

Transition From Pediatric to Adult Gastroenterology Care in Patients With Inflammatory Bowel Disease

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Overview of IBD in Pediatric Patients

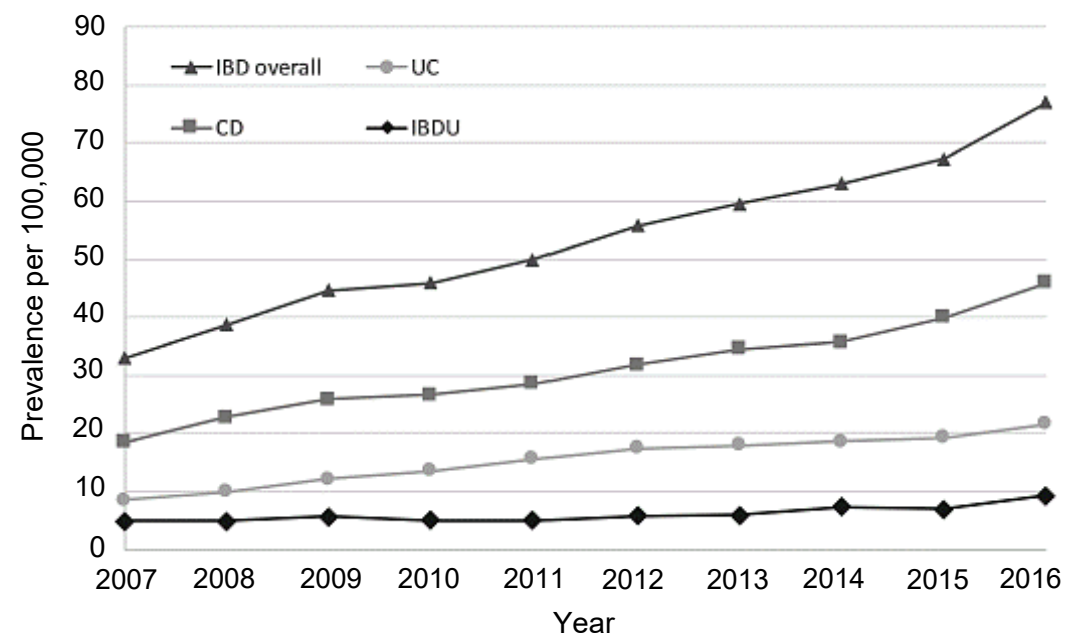
Epidemiology of Pediatric IBD

- Incidence and prevalence of pediatric IBD is increasing worldwide^{1,2}
- In a source population of 12,538,475 commercially insured Americans during the period of 2008 through 2009, the CD and UC prevalence in the pediatric population (<20 years of age) was 58 per 100,000 and 34 per 100,000, respectively³

Note: This study was limited by diagnostic misclassification due to lack of clinical details and possible underestimation of cases with low healthcare utilization

- Because IBD is a chronic, lifelong disorder, every patient with pediatric-onset IBD will eventually need to transition to an adult gastroenterologist for continuity of care⁴

Increased Prevalence of IBD in Pediatric Patients Aged 2 to 17 Years in Optum and Truven Claims Data Analysis (2007-2016; N=5,729,107)²



Note: This claims-based study was limited by potential misclassification due to inaccurate and inconsistent coding practice. Because the databases included mostly privately insured patients, older and low-income populations may also be underrepresented

CD=Crohn's disease; IBD=inflammatory bowel disease; IBDU=inflammatory bowel disease unspecified; UC=ulcerative colitis.

1. Bishop J, et al. *Adolesc Health Med Ther*. 2014;5:1-13. 2. Ye Y, et al. *Inflamm Bowel Dis*. 2020;26(4):619-625. 3. Kappelman MD, et al. *Dig Dis Sci*. 2013;58(2):519-525. 4. Abraham BP, Kahn SA. *Gastroenterol Hepatol*. 2014;10(10):633-640.

Pediatric-Onset and Adult-Onset IBD Differ in Presentation and Disease Course

Phenotype	<ul style="list-style-type: none">Colitis phenotype is more common in patients with pediatric-onset IBD (age <6 years) than in those with adult-onset IBD¹
Presentation	<ul style="list-style-type: none">Clinical presentation of IBD in pediatric patients varies and may initially include growth failure, delayed pubertal development, and extraintestinal manifestations²
Disease extent	<ul style="list-style-type: none">Adolescents are more likely to have extensive IBD involvement compared with adults³<ul style="list-style-type: none">Among patients with UC, pancolitis may be more common in pediatric than in adult patients¹Adolescents with CD present with ileocolonic disease more frequently than adults^{3,4}Upper gastrointestinal involvement in CD, which is rarely reported in adults, has been reported in approximately a quarter of adolescents³
Severity and treatment	<ul style="list-style-type: none">In general, adolescents may have more severe disease requiring immunosuppressives and biologics than adults with IBD³<ul style="list-style-type: none">Cumulative steroid, azathioprine, methotrexate, and biologic use may be higher in patients with pediatric-onset vs adult-onset CD⁵

CD=Crohn's disease; IBD=inflammatory bowel disease; UC=ulcerative colitis.

