PEDIATRIC-INTERMED© COMPLEXITY ASSESSMENT GRID MANUAL for Inflammatory Bowel Disease (pIBD-INTERMED)

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Introduction to the INTERMED-method

Chronic illness affects an estimated 10-20% of children and adolescents[1]. Children living with a chronic illness face ongoing challenges to their capacity to negotiate and obtain normative developmental milestones and maintain successful adaptive functioning. The ongoing physical symptoms and associated treatment requirements faced by these children place them at heightened risk for the development of mental health problems. Children and adolescents with physical illness have been found to be at twice or greater the risk of developing psychiatric and behavior disorders than their healthy counterparts [2 3 4 5].

Chronic illness not only impacts directly on the individual child/youth, but also his/her family system, including parents, siblings and significant others. The stress of parenting a child with a chronic illness includes uncertainty about the child's health outcomes, daily hassles related to ensuring compliance with management regimes, and social, role and financial strains [6 7]. Furthermore, parents often report that it is difficult to navigate the complex system of care, resulting in mis-utilization of services [8 9 10].

Failure to address psychosocial issues and co-morbidities (both individual and family) places children/youth with chronic physical symptoms at greater risk for poor treatment adherence, increased utilization of health care services, and increased psychiatric comorbidity [11 12 13 14 15]. As such, improvement in identifying psychosocial complications to chronic medical conditions in children and adolescents offers significant potential for improving health and developmental outcomes in these vulnerable populations along with the potential for improved cost-effectiveness.

The need to address psychosocial issues in the care of children and adolescents with chronic illness is widely acknowledged by most health care professionals guided by Engel's biopsychosocial model [16 17]. Despite this acknowledgement, to date, the systematic assessment of biological, psychological, and social dimensions of children's chronic illness has not been consistently integrated into their clinical management. Although several attempts have been made to operationalize the bio-psycho-social model of disease and to develop related assessment instruments, efficient methods for use in adult and pediatric clinical care are still lacking. The issue of how to approach bio-psycho-social morbidity thus remains an important challenge. As such, the psychosocial and mental health needs of children with chronic health issues are often undetected and underserved within both primary and tertiary health care [2 18 19].

The INTERMED-method aims to operationalize the biopsychosocial model of disease and to fill the gap between general medical and mental health care. Its purpose is to improve healthcare providers' awareness of patients integrated health risks and needs through its systematic assessment and representation in

the Complexity Assessment Grid in order to counteract these risks and deliver preventative and thereby cost-effective care.

The Pediatric Inflammatory Bowel Disease-INTERMED (pIBD-INTERMED) is an interview-based instrument that provides the health care team with a rapid, yet comprehensive assessment of the child/youth presenting for medical care that can be used to identify patients and family needs and to support individual case planning and management. The tool assesses case and care complexity in children and adolescents. Complexity is defined as the interference in standard care by biological, psychological, social, caregiver/family, and health systems factors, which require a shift from standard care to individualized care in order for a child/youth's outcomes to improve. The tool can be used to monitor health care needs and outcomes for children/youth with complex physical and mental health conditions, to support program planning, for outcomes management, and research activities. In the following chapters the core-characteristics of the INTERMED-method are described.

The Structure of the PEDIATRIC INFLAMMATORY BOWEL DISEASE-INTERMED - Complexity Assessment Grid

The primary goal of the pIBD-INTERMED method is to improve the flow of information and the communication with complex patients and among their health care providers. Basic to this goal is the integrated organization of the information in a grid and its measurement/scoring of items using communimetric principles[20]. The following is a description of the Complexity Assessment Grid.

- The grid has horizontal rows and vertical columns

- The "Rows" are titled to describe 5 "Domains"
    - BIOLOGICAL: Items in this domain address how the children/youth's illness duration and severity, diagnostic complexity, and the impact of physical illness factor on functioning, create barriers to the child/youth's optimal health management and outcomes.
    - PSYCHOLOGICAL: Items in this domain capture children/youth's ability to cope and adapt to their environment, and the degree to which mental health factors create barriers to the children/youth's optimal health and management outcomes.
    - SOCIAL: This domain addresses children/youth's social connectedness and supports, and how the children/youth's functioning in their community, school setting, and with peers create barriers to their optimal health management and outcomes.
      FAMILY/CAREGIVER : This domain addresses the quality of the children/youth's home life and relationships with their primary caregivers, as well as how the capacity of caregivers to respond to their children/youth's healthcare situation creates barriers to optimal health management and outcomes.
    - HEALTH SYSTEM: This domain addresses patient and families' experiences in trying to obtain health services and their ability to navigate an increasingly complicated delivery environment as they do so. It considers how factors such as access to appropriate care, treatment experience, availability and ease of access to services, coordination of care, and health system impediments may create barriers to children/youth's optimal health management and outcomes
- The "Columns" divide the Domains into time segments because the PediIBD-INTERMED -Complexity Assessment Grid adopts a lifespan perspective in the assessment of health care needs and complexity. The instrument was developed with the understanding that a determination of the child/youth's future needs and vulnerabilities will be impacted by their historical experiences and developmental backgrounds as well as current adjustment to the health challenges they face.

- HISTORICAL/DEVELOPMENTAL: This time frame refers to a substantial portion of the child/youth's prior life. The one exception is the cell labeled **"Access to Care and Appropriate Treatment"**, which relates to events occurring during the last 6 months.
- CURRENT: Variables in this time frame refer to the 30-day period prior to the date the Pediatric Intermed-CAG assessment is completed.
- VULNERABILITY/ANTICIPATED NEEDS: These variables refer to the 3 to 6 month period after the date the PediIBD-INTERMED - CAG is completed, based on an estimate of the child/youth's clinical state when given standard medical care.

