

## Pediatric IBD INTERMED information for professionals

[Link to supplementary material](#)

### Background:

The pIBD-INTERMED ([link](#)) was developed and validated through the research efforts at the CHEO IBD Centre. Information provided by the pIBD-INTERMED can be used to inform decision support and quality improvement at all levels of the health care system: individual patient, program/hospital, community/systems. At the level of the individual child, the pIBD-INTERMED can guide decision making with regard to psychosocial care, with action plans/interventions directly linked to identified needs. In using the pIBD-INTERMED to develop an intervention plan for a child, individual pIBD-INTERMED items should always be interpreted and considered in the context of the child's overall pIBD-INTERMED profile of needs. For example, if a child is rated as having a significant need on the pIBD-INTERMED "Resistance to Treatment" item, decisions about the type of intervention required will vary depending on whether there is a co-existing mental health need versus a need related to deficits in parenting (pIBD-INTERMED Parental Skills item). The pIBD-INTERMED can also be used to monitor response to psychosocial interventions over time. For children exhibiting sub-clinical levels of psychosocial difficulties, baseline documentation of this sets the stage for ongoing monitoring of the child's functioning over time, including during disease exacerbations/relapses, and identifying patients and families who would benefit from participation in preventive intervention programs. At the program/institution level information from the pIBD-INTERMED can be used for decision-making and planning about the most relevant types of programmatic interventions to offer. For example, these might include targeted skills based programs to build children's coping skills and manage symptoms such as pain, education about how to cope with IBD at school, and support and education to parents/families about managing the challenges of having a child with a chronic illness. Interventions to assist children and family's facing complex health system issues might include enhanced case management, building child and parent self-management and advocacy skills, and periodic case conferences to liaise and coordinate care among providers. Finally, at the community and systems' levels, the pIBD-INTERMED indicators of biopsychosocial case complexity provides metrics to monitor the interface of health and mental across institutions, and in different chronic illness populations, to assist in identifying needs and gaps in the system and ultimately inform policy and planning.

The CHEO IBD Centre within our hospital is currently implementing the pIBD-INTERMED with all newly diagnosed patients. To this end, the pIBD-INTERMED tool has been embedded in the hospital's electronic documentation system (EPIC™ system), so that it is easily accessible to all IBD team members, who have been trained in the use and scoring of the tool. We have trained all the various professionals working at the CHEO IBD Centre (MDs, Nurses, Social Worker and Dieticians). The training involved meeting with the individuals to provide an overview of communimetric measurement theory and the current deficits in providing healthcare for children with chronic diseases under specialist care. In addition, the various domains, variables and scoring system were reviewed. Working vignettes are used initially in a group setting for learner feedback and discussion with the lead psychologist. Following the group session, each person received a vignette to review and score on their own. Scores were submitted to the lead for review. If there were discrepancies, individuals meet with the lead to review and be administered another vignette. Total time for training was approximately 6 hours.

Our current work-flow is that following diagnosis, patients and parents will meet with the team's social worker who will conduct a psychosocial screening interview and then complete the pIBD-INTERMED tool. The pIBD-INTERMED takes about 60 minutes to administer and document in our EPIC™ build but may take longer depending on the complexity of an individual patient. The completed pIBD-INTERMED for each new patient is

presented and discussed at the IBD team rounds and takes about 20 minutes depending on complexity. Input from other team members (e.g. MDs can input their expertise biological domains that the SW would not have expertise in) can be incorporated into a 'consensus' pIBD-INTERMED ratings for a given patient. Based on this initial pIBD-INTERMED review, patients identified as having significant psychosocial needs will be flagged by the team, and a plan and goals for each need will be formulated. The electronic version of the tool has been formatted so that significant needs are highlighted in red with space provided under each pIBD-INTERMED item to insert qualitative information and document the plan developed to address the need. Cases flagged as complex can be reviewed at subsequent rounds, to ensure progress towards addressing the need. Less complex, low risk patients will have their pIBD-INTERMED reviewed at scheduled intervals to track any changes in their psychosocial profiles of needs. The EPIC™ build for the pIBD-INTERMED allows for identification of the consensus pIBD-INTERMED. We have any IBD team member, who has been trained and certified on the pIBD-INTERMED, to update the tool when new patient information or concerns are identified. The EPIC™ build allows for the knowing the person updating the pIBD-INTERMED and time of update are available for all team members. We expect the data from the pIBD-INTERMED could also be used to inform on a number of quality improvement initiatives of a clinic. Key to the implementation of a communimetric measure is addressing its utility validity: its ease of use, relevance to the work goals, and transparency both to users and patients.