1. Fuller MK. *Surg Clin N Am.* 2019;99(6):1177-1183. 2. Rosen MJ, et al. *JAMA Pediatr.* 2015;169(11):1053-1060. 3. Abraham BP, Kahn SA. *Gastroenterol Hepatol.* 2014;10(10):633-640. 4. Goodhand J, et al. *Inflamm Bowel Dis.* 2010;16(6):947-952. 5. Duricova D, et al. *J Crohns Colitis.* 2014;8(11):1351-1361.

Care of Patients With IBD May Differ Between Pediatric and Adult Patients

Pediatric patients with IBD ¹⁻³	Adult patients with IBD ¹⁻³
<ul style="list-style-type: none">• Longer clinic visits• Family focused• Involvement of parental direction and consent• Focuses include growth and development	<ul style="list-style-type: none">• Generally shorter clinic visits• Patient centered• Primarily single healthcare provider (gastroenterologist)• Autonomous and independent• Focuses include cancer surveillance and fertility

- Pediatric patients with IBD have a greater tendency than adult patients to show avoidance behavior toward disease management and to seek support from family, which may lead to delays in emotional maturation and establishment of autonomy^{4,5}

These differences reinforce the need for a transition process supervised by both pediatric and adult care providers to ensure continuous, optimal care⁶

IBD=inflammatory bowel disease.

1. Kahn SA. *Gastroenterol Hepatol*. 2016;12(6):403-406. 2. Kim J, Ye BD. *Intest Res*. 2019;17(1):24-35. 3. Goodhand J, et al. *J Crohns Colitis*. 2011;5(6):509-519. 4. Bishop J, et al. *Adolesc Health Med Ther*. 2014;5:1-13. 5. Gray WN, Maddux MH. *Inflamm Bowel Dis*. 2016;22(2):372-379. 6. Abraham BP, Kahn SA. *Gastroenterol Hepatol*. 2014;10(10):633-640.

Transition From Pediatric to Adult IBD Care

Transition Process

Transition of Care

- Refers to purposeful, planned movement from child-centered care to adult-oriented care, with the following two main components¹:
 - Healthcare responsibility transitions from guardian to patient¹
 - Fear of patients' health being compromised and financial issues (eg, termination of health insurance, loss of social support services) may arise during this process²
 - Patient transfers from pediatric to adult provider¹
 - Transfer of care should be considered part of and not necessarily the end of the transition process³
- Having a structured transition of adolescents with IBD from pediatric to adult healthcare may be associated with improved medication adherence and disease outcomes^{4,5}

