

# crohn's colitis

Name of Clinical Care Pathway (CCP)

Transition of Care in Inflammatory Bowel Disease (IBD)

Objective

To provide practical clinical advice for gastroenterologists involved in the transfer of care of patients with pediatric onset IBD from pediatric to adult care based on the best available literature and clinical tools.

Patient Population

Adolescents and young adults with IBD

Dr. Natasha Bollegala HonBSc MD MSc FRCPC (Women's College Hospital & University of Toronto)

Dr. Nancy Fu MD, MHSc, FRCPC (University of British Columbia)

*These clinical decision support tools were developed by Canadian experts in IBD, based on their interpretation of current evidence and considerations specific to Canadian healthcare. International guidelines from Europe and the United States are available. However, these may reflect regional factors not directly applicable in Canada.*

## Abbreviations

AYA	Adolescents and young adult
BMQ	Beliefs about Medicines Questionnaire
CANIBD	Canadian IBD Nurses
CCP	Clinical Care Pathway
CD-RISC	Connor-Davidson Resilience Scale
IBD	Inflammatory bowel disease
IBD-DI	Inflammatory Bowel Disease Disability Index
IBD-KID2	Inflammatory Bowel Disease Knowledge Inventory Device 2
IBD-SES A	Inflammatory Bowel Disease Self-Efficacy Scale Adolescent
MARS	Medication Adherence Report Scale
MMS-8	Morisky Medication Scale-8
ON TRAC	Opportunity to Nourish Transition Readiness and Adolescent Care
PAM13 A	Patient Activation Measure 13 Adolescent
STARx	Successful Transition to Adulthood with Therapeutics
TRAQ	Transition Readiness Assessment Questionnaire

## Highlights from this CCP

- A structured transition process is associated with better outcomes.
- A prospective clinical trial evaluating the role of a transition program involving clinical resources such as a transition navigator and a comprehensive educational program is underway. This CCP will be updated based on the results obtained.
- This CCP is created based on currently available evidence and clinical tools.

## Introduction

Pediatric to adult transition of care is the process of migrating a patient with chronic disease from pediatric to adult care. It requires continuous, coordinated, and comprehensive care while paying attention to the clinical, psychosocial, and educational/vocational needs of adolescent and young adult (AYA) patients. If the transition and transfer process fail, it can lead to an increase in emergency department visits, hospitalizations, medication adjustments, surgeries, adherence and negatively impact quality of life.

Due to the growing number of cases of inflammatory bowel disease (IBD) in children, it has become increasingly necessary to establish a structured transition plan for AYAs. To achieve this goal, the Canadian IBD Transition Network and Crohn's and Colitis Canada joined forces to develop a set of care consensus statements to provide a framework for transitioning AYA from pediatric to adult care. Since then, the Canadian IBD Nurses (CANIBD) have developed an online clinical tool for transition of care with practical tools.

This CCP is primarily based on the March 2022 published Canadian Consensus statements on transition of AYAs with IBD (Bollegala et al., 2022) and also incorporates the results of an updated literature search conducted from June 2019 to July 2022.

### **Phase 1: Pediatric phase**

#### **Clinical**

- Identify the IBD transition patient:
  - Age 12+
  - Consider special needs (developmental, pregnancy, psychosocial)
- Discuss goals (treatment, transition, others) and expectations
- Review the transition/transfer timeline
- Review the assessment plan
- Clarify communication strategies

## Operational

- Please refer to the [TransitionIBD Flowsheet \(PDF\)](#) (CANIBD, 2024)
  - Initiate the transfer summary
  - Initiate a transfer checklist

