., Howarth, L., Mallikarjuna, A., Chanchlani, N., Hart, J. W., Bakewell, C., Lee, K. Y., Wahid, A., & Beattie, R. M. (2024). Sustained increase in pediatric inflammatory bowel disease incidence across the South West United Kingdom over the last 10 years. *Inflammatory Bowel Diseases, Crohn's & Colitis*. <https://pubmed.ncbi.nlm.nih.gov/38372691/>
- Sebastian, S., Jenkins, H., McCartney, S., Ahmad, T., Arnott, I., Croft, N., Russell, R. K., & Lindsay, J. O. (2012). The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: Differing perceptions from a survey of adult and paediatric gastroenterologists. *Journal of Crohn's and Colitis*, 6(8), 830–844.
- van Rheeën, P. F., Aloï, M., Biron, I. A., Carlsen, K., Cooney, R., Cucchiara, S., Cullen, G., Escher, J. C., Kierkus, J., Lindsay, J. O., Roma, E., Russell, R. K., Sieczkowska-Golub, J., & Harbord, M. (2017). European Crohn's and Colitis Organisation Topical Review on Transitional Care in Inflammatory Bowel Disease. *Journal of Crohn's & colitis*, 11(9), 1032–1038.
- Gray, W. N., Holbrook, E., Dykes, D. M. H., Morgan, P., Saeed, S. A., & Denson, L. A. (2019). Improving IBD transition, self-management, and disease outcomes with an in-clinic transition coordinator. *Journal of Pediatric Gastroenterology and Nutrition*, 69(2), 194–199.
- Robinson, J., Furuta, G. T., Hadker, N., Kolev, I., Williams, J. E., Juethner, S., & Falk, G. W. (2021). Transition of Care from Pediatric to Adult Care in Eosinophilic Esophagitis. *Journal of Pediatric Gastroenterology and Nutrition*, 73(6), 722–726.
- Hames, A., Matcham, F., Joshi, D., Heneghan, M., Dhawan, A., Heaton, N., & Samyn, M. (2016). Liver transplantation and adolescence: The role of mental health. *Liver Transplantation*, 22(11), 1544–1553.
- Feingold, J., Kaye-Kauderer, H., Mendiola, M., Dubinsky, M., Keefer, L., & Gorbenko, K. (2021). Empowered transitions: Understanding the experience of transitioning from pediatric to adult care among adolescents with inflammatory bowel disease and their parents using photovoice. *Journal of Psychosomatic Research*, 143, 110400.
- Benchimol, E. I., Walters, T. D., Kaufman, M., Frost, K., Fiedler, K., China, Z., & Zachos, M. (2011). Assessment of knowledge in adolescents with inflammatory bowel disease using a novel transition tool. *Inflammatory bowel diseases*, 17(5), 1131–1137.
- Chabrol, B., Jacquin, P., François, L. A., Broué, P., Dobbelaere, D., Douillard, C., Dubois, S., Feillet, F., Perrier, A., Fouilhoux, A., Labarthe, F., Lamireau, D., Mazodier, K., Maillot, F., Mochel, F., Schiff, M., & Belmatoug, N. (2018). Transition from pediatric to adult care in adolescents with hereditary metabolic diseases: Specific guidelines from the French network for rare inherited metabolic diseases (G2M). *Archives De Pédiatrie*, 25(5), 344–349.
- United European Gastroenterology. (2023). Burden, economic impact, and research gaps: Key findings from the Pan-European study on digestive diseases and cancers. <https://ueg.eu/publications/white-book-2>

UEG's vision is to reduce the burden of digestive diseases and improve digestive health

ueg.eu/publications#public-affairs



Published: October 2024

United European Gastroenterology
House of European Gastroenterology
Wickenburggasse 1
1080 Vienna, Austria

T +43 1 997 1639
F +43 1 997 1639 10
office@ueg.eu

Registered in Austria
Registration Authority: Bundespolizeidirektion
Wien – Vereinsbehörde, ZVR: 570340662
(Austrian Register of Associations)
Place of jurisdiction: Vienna, Austria

All rights reserved. Use of this content constitutes acceptance of the General Terms and Privacy Policy on ueg.eu