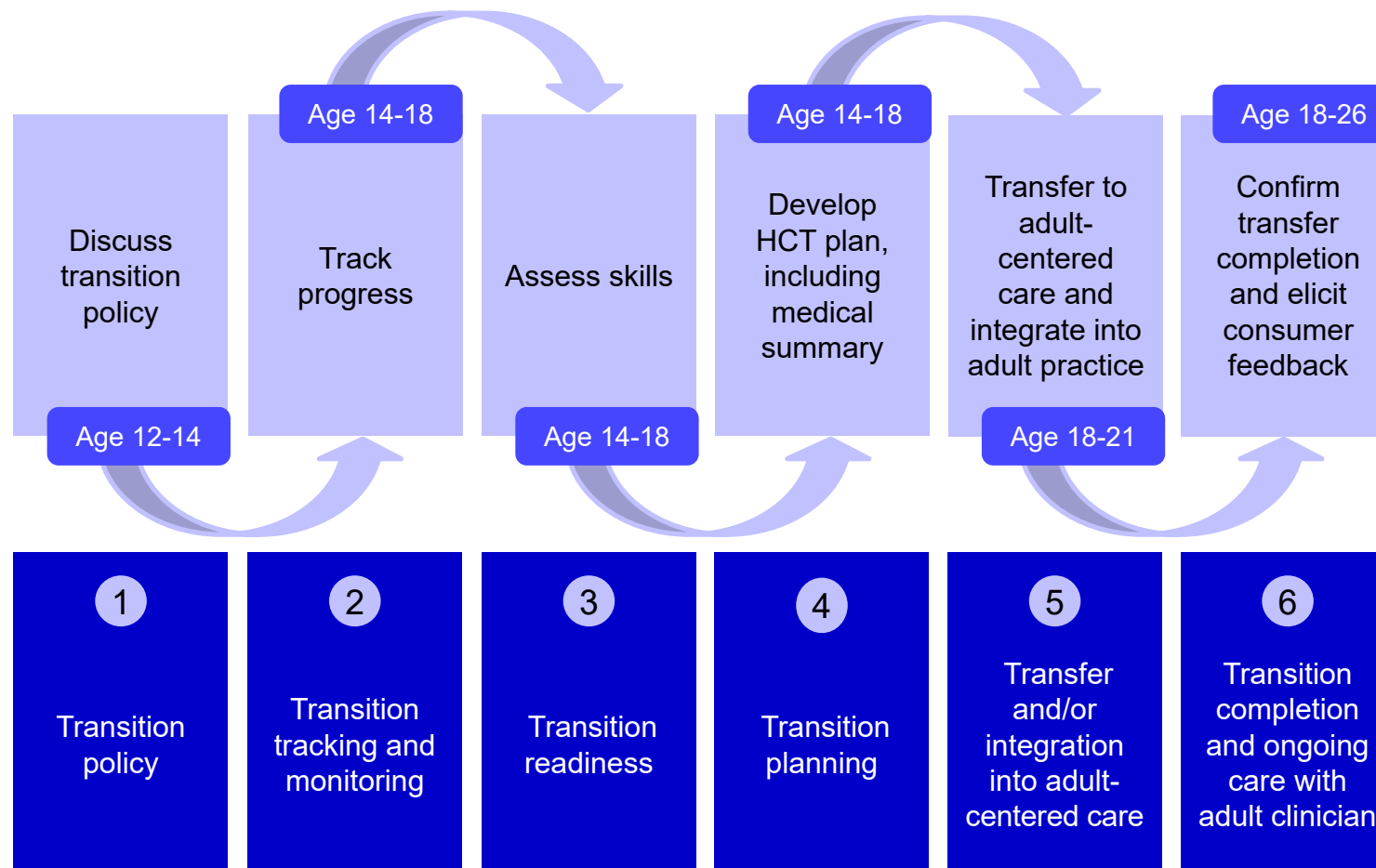
IBD=inflammatory bowel disease.

1. Philpott JR, Kurowski JA. *Inflamm Bowel Dis*. 2019;25(1):45-55. 2. Philpott JR. *Gastroenterol Hepatol*. 2011;7(1):26-32. 3. Goodhand J, et al. *J Crohns Colitis*. 2011;5(6):509-519. 4. Gumidyala AP, et al. *Inflamm Bowel Dis*. 2018;24(3):482-489. 5. Kim J, Ye BD. *Intest Res*. 2019;17(1):24-35.

Transition Timeline

- When possible, discussion about transition of care should be started early (patient age 10-12 years)^{1,2}
 - Transfer to adult care most often occurs between 18 and 23 years of age²
- Transition should focus on¹
 - Patient and family readiness
 - Transfer of an accurate and complete medical history
 - Close follow-up to ensure continuity of care, monitoring of disease activity, and patient self-management

Timeline for Introduction of the 6 Core Elements of Healthcare Transition³



HCT=healthcare transition.

1. Abraham BP, Kahn SA. *Gastroenterol Hepatol.* 2014;10(10):633-640. 2. Zeisler B, Hyams JS. *Nat Rev Gastroenterol Hepatol.* 2014;11(2):109-115. 3. White PH, Cooley WC. *Pediatrics.* 2018;142(5):e20182587.

Challenges in Transitioning Patients

Barriers to Successful Transitioning of IBD Care^{1,2}

- Poor adherence to therapy
- Psychological stress (eg, anxiety and depression)
- Inadequate self-efficacy and knowledge of disease
- Patient readiness and maturity
- Parental and provider reluctance to transfer care
- Differences between pediatric and adult IBD care

- In an online survey of pediatric IBD providers in the US (N=141), 40.4% reported basing their approach to transition on published transition guidelines, and only 14.2% reported having a written transition policy at their institution³

Note: This study was limited by possible low response rates, self-selection bias, and logistical issues

- In a survey of patients previously registered in a pediatric IBD registry (N=605) in Germany and Austria, 52% received assistance with preparing for transition to adult providers⁴

Note: This study was limited by possible oversampling of patients remaining in close contact with home and possible parent interference with patient responses due to the requirement of approaching patients via their parents. Also, there are limitations of applicability of ex-US data to patients with IBD in the US.

IBD=inflammatory bowel disease.

1. Abraham BP, Kahn SA. *Gastroenterol Hepatol*. 2014;10(10):633-640. 2. Kahn SA. *Gastroenterol Hepatol*. 2016;12(6):403-406. 3. Gray WN, Maddux MH. *Inflamm Bowel Dis*. 2016;22(2):372-379. 4. Timmer A, et al. *PLoS One*. 2017;12(5):e0177757.