- Each of these time periods is further divided into cells which contain "Variables" describing "Health Risks and Needs."
  - Chronicity
  - Diagnostic Dilemma
  - Symptom Severity
  - Diagnostic/Therapeutic Challenge
  - Therapeutic Complexity
  - Complications and Life Threat
  - Barriers to Coping
  - Resiliency
  - Mental Health History
  - Cognitive/Intellectual Development
  - Adverse Developmental Events
  - Resistance to Treatment
  - Mental Health Symptoms
  - Cognitive/Functional Impairment
  - Mental Health/Cognitive Threat
  - School Functioning
  - Social Functioning
  - Child/Youth Supports
  - School Attendance
  - Educational Needs
  - Community Participation
  - Social System Vulnerability
  - Family Relationships
  - Caregiver (Parent) Health and Function
  - Residential Stability
  - Caregiver/Family Support
  - Family Stress
  - Parenting Skills
  - Family/Caregiver System Vulnerability
  - Access to Health Care
  - Treatment Experience
  - Organization of Care
  - Coordination of Care

    - Health System Impediments
- Each “Variable” has 4 corresponding action levels used for scoring

Scoring of the Variables

Each item on the pIBD-INTERMED is rated using a 4-point Likert-type scale. There are four clinical anchor points for each item on the scale. Each anchor point is designed to reflect the level of need or actions to be taken by the health care team in the management of the patient or family.

Whenever a variable is rated, in addition to the clinical anchor points as defined, one should keep the following question in mind: “Will the situation recorded for this “Variable” interfere with the clinical outcomes if standard medical care were given?” Another important consideration, particularly when there is a debate between two anchor point levels for an individual item, (e.g., scoring a ‘1’ vs. a ‘2’, or a ‘2’ vs. ‘3’) is to consider the immediacy of need for action on behalf of the child/youth, The time frame for action can inform the final decision

The specific clinical anchor points were defined to facilitate reliable scoring. The scores on the variables can be summed up to a total score ranging from 0 to 102 and reflecting the complexity of the case.

0- No vulnerability or need to act.

1- Mild vulnerability indicates a need for monitoring or prevention (i.e., flag for later review to see if any circumstances change or initiate a preventative action).

2- Moderate vulnerability and need for action or development of an intervention plan.

3- Severe vulnerability and need for immediate action or intensive action/plans.

?- Unknown. This rating should be used where there is no information available to rate the item. It should be considered a flag for a need to find the information to provide a complete picture of the biopsychosocial profile of the child/youth.

The Grid

pIBD-INTERMED – Complexity Assessment Grid
Summary Form

Name _____ **Age** _____ **Gender** _____

Domain	Developmental/Historical Antecedents		Current State		Anticipated Needs	
Total Score =	*Consideration*	*Score*	*Consideration*	*Score*	*Consideration*	*Score*
Biological	Chronicity (HB1)		Symptom Severity (CB1)		Complications and Life Threat (VB1)	
			Diagnostic/Therapeutic Challenge (CB2)			
	Diagnostic Dilemma (HB2)		Therapeutic Complexity (CB3)			
Psychological	Barriers to Coping (HP1)		Resistance to Treatment (CP1)		Mental Health/ Cognitive Threat (VP1)	
	Resiliency (HP2)					
	Mental Health (HP3)		Mental Health Symptoms (CP2)			
	Cognitive/Intellectual Development (HP4)		Cognitive/Functional Impairment (CP3)			
	Adverse Developmental Events (HP5)					
Social	School Functioning (HS1)		Child/Youth Supports (CS1)		Social System Vulnerability (VS1)	
			School Attendance (CS2)			
	Social Functioning (HS2)		Educational Needs (CS3)			
			Community Participation (CS4)			
Caregiver/Family	Family Relationships (HF1)		Residential Stability (CF1)		Family/Caregiver System Vulnerability (VF1)	
			Caregiver/Family Support (CF2)			
	Caregiver (Parent) Health & Function (HF2)		Family Stress (CF3)			
			Parenting Skills (CF4)			
Health System	Access to Health Care (HHS1)		Organization of Care (CHS1)		Health System Impediments (VHS1)	
	Treatment Experience (HHS2)		Coordination of Care (CHS2)			

Description of the Variables and their Anchor Points

BIOLOGICAL DOMAIN

Developmental Antecedents/History:

HB1	**Chronicity:** *This item describes the extent to which child/youth has had physical health issues prior to current presentation. Has the patient suffered any periods of physical complaints or diseases? Did these complaints or diseases disappear, or were diseases diagnosed requiring chronic care?*
?	Unknown
0	Less than 3 months of physical symptoms/dysfunction; acute health condition.
1	More than 3 months of physical symptoms/dysfunction or several periods of less than 3 months.
2	A chronic condition.
3	Several chronic conditions.

HB2	**Diagnostic Dilemma:** *This item concerns whether or not the child/youth has been seeking care for physical complaints across a substantial portion of his/her life and whether or not these complaints have been resolved.*
?	Unknown
0	No period of diagnostic complexity.
1	Diagnosis was clarified quickly.
2	Diagnostic dilemma solved but only with considerable diagnostic effort.
3	Diagnostic dilemma not solved despite considerable diagnostic effort.

Current State

CB1	**Symptom Severity**: *This item describes severity or acuity of physical symptoms related to the reason for current illness presentation. In case of an acute illness most often these symptoms will disappear or diminish, while in an existing chronic disease these symptoms might disappear, remain or increase.*
?	Unknown
0	No physical symptoms or symptoms resolve with treatment.
1	Mild symptoms, which do not interfere with current functioning.
2	Moderate symptoms, which interfere with current functioning.
3	Severe symptoms leading to inability to perform most functional activities.

CB2	**<u>Diagnostic/Therapeutic Challenge</u>:** *This items refers to the presence of physical symptoms that result in diagnostic questions or therapeutic challenges. Patients may not have physical symptoms that result in diagnostic questions and the treatment for their diseases might be clear and unequivocal. However, it might be that physical complaints are related to complex physical disorder (rare or systemic disease) that requires extensive diagnostic evaluation or more complex treatment regimens or to a psychiatric disorder and/or psychosocial stressors.*
?	Unknown
0	The child and youth's medical diagnoses are clear and there is no doubt as to the correct diagnoses; Symptom presentation is clear with clear treatments.
1	Although there is some confidence in the accuracy of child/youth's diagnoses, there also exists sufficient complexity in the child/youth's symptoms presentation to raise concerns that the diagnoses may not be accurate. Clear differential diagnoses and/or diagnosis expected with clear treatments.
2	There is substantial concern about the accuracy of the child/youth's medical diagnoses due to the complexity of the symptom presentation. Difficult to diagnose and treat, physical cause/origin and treatment expected
3	The child/youth's medical condition is difficult to accurately diagnose and treat. Other issues than physical causes interfering with the diagnostic and therapeutic process.

