TRANSITION OF INFLAMMATORY BOWEL DISEASE PATIENTS FROM PEDIATRIC TO ADULT CARE

Target Audience:
Physicians, Physician Assistants, Nurse Practitioners, Nurses and Social Workers impacted by the protocol.

Scope/Patient Population:
Adolescent and young adult patients with Inflammatory Bowel Disease (IBD).

Rationale:
Approximately 30% of Crohn's disease (CD) and 20% of ulcerative colitis (UC) present before the age of 20.[1,2] The American academy of pediatrics recommends that all children with chronic illness have a written transition of care plan. Transition is a process, and not a one-time event. Characteristics of a successful transition program include:[3]

- Providing continuity of care
- Improving treatment adherence and disease knowledge
- Encouraging independent disease management
- Building confidence in the new adult healthcare team
- Improving or maintaining disease control

Objective

1. Getting the patient ready for transfer, having attained specific skills and knowledge
2. Getting the parents ready for transfer
3. Providing the adult gastroenterologist to provide high quality and continuous care of the patient

Recommendations:

The general age of transition is 18. However, there may be exceptions to that depending on the specific needs of the patient and family.

Knowledge and tasks that should be completed by the time the patient is ready to be cared for by adult GI. The checklist in Appendix A can be used to support this.

- Diagnosis- Crohn's UC , Indeterminate
- Location of disease small bowel, large bowel, perianal disease
- Stricture, abscess or fistula?
- Year of diagnosis, where and by whom
- Extraintestinal manifestations

	• Medication name and dose • Allergies • Surgeries if performed • Understand name of blood test and common radiology test and why they are completed • Understand symptoms and when to report to provider's office • Call for refill of medication • Able to call for appointment with provider • Be able to discuss healthy habits for diet, alcohol, relationships • Understands what symptoms need to be reported urgently and who to contact in case of an emergency • Able to ask provider a question • Sees provider independently • Takes charge of their own daily healthcare • Schedule visit with adult provider • Diet concerns addressed • Psychosocial concerns met **Transition folder to include (Appendix B)** • Face sheet • Vaccinations • DEXA • All endoscopy reports and pathology • All radiology reports • Surgery or hospital out comes and dates • Any consult H&P i.e. rheumatology, hematology • Medications current and previous with response • Allergies or Adverse reactions • Check list of knowledge and task with date completed • At last visit –brief note to adult provider with current status, concerns, etc. • Quantiferon and/or PPD **Communication Back to Pediatric Provider** • A note will go back from the adult provider to the pediatric provider with a summary of the transition • As needed, the adult providers may be contacted to arrange special visits to help ease the transition • A follow-up with performed with the pediatric social worker to assure that the transition is meeting everybody's needs.
	Evidence: [1]Kelsen J., Baldassano R. N. Inflammatory bowel disease: the difference between children and adults. *Inflammatory Bowel Diseases*. 2008;14(supplement 2):S9–S11.

	[2]Mamula P., Markowitz J., Baldassano R. N. *Pediatric Inflammatory Bowel Disease*. New York, NY, USA: Springer; 2008. [3]Blum R. W., Dale Garell D., Hodgman C. H., et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*. 1993;14(7):570–576. doi: 10.1016/1054-139x(93)90143-d Bollegala N, Nguyen GC. Transitioning the Adolescent with IBD from Pediatric to Adult Care: A Review of the Literature. *Gastroenterology Research and Practice*. 2015;2015:853530. doi:10.1155/2015/853530.
	List of Implementation Items and Patient Education: *Appendix A: Transition Checklist* *Appendix B: Medical Information Provided at Transition*
	Metrics Plan: • 90% of patients complete all of the competencies needed for a safe and effective transition to manage care independently as an adult. • 90% of patients feel like the transition has been successful based on the social worker visit. • The clinical status remains unchanged through the first six months of transition to adult care.
	PDCA Plan: Review annually by the Pediatric and Surgery Collaboratives.
	Point of Contact: Ops Lead for Pediatric and Surgery Collaboratives.

Approval By:	***Date of Approval:***
Collaborative (Pediatric) MCC/Collaborative Leadership	*09/2016* *Xx/XX; X/XX*
Original Date: Revision Dates: Reviewed with no Changes Dates:	*X/XX* *X/XX; X/XX* *X/XX; X/XX*

Distribution: MultiCare Connected Care + MultiCare Health System

Appendix A

Pediatric Transition Readiness Checklist

Patient Knowledge

Target Age	Competency	Yes/No	Date
10-12	Can you describe your type of IBD?		
	Can you tell us where you disease is located?		
	Do you know what medications you take and what they are for?		
	Do you know what symptoms to report?		
12-14	Do you know medication dosages?		
	Do you take your medications at the correct time and dosage without assistance?		
	Can you ask questions at your provider visits?		
	Do you know what warning signs to report urgently to your parents or provider?		
	Can you describe test that helped diagnose your IBD?		
14-16	Do you keep track of your own provider appointments?		
	Do you tell your provider how you are feeling at your appointment?		
	Do you know how to call your providers office?		
	Can you identify 1-2 medical risk of not being adherent to medications?		
16-18	Can you fill out your health history form independently?		
	Do you come to your appointments alone?		
	Do you prepare your own meals?		
	Do you call the pharmacy for medication refills?		
	Do you know who your health insurance is through?		

Provider Office Activities

Target Age	Activity	Date Completed
10-12	Provide handbook for transition	
	Patient provided pictures of intestines showing where their disease was located.	
	Provide patient with IBD Type	
	Provide patient with list of medications and indications	
12-14	Provide a more detailed list of medications with dosage, timing, and indication.	
	Suggest patient takes a more active role in taking medications.	
	Provide list of warning signs to report to providers	
	Discuss role of colonoscopy.	
14-16	Discuss allowing patient to schedule their own follow up appointments.	
	Provide patient with discussion prompt prior to appointments.	
	Provide patient phone number for provider and encourage calling if concerns, refills or appointments needed.	
	Discuss challenges with smoking and IBD.	
	Review risk of non-adherence to treatment.	
16-18	Consider having patient carry insurance information and providing to provider for appointments.	
	Consider independent appointments with providers.	
	Provide pharmacy information and review process for refilling medications.	
	Introduce to adult GI provider (consider joint meeting if possible)	
	Discuss timing of transfer of care so relationship can be established prior to college.	

Appendix B: Proposed EPIC Report (Request for Enhancement has been submitted)

Medical summary for transition
- Diagnosis
- Date of diagnosis
- Location
- Severity or complications
- Medical therapy currently
- Medical therapy previously tried

Previous Surgeries

Procedures
- At Diagnosis
- Most Recent

Most recent
- Imaging
- Labs

Comorbidities

What the patient wants the adult provider to know about them.