Concerns With Not Properly Transitioning a Patient

- The following negative outcomes may occur if transition from pediatric to adult IBD care is not well planned and executed^{1,2}:
 - Increased patient and family stress
 - Delayed psychosocial development
 - Poor healthcare attendance
 - Loss of continuity of care
 - Nonadherence to medications
 - Worsening of disease activity and increased hospitalizations
 - Escalation of therapy and/or requirement for surgery

Retrospective Chart Review of Pediatric Patients With IBD (N=95) Demonstrated Fewer Clinic Visits and More Noncompliance After Transition to Adult Care³

Study outcomes	Pediatric care	Adult care	P value
Primary outcomes, no./year			
ED visits	0.18	0.15	0.71
Hospitalizations	0.23	0.13	0.13
Surgical interventions	0.05	0.03	0.53
Endoscopies	0.25	0.37	0.11
Outpatient clinic visits	3.05	2.56	0.01 ^a
Secondary outcome, n (%)			
Documented compliance: noncompliance	67(71):28(29)	54(57):41(43)	0.01 ^a

Note: This retrospective study was limited by information bias as it relied on medical records; observational data may also have limited ability to make inference about causation

Pediatric patients with IBD are at risk of being lost to follow-up and nonadherent to medications and clinic visits,⁴ highlighting the need for a well-planned transition

^aP<0.05 was considered significant.³

ED=emergency department; IBD=inflammatory bowel disease.

1. Abraham BP, Kahn SA. *Gastroenterol Hepatol*. 2014;10(10):633-640. 2. Kim J, Ye BD. *Intest Res*. 2019;17(1):24-35. 3. Bollegala N, et al. *J Crohns Colitis*. 2013;7(2):e55-e60. 4. Rosen D, et al. *Inflamm Bowel Dis*. 2016;22(3):702-708.

Keys to a Successful Transition

Skills Needed for Patients to Be “Transfer Ready”

Knowledge^{1,2}	<ul style="list-style-type: none">• Basic medical history• Nature of the condition• Procedures and tests• Names and doses of medications• Allergies• Names of and how to contact the medical team
Self-efficacy^{1,2}	<ul style="list-style-type: none">• Belief in one’s ability to attain specific goals and be successful• Self-management (making informed and healthy lifestyle choices)• Medication adherence
Self-advocacy¹	<ul style="list-style-type: none">• Effective communication• Maturity and experience• Decision-making and problem-solving
Information gathering¹	<ul style="list-style-type: none">• Health literacy• Ability to research the condition outside of the medical visits

Factors Affecting Transition Readiness

- Adolescents and young adults with IBD generally have low mastery in areas of healthcare utilization and self-advocacy^{1,2}
 - A cross-sectional US multicenter study identified knowledge deficits in availability of healthcare resources (eg, insurance coverage) and completing self-management tasks (eg, scheduling appointments, ordering medication refills) among patients with IBD aged 16 to 22 years (N=75)³

Note: This study was limited by patient selection bias and a relatively small number of patients; patients who were nonadherent to clinic appointments may have been excluded

Factors associated with transition readiness

- Older age (independently associated with transition readiness)^{3,4}
- Self-efficacy³
- Increased patient-provider transition communication on disease condition and management and on healthcare resources³
- Patient healthcare satisfaction with communication, time spent with provider, and accessibility and convenience of medical care⁵

IBD=inflammatory bowel disease.

1. Gray WN, et al. *Inflamm Bowel Dis*. 2015;21(5):1125-1131. 2. Abraham BP, Kahn SA. *Gastroenterol Hepatol*. 2014;10(10):633-640. 3. Gumidyala AP, et al. *Inflamm Bowel Dis*. 2018;24(3):482-489. 4. Rosen D, et al. *Inflamm Bowel Dis*. 2016;22(3):702-708. 5. Gumidyala AP, et al. *Inflamm Bowel Dis*. 2017;23(1):89-96.

Tools to Assess Transition Readiness

- AAP recommends that providers assess transition readiness¹
 - Among 141 pediatric gastroenterology providers surveyed, 75.9% reported using objective measures to assess transition readiness, most common were the NASPGHAN transition checklist or [TRAQ](#)^{2-4,a}
- Note:** This study was limited by possible low response rates, self-selection bias, and logistical issues²
- IBD-KID2 can also be used to assess disease-specific knowledge as component of transition readiness^{5,6}