CB3	**<u>Therapeutic Complexity:</u>** *This item describes whether a child/youth's treatment for their disease is clear, unequivocal, or non-invasive or requires more complex regimens which are perceived by the patient and/or caregivers/family to be time-consuming, demanding and aversive.*
?	Unknown
0	Uncomplicated treatment with no unpleasant side effects or risks.
1	Uncomplicated treatment with multiple components and/or minor but tolerable side effects.
2	Complex treatment and/or multiple components with some risks and toxic side effects.
3	Complex, demanding and/or multiple component treatment (e.g., daily interventions, demanding, invasive) with potentially serious risks and toxic side effects.

Anticipated Needs/Vulnerabilities

VB1	**Complications and Life Threat:** *This item describes the expected functional impact of the present medical condition based on the child/youth's condition and experience with similar cases.*
?	Unknown
0	Little or no risk of premature physical complications or limitations in activities of daily living.
1	Mild risk of premature physical complications or limitations in activities of daily living.
2	Moderate risk of premature physical complications or permanent and/or substantial limitations of activities of daily living.
3	Severe risk of physical complications associated with serious permanent functional deficits and/or dying.

PSYCHOLOGICAL DOMAIN

Developmental Antecedents/History

HP1	**Barriers to Coping:** *This item refers to risks associated with child/youth's coping capacities that may interfere with their adaptation to life stresses, including their medical and mental health circumstances.*
?	Unknown
0	Able to adapt well to life stresses and health circumstances. Child/youth is flexible and able to positively and easily resolve feelings/emotions related to changes in his/her life and daily routines.
1	Reduced coping skills. Child/youth may have mild difficulties adapting to life stresses, changes, and health circumstances, as evidenced by minor alterations from their typical behaviors/temperament (e.g., more irritable, dependent, non-compliant). No long-term difficulties.
2	Impaired coping skills. Child/youth has significant difficulty adjusting to stresses and changes in his/her life, and in resolving related feelings and emotions. This may be evidenced by significant alterations from their typical behaviors/temperament (e.g., frequent conflicts with parents/teachers, substance abuse but without serious impact on medical condition, withdrawal from others). Potential long-term difficulties.
3	No evidence of any coping skills. Inability to adapt to life stresses, changes, or to deal with unresolved feelings/emotions. Child/youth may engage in destructive "high risk" behaviors, such as substance dependence, self-inflicted harm, or illegal behavior. Behavior places child/youth at immediate risk.

HP2	**Resiliency:** *This item refers to the child or youth's ability to identify and use internal strengths in managing their lives.*
?	Unknown
0	Child/youth is able to identify and use internal strengths for healthy development and problem solving.
1	Child/youth is able to identify most of his/her internal strengths and is able to partially use them to support healthy development and/or problem solving.
2	Child/youth who is able to identify some internal strengths, but is not able to able to utilize them effectively in support of their healthy development or problem solving.
3	Child/youth fails to identify his/her internal strengths and is therefore unable to utilize them in support of their healthy development or problem solving.

HP3	**Mental Health** *This item describes the child/youth's history of diagnosable emotional or behavioral disorders prior to the current medical condition.*
?	Unknown
0	No history of mental health problems or conditions. (e.g., depression, anxiety, traumatic response, psychosis, oppositional or defiant behavior with authority, hyperactivity/inattention, delinquency, high risk behaviors).
1	Mental health problems or conditions existed, but have been resolved or are without clear effects on daily function.
2	Mental health conditions with clear effects on daily function, needing mental health intervention (therapy, medication, day treatment, partial hospitalization program etc.).
3	Mental health problems, which have disabled the child/youth's functioning in all areas of life, needing intensive mental health interventions (psychiatric admission).

HP4	**Cognitive/Intellectual Development**: *This item describes the child/youth's level of cognitive functioning and development at the start of his/her present illness.*
?	Unknown
0	Child/youth has no developmental problems and his/her intellectual functioning appears to be in the normal range. There is no reason to believe that the child/youth has any problems with intellectual functioning.
1	Low IQ (IQ between 70 and 85) or learning disability or mild intellectual or developmental delay.
2	Mild to moderate intellectual disability (IQ between 50 and 69) or significant developmental delay.
3	Severe or profound intellectual disability (IQ less than 50) or pervasive developmental delay.

HP5	**Adverse Developmental Events:** *This item describes all traumatic events that the child/youth may have experienced in his/her life prior to the current symptom presentation, which affected their physical and/or mental health.*
?	Unknown
0	No identified developmental traumas or injuries, e.g. physical or sexual abuse, meningitis, lead exposure, etc.
1	Traumatic prior experiences or injuries with no apparent or stated impact on child/youth.
2	Traumatic prior experiences or injuries with potential relation to impairment in child/youth.
3	Traumatic prior experiences with apparent and significant direct relation to impairment in child/youth.

Current State

CP1	**Resistance to Treatment:** *This item evaluates child/youth's and parents' (caregivers) capacity to comply with treatment recommendations, including drugs, health behavior and life-style.*
?	Unknown
0	Parents (caregivers) and/or child/youth are interested in receiving treatment and cooperate actively
1	Some parent and/or child/youth ambivalence, though willing to cooperate with the treatment
2	Considerable parent and/or child/youth resistance with non-adherence/compliance, hostility or indifference towards health care professionals and/or treatments
3	Active parent and/or child/youth resistance to important medical care.