## Phase 2: Care transfer

- **Identify & initiate referral to adult gastroenterology**
  - Be aware of target recipient providers, associated wait times, geographic availability
  - Discuss impending transfer with the patient and their care partners. Consider the discussion points listed in Table 1.
- **Send transfer of care summary** to the target adult gastroenterologist early (according to local wait times) and clearly indicate the priority of transfer and any time-sensitive issues that need to be addressed early in adult care.
- **Adult providers should prioritize transfers of care within 6 months of referral receipt**
  - Be aware of age restrictions for local health facilities (ambulatory clinics, hospital admissions, endoscopic procedures, surgical procedures).
  - Consider a more comprehensive handover plan for complex cases (e.g. multi-disciplinary case conferences).
- **Ensure continuity of the larger healthcare team**
  - Primary care providers (especially for children leaving the care of pediatricians, be aware of local availability) should be aware of the transfer.
  - Health insurance (for medications, stoma devices, etc.) should be up to date. Additional sub-specialists and allied health providers should have a transfer of care plan if appropriate and should be included in the correspondence.

**Table 1: Topics to review with AYAs and families regarding adult care**

<b>By the pediatric healthcare team before the transfer</b>
Differences in procedural sedation
How to access pediatric medical records
The role of the primary care provider in IBD care
The intended receiving adult gastroenterology health care team and location
<b>By the adult health care team at intake meetings</b>
Expectations related to IBD related care
Collaborative realistic goal setting
Roles of AYA in adult care
Roles of parents/caregivers in adult care
How, who and when to contact the adult healthcare team
How to access adult medical records
Differences in procedural sedation

AYA, adolescents and young adults; IBD, inflammatory bowel disease

### **Phase 3: Adult phase**

- **Transition skills assessment**  
Consider using the Transition Readiness Assessment Questionnaire (TRAQ) (Rosen et al., 2016) and the [TransitionIBD Flowsheet \(PDF\)](#) (CANIBD, 2024). The appendix provides a comprehensive listing of available transition skills assessment tools.
- **Engage healthcare partners in addressing the healthcare needs of the patient**  
Be aware of local allied health resources (e.g. nursing support, dietitians, psychologists/psychiatrists, social workers, etc.).
  - Potential issues to address: Preventative health, contraception, mental health, and monitoring related to advanced IBD therapies.
- **Identify and address special populations**
  - Young adults who may live elsewhere for occupational or academic reasons
    - Establish an emergency care plan.
    - Consider medication routes of administration that may be more convenient.
    - Discuss local resources such as student health services and local laboratories to assist with ongoing care.
    - Ensure a communication plan that accommodates distance (e.g. virtual care, secure patient messaging systems, etc.)
  - Special needs patients
  - Pregnancy

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## Appendix

### Transition-related skills or characteristics and assessment tools

Skills or characteristics	Assessment tools
IBD-specific knowledge	IBD-yourself (Zijlstra et al., 2013) MyHealth Passport (Benchimol et al., 2011) IBD-KID2 (Vernon et al., 2020)
Transition Readiness	Transition Readiness Assessment Questionnaire (TRAQ) (Rosen et al., 2016) Successful Transition to Adulthood with Therapeutics (STARx) (Nazareth et al., 2018) Got-Transition (GoodToGo) (Benchimol et al., 2011) UNC TR(x)ANSITION (Kelly et al., 2009) ON TRAC (BC Children's Hospital, 2021) NASPGHAN Transition Checklist (NASPGHAN, 2021)
Self-efficacy and Self-management	IBD Self-Efficacy Scale Adolescent (IBD-SES A) (Carlsen et al., 2017) HealthPROMISE (Atreja et al., 2015) ImproveCareNow Self-management Handbook (ImproveCareNow™, 2019)
Functional Status	IBD Disk (Ghosh et al., 2017) IBD Disability Index (IBD-DI) (Gower-Rousseau et al., 2017)
Resilience	Conner-Davidson Resilience Scale (CD-RISC) (Carlsen et al., 2017)
Self-activation	Patient activation measure 13 Adolescent (PAM13 A) (Bomba et al., 2018)
Adherence	Beliefs in Medicine (BMQ) (Horne et al., 1999) MMS-8 (Kiser et al., 2012) MARS (Horne & Weinman, 2002)