NASPGHAN Transition Checklist³

AGE	PATIENT	HEALTH CARE TEAM
12-14	EARLY ADOLESCENCE <i>New knowledge and responsibilities</i> <ul style="list-style-type: none"> <input type="checkbox"/> I can describe my GI condition <input type="checkbox"/> I can name my medications, the amount and times I take them <input type="checkbox"/> I can describe the common side effects of my medications <input type="checkbox"/> I know my doctors' and nurses' names and roles <input type="checkbox"/> I can use and read a thermometer <input type="checkbox"/> I can answer at least 1 question during my health care visit <input type="checkbox"/> I can manage my regular medical tasks at school <input type="checkbox"/> I can call my doctor's office to make or change an appointment <input type="checkbox"/> I can describe how my GI condition affects me on a daily basis 	<ul style="list-style-type: none"> <input type="checkbox"/> Discuss the idea of visiting the office without parents or guardians in the future <input type="checkbox"/> Encourage independence by performing part of the exam with the parents or guardians out of the examining room <input type="checkbox"/> Begin to provide information about drugs, alcohol, sexuality and fitness <input type="checkbox"/> Establish specific self-management goals during office visit
14-17	MID ADOLESCENCE <i>Building knowledge and practicing independence</i> <ul style="list-style-type: none"> <input type="checkbox"/> I know the names and purposes of the tests that are done <input type="checkbox"/> I know what can trigger a flare of my disease <input type="checkbox"/> I know my medical history <input type="checkbox"/> I know if I need to transition to an adult gastroenterologist <input type="checkbox"/> I reorder my medications and call my doctor for refills <input type="checkbox"/> I answer many questions during a health care visit <input type="checkbox"/> I spend most of my time alone with the doctor during visit <input type="checkbox"/> I understand the risk of medical nonadherence <input type="checkbox"/> I understand the impact of drugs and alcohol on my condition <input type="checkbox"/> I understand the impact of my GI condition on my sexuality 	<ul style="list-style-type: none"> <input type="checkbox"/> Always focus on the patient instead of the parents or guardians when providing any explanations and <input type="checkbox"/> Allow the patient to select when the parent or guardian is in the room for the exam <input type="checkbox"/> Inform the patient of what the parent or guardian must legally be informed about with regards to the patient condition <input type="checkbox"/> Discuss the importance of preparing the patient for independent status with the parents or guardian and address any anxiety they may have <input type="checkbox"/> Continue to set specific goals which should include: <ul style="list-style-type: none"> • Filling prescriptions and scheduling appointments • Keeping a list of medications and medical team contact information in wallet and backpack
17+	LATE ADOLESCENCE <i>Taking charge</i> <ul style="list-style-type: none"> <input type="checkbox"/> I can describe what medications I should not take because they might interact with the medications I am taking for my health condition <input type="checkbox"/> I am alone with the doctor or choose who is with me during a health care visit <input type="checkbox"/> I can tell someone what new legal rights and responsibilities I gained when I turned 18 <input type="checkbox"/> I manage all my medical tasks outside the home (school, work) <input type="checkbox"/> I know how to get more information about IBD <input type="checkbox"/> I can book my own appointments, refill prescriptions and contact medical team <input type="checkbox"/> I can tell someone how long I can be covered under my parents' health insurance plan and what I need to do to maintain coverage for the next 2 years. <input type="checkbox"/> I carry insurance information (card) with me in my wallet/purse/backpack. 	<p>DISCUSS IN MORE DEPTH:</p> <ul style="list-style-type: none"> <input type="checkbox"/> The impact of drugs, alcohol and non adherence on their disease <input type="checkbox"/> The impact of their disease on sexuality, fertility <input type="checkbox"/> Future plans for school/work and impact on health care including insurance coverage. <input type="checkbox"/> How eventual transfer of care to an adult gastroenterologist will coordinate with future school or employment plans <ul style="list-style-type: none"> <input type="checkbox"/> Remind patient and family that at age 18 the patient has the right to make his or her own health choices <input type="checkbox"/> Develop specific plans for self-management outside the home (work/school) <input type="checkbox"/> Provide the patient with a medical summary for work, school or transition <input type="checkbox"/> Discuss plans for insurance coverage <input type="checkbox"/> If transitioning to an adult subspecialist, provide a list of potential providers and encourage/facilitate an initial visit.

^aTransition Readiness Assessment Questionnaire (TRAQ) consists of 20 items with a 5-point Likert scale (range, 20-100) and is divided among 5 domains; higher score represents better performance.^{4,7} AAP=American Academy of Pediatrics; HCP=healthcare professional; IBD=inflammatory bowel disease; IBD-KID2=Inflammatory Bowel Disease Knowledge Inventory Device Version 2; NASPGHAN=North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition.

1. Philpott JR, Kurowski JA. *Inflamm Bowel Dis*. 2019;25(1):45-55. 2. Gray WN, Maddux MH. *Inflamm Bowel Dis*. 2016;22(2):372-379. 3. NASPGHAN with support from Centocor Inc. https://www.naspgghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProdiver_TransitionfromPedtoAdult.pdf. Accessed June 3, 2021. 4. Johnson K, et al. *J Pediatr Nurs*. 2021;59:188-195. 5. Bishop J, et al. *Adolesc Health Med Ther*. 2014;5:1-13. 6. The Inflammatory Bowel Disease Knowledge Inventory Device Version 2. https://karger.figshare.com/articles/dataset/Supplementary_Material_for_Validation_of_a_Revised_Knowledge_Assessment_Tool_for_Children_with_Inflammatory_Bowel_Disease_IBD-KID2_/11881200. Accessed June 11, 2021. 7. Feingold JH, et al. *J Psychosom Res*. 2021;143:110400.