CP2	**Mental Health Symptoms:** *This item refers strictly to emotional and behavioral concerns that are anticipated to impact the child/youth's physical well-being or health care management and should be rated in reference to the past 30 days. A history of mental health concerns prior to current illness is not rated here as it is assessed elsewhere.*
?	Unknown
0	No mental health symptoms
1	Mild mental health symptoms, such as sadness, anxiety, withdrawal, increased dependency, risky behaviours, irritability, which do not interfere with current functioning (including response to healthcare).
2	Moderate mental health symptoms such as withdrawal, death preoccupation, significant anxiety, defiance, or cognitive impairment, which interfere with current functioning.
3	Severe mental health symptoms and/or behavioral/emotional disturbances, such as violence, self-inflicted harm or acute risk of harm to self or other, criminal behaviour, psychosis or mania

CP3	**Cognitive/Functional Impairment:** *This item refers to the extent to which a child/youth's medical condition affects their CNS function and leads to cognitive, emotional or behavioral limitations.*
?	Unknown
0	Child/youth's medical condition is not suspected to affect CNS function or to be associated with cognitive/emotional/behavioral limitations; or child has been healthy.
1	Child/youth's medical condition is known/suspected to affect CNS function and to be associated with cognitive/emotional/behavioral limitations, but at this time there is no impact on child's overall functioning.
2	Child/youth's medical condition is known/suspected to affect CNS function and to be associated with cognitive/emotional/behavioral limitations, and limitations have impacted on child's functioning in one area of his/her life.
3	Child/youth's medical condition is known/suspected to affect CNS function and to be associated with cognitive/emotional/behavioral limitations, and limitations have impacted on child's functioning in more than one area of his/her life.

Anticipated Needs/Vulnerabilities

VP1	**Mental Health/Cognitive Threat:** *With the data collected in the "History" and "Current State" domains, one determines child/youth's anticipated mental health needs, including his/her capacity to collaborate with treatment.*
?	Unknown
0	No mental health threat or risk of cognitive limitations.
1	Risk of mild worsening mental health or cognitive symptoms, such as home or school conflict, anxiety, feel blue, substance abuse or cognitive deterioration, with limited impact on function; mild risk of treatment resistance (ambivalence).
2	Moderate risk of mental health disorder or impaired cognitive functioning requiring additional mental health care: moderate risk of treatment resistance.
3	Severe risk of psychiatric disorder or cognitive impairment requiring immediate attention (e.g., crisis/urgent assessment, admission for safety, neuropsychological assessment). Mental health needs significantly compromise physical well-being and health care management (risk of treatment refusal for serious disorder).

SOCIAL DOMAIN

Developmental Antecedents/History

HS1	**School Functioning:** *This item captures 3 aspects of the child/youth's past school functioning; the degree to which the child/youth attended school; the child/youth's behavior at school; the extent to which the child/youth experienced achievement problems in school, such as failing subjects.*
?	Unknown
0	Performing well in school with good achievement, attendance and behavior.
1	Performing adequately in school although some achievement, attendance and behavior problems (e.g., missed classes, pranks.)
2	Experiencing moderate problems with school achievement, attendance and/or behavior (e.g., school disciplinary action, academic probation.)
3	Experiencing severe problems with school achievement, attendance, and/or behavior (e.g., home bound education, school suspension, violence, illegal activities at school, academic failure, school dropout.)

HS2	**Social Functioning:** *This item describes the child/youth's interactions with others and his/her ability to form and maintain healthy, and age appropriate relationships with both adults and peers.*
?	Unknown
0	Child/youth has demonstrated healthy social development and relationships in the past (e.g., good peer relationships, friendships, age-appropriate independence from caregiver(s).)
1	Child/youth has demonstrated some minor problems with regard to his/her social development and relationships (e.g. few close friends, limited integration into peer group).
2	Child/youth has demonstrated some moderate problems with his/her social development and relationships (e.g., difficulties in maintaining same age peer relationships, no friends, teased or bullied by peers).
3	Child/youth has demonstrated severe disruptions in his/her social development and relationships (e.g., complete social isolation, little or no association with peers, disruptive peer group activity).

Current State

CS1	**Child/Youth Support:** *This item rates the extent to which the child/youth can rely on others such as family/caregiver, friends, teachers etc. for support in successfully completing their activities and fulfilling their roles.*
?	Unknown
0	Supervision and/or assistance readily available from family/caregiver, friends/peers, teachers, and/or community social networks (e.g., spiritual religious groups) at all times.
1	Supervision and/or assistance generally available from family/caregiver, friends/peers, teachers, and/or community social networks; but with possible delays.
2	Limited supervision and/or assistance generally available from family/caregiver, friends/peers, teachers, and/or community social networks.
3	No effective supervision and/or assistance available from family/caregiver, friends/peers, teachers and/or community social networks at any time.

CS2	**School Attendance:** *This item assesses the degree to which the child/youth currently attends school by looking at the pattern of coming to and staying at school for each required day.*
?	Unknown
0	Attending school regularly, achieving and participating well.
1	Child/youth has some problems attending school, but generally goes to school. Average of one day of school missed/week.
2	Child/youth is having problems attending school. Average of two or more days of school missed/week.
3	Truant or school refusal and/or non-attendance.

CS3	**Educational Needs:** *This item assesses both the academic needs of the child and how well they are being addressed by the educational institution with which the child is affiliated.*
?	Unknown
0	No academic concerns.
1	Academic concerns, which are being addressed adequately.
2	Academic concerns, which are only being partially addressed.
3	Academic concerns, which are not currently being addressed.

CS4	**Community Participation:** *This item reflects the child/youth's connection to and involvement in his/her community. Kids with a sense of belonging and a stake in their community react better to their illness than those that don't.*
?	Unknown
0	Child/youth is well integrated into community. He/she participates in age-appropriate community organizations/programs (e.g., social/leisure/sports/spiritual/religious activities.)
1	Child/youth is somewhat involved with community. Participates in some, but limited community/extra-curricular activities.
2	Child/youth has an identified community, but does not participate in community activities/extra-curricular programs.
3	Child/youth has not identified a community in which he/she is a member or participates in any way.

Anticipated Needs/Vulnerabilities

VS1	**Social System Vulnerability:** *With the data collected in the "History" and "Current State" domains, one determines child/youth's anticipated social needs and how they may impact on the child's response to health care and optimal functioning.*
?	Unknown
0	Adequate social, school and community support. No need for intervention.
1	Risk of need for additional social, school or community supports or interventions.
2	Risk of need for temporary or permanent alterations or intervention in the social, school, or community environment in the foreseeable future.
3	Immediate need for temporary or permanent alteration or intervention with regard to the social, school, or community environment.

CAREGIVER/FAMILY DOMAIN

Developmental Antecedents/History

HF1	**Family Relationships:** *This item rates how the child's family system is functioning. Diminished functioning includes, but is not limited to, parent-child conflict, problems with siblings, and marital difficulties.*
?	Unknown
0	Stable nurturing home, good relationships with family members.
1	Mild family problems (e.g., parent-child conflict, sibling conflict, marital discord).
2	Significant level of family problems/disruption, including neglect, difficult separation/divorce, alcohol abuse, hostile caregiver, siblings with significant mental health, developmental or justice problems.
3	Severe family problems (e.g., significant abuse, hostile child custody battles, addiction issues, parental criminality.)

HF2	**Caregiver (Parent) Health & Function:** *This item attempts to identify any medical, physical, mental health, or substance use related problems that the caregiver(s) may be experiencing that limit or prevent their ability to provide care for the child.*
?	Unknown
0	All caregivers are healthy.
1	Physical and/or mental health issues, including poor coping skills, and/or permanent disability, present in one or more caregiver, which do not impact parenting.
2	Physical and/or mental health conditions, including disrupted coping resources, and/or permanent disability, present in one or more caregiver that interfere with parenting.
3	Physical and/or mental health conditions, including disrupted coping styles, and/or permanent disability present in one or more caregiver that prevent effective parenting and/or create a dangerous situation for child/youth.

Current State

CF1	**Residential Stability:** *This item takes into account the family's current living environment and how that is or is not having an adverse effect on the child/youth. This includes housing stability, adequate nutrition, caregiver employment etc.*
?	Unknown
0	Stable housing and financial support for personal growth needs.
1	Mild stress with multiple moves, school changes, financial issues.
2	Moderate stress with unstable housing and/or living situation support (e.g., living in a shelter, poor nutrition, change of current living situation is required, unemployment.)
3	Severe stress with no current satisfactory housing (e.g., homelessness, transient housing, child/youth malnourished or dangerous environment; immediate change is necessary.)

CF2	**Caregiver/Family Support:** *This item rates the extent to which the caregiver(s) can rely on others such as family, friends, and/or acquaintances for support in completing their activities and fulfilling their roles.*
?	Unknown
0	Assistance readily available from family, friends, and/or acquaintances, such as work colleagues/employer, at all times
1	Assistance generally available from family, friends, and/or acquaintances, such as work colleagues/employer, but with possible delays.
2	Limited assistance available from family, friends and/or acquaintances, such as work colleagues/employer.
3	No assistance available from family, friends and/or acquaintances, such as work colleagues/employer at any time.

CF3	**Family Stress:** *This item describes the extent to which the child's medical condition is putting a strain on healthy family functioning and if the family requires external support in managing the stress caused by the situation.*
?	Unknown
0	Child/youth's medical condition is not adding any stress to the family.
1	Child/youth's medical condition is a mild stressor on the family.
2	Child/youth's medical condition is a stressor on the family and is interfering with healthy family functioning. Family will benefit from support.
3	Child/youth's medical condition is a severe stressor on the family and is resulting in problems in multiple family domains. Family requires immediate support.

CF4	**Parenting Skills:** *This item refers to the skills required to properly monitor, supervise and discipline the child/youth, to the extent necessitated by their health condition and associated care needs.*
?	Unknown
0	Parents (caregivers) have good monitoring and discipline skills, and have no difficulty supervising child/youth's medical care.
1	Parents/caregivers provide generally adequate monitoring/discipline, but they may occasionally encounter difficulty supervising child/youth's medical care.
2	Parent/caregivers report difficulties monitoring and/or disciplining the child/youth, and have problems supervising child/youth's medical care.
3	Parents/caregivers are unable to discipline and monitor the child/youth and the child/youth is at medical risk due to the absence of supervision of his/her medical care.

Anticipated Needs/Vulnerabilities

VF1	**Caregiver/Family System Vulnerability :** *With the data collected in the "History" and "Current State" domains, one determines caregiver/family, needs, including the anticipated impact of these on the caregiver's capacity to collaborate in their child's treatment and support his/her health care needs.*
?	Unknown
0	No risk from living situation, adequate caregiver health and function.
1	Risk of need for additional living situation stability and/or family/caregiver intervention.
2	Risk of need for temporary or permanent alteration in home, and or family/caregiver environment in the foreseeable future. Family/caregiver will require intervention in the foreseeable future.
3	Immediate need for temporary or permanent alteration in home and/or family/caregiver environment soon (e.g., referral to child protective services. Family/caregivers require immediate support.)

HEALTH SYSTEM DOMAIN

Developmental Antecedents/History

HHS1	**Access to Health Care**: *This item refers to anything in the past that served as an obstacle, hindering the family's access to healthcare. This can include, but is not limited to financial/insurance problems, geographic location, family issues, and language or cultural barriers.*
?	Unknown
0	Adequate access to care with insurance coverage stability.
1	Some limitations in access to heath care due to financial/insurance problems, geographic reasons, family issues, language or cultural barriers.
2	Difficulties in accessing care due to financial/insurance problems, geographic reasons, family issues, language or cultural barriers.
3	No adequate access to care due to financial/insurance problems, geographic reasons, family issues, language or cultural barriers.

HHS2	**Treatment Experience:** *An inconsistent patient-provider relationship or prior ones without trust and positive regard predicts future non-adherence and non-treatment for existing health problems. This item captures the nature of this relationship and describes the degree to which the child/youth and family's prior health care experiences have been positive both in terms of good outcomes and relationships with health care providers.*
?	Unknown
0	No child/youth or parent/caregiver problems with healthcare professionals.
1	Negative child/youth or parent/caregiver experience with health care professionals.
2	Child/youth or parent/caregiver dissatisfaction or distrust of doctors; multiple providers for the same health problem; trouble keeping consistent and/or preferred provider(s).
3	Repeated major child/youth or parent/caregiver conflicts with or distrust of doctors, frequent ER visits of involuntary admissions

Current

CHS1	**Organization of Care:** *This item describes the nature of the health care services that that the child and youth is receiving.*
?	Unknown
0	All health care is provided by a single primary care health professional (e.g., family doctor in the community)
1	Child's specialized health care is generally provided by a coordinated team of medical/health professionals who all work for the same organization (e.g., care provided by a GI team and mental health professionals in one hospital).
2	Child's specialized health care is provided by multiple health professionals who work for more than one organization (e.g., GI health care team in a hospital and mental health services at school, in the community or at another institution).
3	Hospitalization or discharge/transfer from inpatient hospitalization and return to care provided by multiple health professionals who work for more than one organization (Level 2).