Improving Self-management in Patients With IBD

- Self-management involves taking responsibility and making informed choices regarding diet and lifestyle, monitoring symptoms, managing treatment, and working in partnership with providers^{1,2}
- Adolescents and young adults are considered at risk of poor self-management, which may affect adherence to medications and disease outcomes^{3,4}
- A transition coordinator may help increase self-management skills that support maintenance of disease remission and transition readiness in pediatric patients with IBD⁵

Skills Targeted by a Transition Coordinator and Goals Set by Families⁵

Target Skills	Goals for Patients
IBD education	<ul style="list-style-type: none"> • Able to explain IBD to another person • Lists current medications • Identifies triggers to IBD symptoms
Adherence	<ul style="list-style-type: none"> • Knowledgeable of when to renew pharmacy medications before they run out • Adherent to prescribed medication without parental prompting
Transition of responsibility	<ul style="list-style-type: none"> • Calls in pharmacy refills • Communicates with medical staff about care • Seen alone for part of next clinic appointment
Transfer	<ul style="list-style-type: none"> • Family will set a target date for transfer • Family will choose a local adult provider from a list of providers given to the family

IBD=inflammatory bowel disease.

1. Leung Y, et al. *Inflamm Bowel Dis*. 2011;17(10):2169-2173. 2. de Silva PSA, Fishman LN. *Inflamm Bowel Dis*. 2014;20(8):1458-1464. 3. Hommel KA, et al. *J Pediatr Gastroenterol Nutr*. 2013;57(2):250-257. 4. Plevinsky JM, et al. *Clin Exp Gastroenterol*. 2016;9:259-267. 5. Gray WN, et al. *J Pediatr Gastroenterol Nutr*. 2019;69(2):194-199.

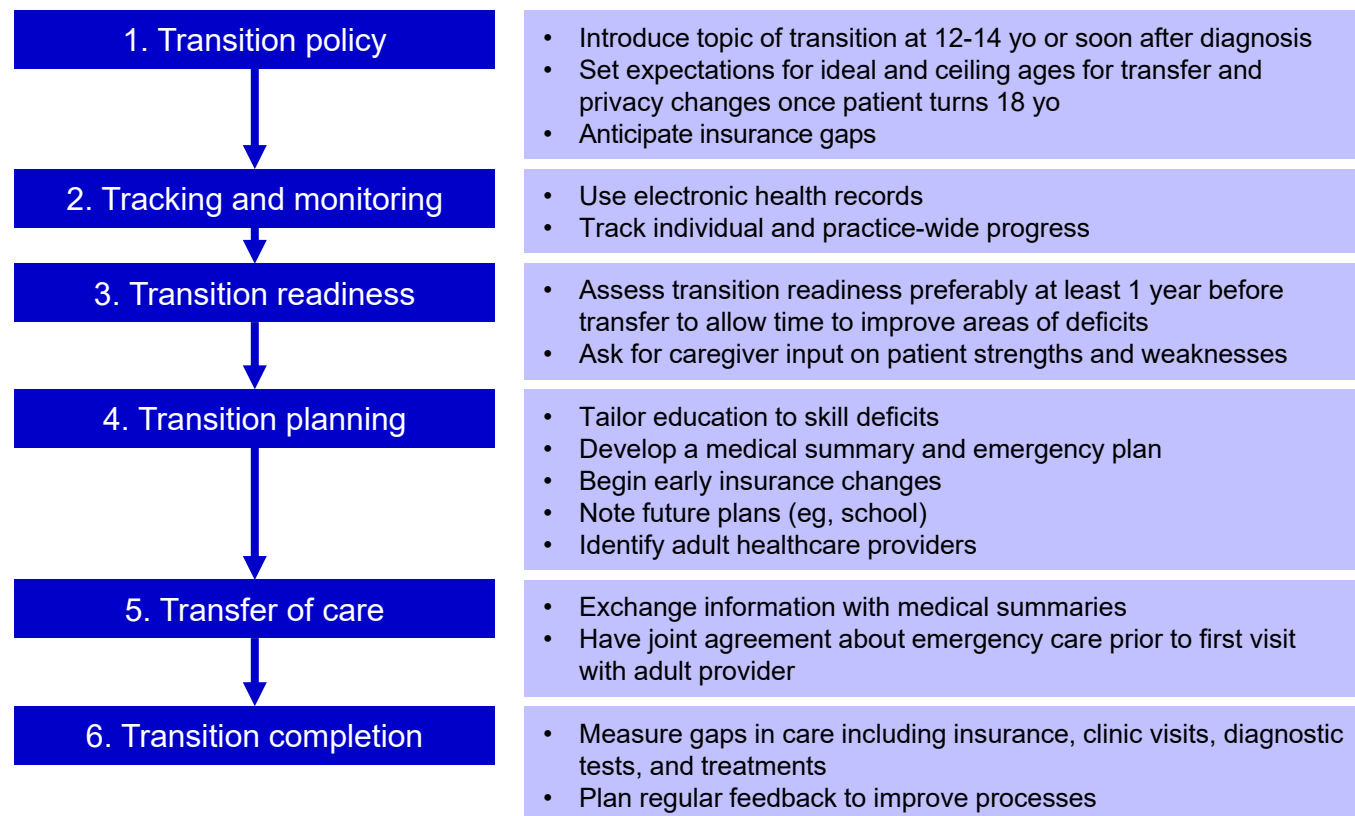
Recommendations for a Successful Transition

Recommendations for Physicians

Clinical Recommendations for Transition of IBD Care¹

Six Core Elements of Transition

Recommendations



- A joint visit with pediatric and adult providers along with patient and family should be considered in transition of care²
 - An IBD transition clinic^a in a single tertiary center in the US was shown to improve patient retention from 33% to 80% and lower no-show rates from 46% to 0% among pediatric patients transitioning to adult care (N=35)³

Note: This study was limited by a relatively small number of patients and should be further evaluated in larger studies
- At time of transfer, the patient should bring a medical summary including the following⁴:
 - Date of diagnosis
 - Location and severity of disease
 - Surgical procedures and complications
 - Medical therapies and adverse reactions
 - Complete vaccination history

^aIBD transition clinic involved an initial visit with a pediatric IBD specialist followed by a multidisciplinary meeting where a summary transition letter was reviewed by adult and pediatric gastroenterologists, a nurse navigator, a social worker, and a nutritionist.³

IBD=inflammatory bowel disease; yo=years old.

1. Shapiro JM, et al. *Clin Gastroenterol Hepatol*. 2020;18(2):276-289. 2. Philpott JR, Kurowski JA. *Inflamm Bowel Dis*. 2019;25(1):45-55. 3. Williams E, et al. *Am J Gastroenterol*. 2017;112(suppl 1):S388.

4. Bollegala N, Nguyen GC. *Gastroenterol Res Pract*. 2015;2015:853530.

Transition Recommendations

Starting the transition process early is recommended to help patient and family recognize that all providers are working together to ensure continuous, optimal care¹

NASPGHAN Transition Recommendations^{2,3}

- Start seeing patient without parents to build independence and self-reliance
- Discuss benefits of transition to internal medicine gastroenterology practice
- Select an adult gastroenterologist who recognizes special considerations in childhood-onset disease
- Provide all necessary medical records and summaries to patient and adult provider
- Allow flexibility in transition timing according to individual patient needs

NASPGHAN=North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition.

1. Abraham BP, Kahn SA. *Gastroenterol Hepatol*. 2014;10(10):633-640. 2. NASPGHAN. <https://naspghan.org/files/documents/pdfs/medical-resources/Improving%20the%20Transition%20Process%20for%20Pediatric%20IBD%20Patients%20in%20Canada.%20A%20Case-Based%20Monograph%20Focusing%20on%20IBD.pdf>. Accessed June 3, 2021. 3. Baldassano R, et al. *J Pediatr Gastroenterol Nutr*. 2002;34(3):245-248.

Guidelines for Pediatric and Adult Gastroenterologists

Recommendations for Pediatric Gastroenterologists

- Be aware that transition is an ongoing process that may begin as early as the time of diagnosis of IBD
- Ask patients and families about their expectations of the transition process
- Provide patients with information about their disease and treatment plans both verbally and in written form
- Provide an opportunity for patients to be seen in the clinic on their own for at least part of the visit
- Create a written healthcare transition plan together with the patient and family that can be updated on an annual basis
- Highlight differences between pediatric and adult healthcare

Recommendations for Adult Gastroenterologists

- Recognize that patients may not be fully prepared for or aware of the differences between pediatric and adult healthcare
- Collaborate with the pediatric gastroenterologist and team prior to the actual transfer of care
- Anticipate questions from patients about IBD, treatment plans, and impact on body image and sexual health
- Educate patients in understanding adult healthcare system
- Anticipate that newly transferred patients may require longer appointment times during the first few visits
- Recognize that the process of patients taking responsibility for their own care may be gradual

Recommendations for Patients

- Adolescent patients with IBD may use resources and tools to promote self-management during their transition to adult care¹

Smartphone applications¹⁻³

- GI Buddy (from Crohn's and Colitis Foundation): tracks symptoms, diet, and medications
- MyIBD (from Hospital for Sick Children): tracks symptoms, medication adherence, and medical history

Websites^{1,4-6}

- Crohn's and Colitis Foundation and GotTransition.org: provide information and resources for patients, families, and providers about the transition process

MyHealth Passport^{4,7}

- Website that generates a customized, comprehensive summary card of patient information to expedite medical history review during visits to new physicians
- Should be routinely updated by patients

IBD=inflammatory bowel disease.