CHS2	**Coordination of Care:** *This item describes the extent to which different providers working with the child/youth are in contact with each other. If providers don't know what each other are doing, duplication and/or missed services can occur which increases chances for conflicting treatments and/or drug interactions. This includes both traditional and alternative treatment approaches.*
?	Unknown
0	Complete practitioner communication with good coordination and transition of care.
1	Limited practitioner communication and coordination of care; primary care physician coordinates medical and mental health services.
2	Poor communication and coordination of care among practitioners; no routine primary care physician; difficulty in transitioning to age appropriate care.
3	No communication and coordination of care among practitioners; primary ER use to meet non-emergent health needs; systemic barriers to age appropriate care transition.

Anticipated Needs/Vulnerabilities

VHS1	**Health System Impediments*:*** *This item anticipates the problems that the child/youth may encounter in receiving the services he/she requires. These include, but are not limited to, insurance restrictions, distant services access, and inconsistent or limited provider communication.*
?	Unknown
0	No risk of impediments to coordinated physical and mental health care
1	Mild risk of impediments to care (e.g., insurance restrictions, distant service assess, limited provider communication and/or care coordination/transition.)
2	Moderate risk of impediments to care (e.g., potential insurance loss, inconsistent practitioners, communication barriers, poor care coordination/transition.)
3	Severe risk of impediments to care (e.g., little or no insurance, resistance to communication and or/disruptive work processes that lead to poor coordination/transition among providers.)

GLOSSARY FOR THE PEDIATRIC INFLAMMATORY BOWEL DISEASE-INTERMED

Action Levels Corresponding to Ratings

0 – No vulnerability or need to act

1 – Mild vulnerability, indicates a need for monitoring or prevention This level of rating indicates that you need to flag this item for later review to determine if any circumstances change or think about putting in place some preventive actions to make sure things do not get worse. For example, a child experiences occasional headache symptoms which are not impairing their functioning at present, would not necessarily require active intervention at this time, but would need to be monitored closely to assure that that the severity of their symptoms does not increase and begin to impact on their functioning.

2 – Moderate vulnerability of need for action or development of an intervention plan – This rating implies that something must be done to address the situation. The item in question is sufficiently problematic in that it is interfering in the child or family's life, or their response to health care in a notable way.

3 – Severe vulnerability and need for immediate action or intensive action/plans – This level rating indicates the need for immediate or intensive action. Dangerous or disabling levels of needs are rated with this level. A child/youth that is not attending school at all, or is acutely suicidal would be rated with a '3' on the relevant item. Similarly a youth who is completely non-compliant with essential life-supporting medical care, such as a Type 1 Diabetic who is not taking their insulin, would merit a rating of "3" on the relevant items.

? – Unknown – This rating should be used when there is no information available to rate the item. It should be considered a flag for a need to find the information to provide a complete picture of the biopsychosocial profile of the child/youth.

Time Frames for the Items

Historical/Developmental

Risks related to the past occurrence of the item in question are documented here. All "historical/developmental" variables refer to a substantial portion of the child/youth's prior life, up to, but not including the current presentation. The one exception is the cell labeled "**Access to Care and Appropriate Treatment**", which relates to events occurring during the last 6 months.

Current

All "current" variables refer to the 30 day period prior to the date the PIM-CAG assessment is completed.

Anticipated Needs/Vulnerabilities

These items refer to the 3 to 6 month period after the completion of the PIM – CAG. Items are rated based on an estimate of the natural history of the child/youth's clinical state assuming they are provided with standard health/medical care (i.e., no specific interventions put in place to address their needs). For example, a child who has a longstanding history of non-compliance with medical treatment, poor coping skills and some mild intellectual delay, would likely be given a rating of "2" on the "Mental Health/Cognitive Threat" vulnerability item within the Psychological Domain Vulnerability Item.

BIOLOGICAL DOMAIN

HISTORICAL/DEVELOPMENTAL

These items document risks related to the child/youth's physical health history since birth. They include risks related to duration of episodes of physical complaints/symptoms, existing chronic diseases and their interaction, and the manner in which these complaints and diseases were diagnosed.

Chronicity (HB1)

This item describes the existence of physical complaints or diseases present prior to the current 30 day period. The ratings are based on the following information: Has the child/youth suffered any periods of physical complaints or diseases since birth? Did these complaints or diseases disappear, or were diseases diagnosed requiring chronic care, such as inflammatory bowel diseases, diabetes, and cystic fibrosis?

Diagnostic Dilemma (HB2)

This item addresses whether or not the child/youth and his/her caregivers have been seeking care for physical complaints during the child/youth's life time, and whether or not these complaints have been resolved. Physical complaints may lead to a diagnosis of a physical illness/disease. However, the majority of physical complaints that children/youth present with gradually disappear and cannot be identified by doctors as resulting from a specific illness/disease (e.g., recurrent abdominal pain). They can be the result of several factors. Many children/youth have waxing and waning physical complaints without any sign of a disease. Children may also have physical complaints that cannot be linked to a disease as the disease has not had enough illness expression at the moment of the investigation, for example in illnesses/diseases which develop very slowly and with diverse symptom patterns. (e.g., GI symptoms in the year preceding the formal diagnosis of Crohn's disease, rheumatoid conditions such as systemic lupus erythematosus **(**SLE). In addition, physical complaints can be part of a symptom pattern of a psychiatric disorder. For example, children or youth with a depressive or anxiety disorder may present with multiple physical complaints, such as fatigue, weight loss, low energy, sleep disturbances and pain (e.g., headaches, recurrent abdominal pain). Often, these underlying mental health concerns go undetected or undiagnosed.

CURRENT

These items document needs and risks related to the child/youth's current physical complaints/symptoms, the related impairment, and their impact on activities of daily living. Items also address risks and needs related to diagnostic questions and the complexity of the treatment regimen that the patient must undergo.

Symptom Severity (CB1)

The severity of children and youth's physical complaints is an important determinant of their capacity to function in their daily lives (e.g., school, socially, extra-curricular activities, chores). In the case of an acute illness, most often these symptoms will disappear or diminish; while in an existing chronic disease these symptoms might disappear, remain or increase. Functioning refers to the child/youth's ability to continue to participate in their daily activities including attending school, completing homework and chores, social, extracurricular and physical activities.

Diagnostic/Therapeutic Challenge (CB2)

This item refers to diagnostic/therapeutic issues associated with the current presenting physical symptoms. Patients may have physical symptoms that result in diagnostic questions. Treatment may also be rendered more complex and challenging when a youth's symptoms are linked to a mental health condition, but the youth and her caregivers remain convinced that other "medical causes" of the physical complaints need to be explored.

0 - The diagnosis/treatment of these symptoms will be very straightforward and obvious, not requiring any differential diagnostic evaluation.

1- Some differential diagnostic/treatment questions, but which can be easily investigated.

2- Physical complaints are likely related to a complex physical disorder (rare or systemic disease), but extensive diagnostic evaluation is required to clarify diagnosis/treatment.

3- Efforts to arrive at a diagnosis/effective treatment of the physical symptoms have been challenging. It is anticipated that psychosocial stresses or a psychiatric disorder may be contributing to the symptom presentation (e.g., conversion disorder, somatic symptom disorder, chronic pain condition).

Therapeutic Complexity (CB3)

This item addresses the complexity of the treatment that the child/youth must undergo for management of his/her disease or physical symptoms. In some cases, required treatment will be simple, clear and unequivocal. In other cases, physical symptoms will require complex treatment regimes, which are perceived by the patient and/or parents/family to be time-consuming, and aversive (significant side effects).

Anticipated Needs/Vulnerabilities

Complications and Life Threat (VB1)

Information collected during the interview is critical to scoring the items that fall within the "Historical/Developmental" and "Current State" columns. In contrast, rating of items falling with the "Vulnerability/Prognosis column are based on the health care provider's consideration and translation of how the historical/developmental and current biological risks identified contribute to the understanding of the needs and likely course of the patient's physical health situation in the next 3-6 months, assuming the delivery of standard health care, with no specific interventions to address these vulnerabilities.

PSYCHOLOGICAL DOMAIN

HISTORICAL/DEVELOPMENTAL

Historical/Developmental items in the psychological domain address the child/youth's ability to adapt to and cope with his/her environment and the presence of mental health dysfunction, including behavioral, emotional, and cognitive problems that may be barriers to health. Items in the psychological domain identify not only risks associated with formal mental health and substance use disorders , but also include developmental antecedents and events that may make the child/youth more vulnerable when faced with their current health issues.

Barriers to Coping (HP1)

Children and youth's style of coping has an important impact on the way that they experience their physical diseases and express their complaints, on their understanding of their physical health issues, as well as on the manner in which they experience and respond to health care professionals. This item captures the extent to which a patient is capable of facing stressors (such as physical health problems) in an adaptive way (such as through seeking help and support from others, use of distraction, active problem solving) vs. in maladaptive ways (e.g., through withdrawal, regression, increased dependency, behavioral acting out, substance use). Coping may be assessed by determining how the child/youth has responded to past stressors/changes in their lives. An important prerequisite for adaptive coping is the adequacy of cognitive processes. Children with restricted intellectual capacity, due to a developmental delay or acquired brain injury, are at greater risk of reacting to stressors in an aggressive and/or anxious manner, as they cannot grasp the impact and consequences of their health difficulties and related interventions. Similarly use of substances, such as alcohol, drugs and psychoactive substances, also reflect barriers to coping. Self-injurious behaviour and suicidal ideation are also important indicators of diminished coping capacity.

Resiliency (HP2)

This item addresses a meta-strength; the child's ability to (1) recognize his/her strengths and (2) to use these strengths to promote healthy development and to cope with their current medical circumstances. Thus, younger children may be less likely to be described as resilient by this definition because they do not recognize their own strengths. The concept of resiliency here is really helping children and youth do their own strength-based planning for their lives.

Mental Health (HP3)

This item addresses the child's history of mental health problems or diagnosed conditions/disorders (e.g., depression, anxiety, psychosis, oppositional or defiant behaviour with authority, traumatic response, hyperactivity/inattention, delinquency, high risk behaviors). A history of past mental health difficulties may be associated with increased vulnerability in children's responses to their current circumstances.

Cognitive/Intellectual Development (HP4)

This item rates the presence of Intellectual or Developmental Disabilities only and does not refer to the broader spectrum of healthy development. A '1" would be a low IQ child. Asperger's syndrome would likely be rated a "2" while PDD or Autism would be rated as a '3". A child/youth that meets the criteria for a pervasive developmental disorder including Autism, Asperger's, pervasive developmental disorder not otherwise specified (PDD NOS), Rett Syndrome, or Child Disintegrative Disorder would be rated a "2". If the condition is severe to the point where the child/youth is unable to meet appropriate developmental milestones then he/she would be rated a "3".

Adverse Developmental Events (HP5)

This item is intended to address physical, psychological, or environmental events occurring during the course of the child's development (e.g., toxic exposures, traumatic brain injuries, physical, emotional or sexual abuse, illness impacting on central nervous system functioning) which may have led to cognitive, emotional, and behavioral adjustment difficulties and/or impairments. While some of the adverse events may be the result of a general medical illness or intoxications (e.g., maternal substance abuse during pregnancy) the item is included in the "Psychological" domain, since the insults typically result in emotional or behavioral symptoms. However, when there are residual physical effects of the early life trauma, they may also be reflected in items falling within the "Biological" domain.

CURRENT

Resistance to Treatment (CP1)

This item rates whether the child/youth is an active partner in planning, complying with and implementing any treatment recommendations and plans. This includes engagement with the health care team, as well as level of compliance in taking medications, attending appointments, and engaging in recommended lifestyle and health behaviors. Resistance may take several forms including, but not limited to, the following: non-adherence, indifference (e.g., missed appointments), or non compliance towards the treatment and/or with the health care professionals. Like all ratings, evaluation of the extent of the child's resistance/cooperation should be done in a developmentally informed way. Expectations for involvement in medical treatment would be lower for younger children than for older children and adolescents, with the parents assuming a greater responsibility in the former case.