1. Kahn SA. *Gastroenterol Hepatol*. 2016;12(6):403-406. 2. MyHealthApps. <http://myhealthapps.net/app/details/345/gi-buddy>. Accessed June 3, 2021. 3. MyHealthApps. <http://myhealthapps.net/app/details/95/myibd>. Accessed June 3, 2021. 4. NASPGHAN. <https://naspghan.org/files/documents/pdfs/medical-resources/Improving%20the%20Transition%20Process%20for%20Pediatric%20IBD%20Patients%20in%20Canada.%20A%20Case-Based%20Monograph%20Focusing%20on%20IBD.pdf>. Accessed June 3, 2021. 5. Crohn's and Colitis Foundation. <https://www.crohnscolitisfoundation.org/justlikeme/living-with-crohns-and-colitis/preparing-adult-care>. Accessed June 3, 2021. 6. Got Transition. <https://gottransition.org/>. Accessed June 3, 2021. 7. SickKids. <https://wapps.sickkids.ca/myhealthpassport/FormPassport.aspx?FormId=43>. Accessed June 3, 2021.

Summary

- Pediatric-onset and adult-onset IBD differ in presentation and disease course, so a structured transition process is necessary to ensure continuous, optimal care
- Structured transition from pediatric to adult healthcare may result in improved medication adherence and improved disease outcomes
- Pediatric providers should start the transition process early and follow age-appropriate goals in transition of care
- Key skills needed for patients to achieve transition readiness include knowledge, self-efficacy, self-advocacy, and information gathering
- Resources and tools are available for pediatric gastroenterologists to assess transition readiness and for adolescent patients with IBD to promote self-management during their transition to adult care

Available Resources

- American Academy of Pediatrics
 - Clinical guidelines for transition
- Crohn's and Colitis Foundation
 - GI Buddy (symptom tracker)
 - crohnscolitisfoundation.org (information and resources)
- Hospital for Sick Children
 - MyIBD (symptom tracker)
 - MyHealth Passport (comprehensive patient information)
- National Alliance to Advance Adolescent Health
 - GotTransition.org (information and resources)
- North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition
 - Transition recommendations
 - Healthcare provider transitioning checklist
- Transition readiness assessment tools
 - Transition Readiness Assessment Questionnaire (TRAQ)
 - Inflammatory Bowel Disease Knowledge Inventory Device Version 2 (IBD-KID2)

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Backup

Transition Readiness Assessment Questionnaire (TRAQ)

Transition Readiness Assessment Questionnaire (TRAQ)

Patient Name: _____ Date of Birth: ___/___/___ Today's Date ___/___/___ (MRN# _____)

Directions to Youth and Young Adults: Please check the box that best describes *your* skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes *your* skill level. **Check here** if you are a parent/caregiver completing this form.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you reorder medications before they run out?					
4. Do you explain any medications (name and dose) you are taking to healthcare providers?					
5. Do you speak with the pharmacist about drug interactions or other concerns related to your medications?					
Appointment Keeping					
6. Do you call the doctor's office to make an appointment?					
7. Do you follow-up on referrals for tests or check-ups or labs?					
8. Do you arrange for your ride to medical appointments?					
9. Do you call the doctor about unusual changes in your health (for example: allergic reactions)?					

Tracking Health Issues					
10. Do you fill out the medical history form, including a list of your allergies?					
11. Do you keep a calendar or list of medical and other appointments?					
12. Do you tell the doctor or nurse what you are feeling?					
13. Do you contact the doctor when you have a health concern?					
14. Do you make or help make medical decisions pertaining to your health?					
15. Do you attend your medical appointment or part of your appointment by yourself?					
Talking with Providers					
16. Do you ask questions of your nurse or doctor about your health or health care?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
18. Do you ask your doctor or nurse to explain things more clearly if you do not understand their instructions to you?					
19. Do you tell the doctor or nurse whether you followed their advice or recommendations?					
20. Do you explain your health history to your healthcare providers (including past surgeries, allergies, and medications)?					
Please circle how you feel about the following statements					
	Not at all important	Not too important	Somewhat important	Important	Very Important
How important is it to you to manage your own health care?	1	2	3	4	5
How confident do you feel about your ability to manage your own health care?	1	2	3	4	5