Mental Health Symptoms (CP2)

This item addresses mental health symptoms that are anticipated to impact the child and youth's physical well-being or health care management, and should be rated in reference to the past 30 days. This item describes aspects of the child/youth's psychological adjustment to his/her health care condition. A child who has developed a depressed mood, become anxious or withdrawn, or had increased dependency on the caregiver since the onset of his/her current physical symptoms would be rated here. A history of mental health concerns/diagnoses prior to current illness is not rated here, as it is assessed elsewhere.

Cognitive/Functional Impairment (CP3)

This item addresses the extent to which a child/youth's current medical condition/treatment affects his/her central nervous system (CNS) function and leads to cognitive, emotional or behavioral limitations. Examples of medical conditions impacting on CNS functioning include seizure disorders, sick cell disease, cardiac conditions, etc. Treatments impacting on CNS function might include chemotherapy or surgery for removal of a brain tumor.

ANTICIPATED NEEDS/VULNERABILITY

Mental Health/Cognitive Threat (VP1)

This item refers strictly to mental health and/or cognitive concerns that are anticipated to impact the child/youth's physical well-being or health care management in the next 3-6 months. Based on the information collected for the "History" and "Current State" items, one determines the patient's mental health needs ("Vulnerability/prognosis), including the child/youth's capacity to collaborate with the treatment.

SOCIAL DOMAIN

HISTORICAL/DEVELOPMENTAL

This domain addresses the quality and the extent of the child/youth's social connectedness and relationships with peers, community, and family members, and their participation in school, leisure and community extra-curricular activities.

School Functioning (HS1)

This item assesses the child/youth's historical functioning in school. The item is a combination of three factors. A vulnerability/actionable level on **any** of these factors would justify ratings of a '2' or '3'.

School Achievement

This addresses the child/youth's level of academic achievement. A child having moderate problems with achievement and failing some subjects would be rated a '2'. A child failing most subjects or who is more than one year behind his/her peers would be a '3'.

School Attendance

This addresses the degree to which the child/youth has attended school. If the child is home schooled one would need to consider the degree to which the child is participating in school-based activities at home.

School Behavior

This addresses the child/youth's behavior in school. This is rated independently from attendance. Sometimes children are often truant but when they are in school they behave appropriately. If the school placement is in jeopardy due to behaviour, this would be rated as a "3".

Note: For the school item, if the child/youth is receiving special education services, rate the child's performance and behavior relative to their peer group. If it is planned for the child to be mainstreamed, rate the child's school functioning relative to that peer group.

Social Relationships/Functioning (HS2)

This item rates the child/youth's ability to socialize and maintain relationships with peers in a healthy and age appropriate manner. This includes age-appropriate behavior with regard to social relationships and the necessary social skills to develop and maintain satisfying relationships with peers.

CURRENT

Here risks/vulnerabilities related to the child/youth's current social supports and adaptive functioning are described.

Child/Youth Support (CS1)

This item rates the extent to which the child/youth has individuals in his/her life who provide support in a positive and helpful manner. This may include supporting and supervising a child in successfully completing activities and fulfilling roles, and providing emotional and instrumental assistance with personal growth issues, and more specifically with regard to the child's current health issues. Providers or support to the child/youth may include family members, friends, peers, teachers, coaches and acquaintances.

School Attendance (CS2)

This item assesses the degree to which the child/youth attends school by looking at the pattern of coming to and staying at school for each required school day during the past 30 days, as well as their current achievement and behavior. If the child/youth is currently home schooled the rating should be based on whether the child is participating in schooling as would be expected.

Educational Needs (CS3)

This item assesses both the academic needs of the child/youth and how well they are being addressed by the educational institution with which the child is affiliated. For example, a child who is struggling in mainstream classes and would benefit from an individualized educational plan (IEP) but does not currently have one would be rated a '2' or a '3'.

Community Participation (CS4)

This item reflects children/youth's connection to and involvement in their community. Kids with a sense of belonging and a stake in their community react better to their illness than those that don't. Children who reduce or discontinue

their participation in community/extra-curricular activities due to their physical symptoms often lose critical social support. Children who have moved a lot or who have been in multiple foster care settings may have lost this sense of connection to community life and so might be rated a '3'. The term "community" may include racial, religious, cultural, and residential or geographic (e.g. neighborhood connections/affiliations).

ANTICIPATED NEEDS/VULNERABILITIES

Social System Vulnerability (VS1)

This item addresses the child/youth's anticipated social needs and how these may impact on his/her response to health care and optimal social and adaptive functioning over the next 3-6 months. Based on the information collected for the "History" and "Current State" items, one determines the patient's social needs ("Vulnerability/Prognosis), including the child/youth's capacity to continue to maintain their school, community and social functioning in the context of his/her current health situation.

CAREGIVER/FAMILY SYSTEM DOMAIN

HISTORICAL/DEVELOPMENTAL

These items assess the nature of the child/youth's family relationships and situation, as well as the capacity of the primary caregiver/parent(s) to effectively meet the child's needs. In situations where there are multiple caregivers, we recommend making the ratings based on the needs of the set of caregivers as they affect the child. For example, the supervision capacity of a father who is uninvolved in monitoring and discipline may not be relevant to the ratings. Alternatively, if the father is responsible for the child because he works the first shift and the mother works the second shift then his skills should be factored into the ratings of on relevant items.

Family Relationships (HF1)

This item addresses how the child's family system has been functioning. Diminished functioning includes but is not limited to parent-child conflict, problems with siblings, and marital difficulties. The degree to which a problem requires attention and subsequent intervention determines the rating that it receives. For example, a child whose parents are pre occupied with a sibling's justice problems to the extent that they have difficulty attending to the child's health care needs would be rated a '2' or a '3' on this item.

Caregiver (Parent) Health & Function (HF2)

This item addresses any medical, physical, mental health or substance-use related problems that the caregiver(s) may be experiencing that limit or prevents his/her ability to provide care for the child. For example a single parent who has recently had a stroke and has mobility or communication limitations might be rated a '2' or even a '3'. If the parent has recently recovered from a serious illness or injury or if there are mild concerns of problems in the immediate future they might be rated a '1'. A parent with serious mental illness would likely be rated a '2' or even a '3' depending upon the impact of the illness. However, a parent whose mental illness is currently well controlled by medication might be rated a '1'. If substance use interferences with parenting a rating of '2' is indicated. If it prevents caregiving a '3' would be used. A '1' indicates a caregiver currently in recovery or a situation where situation where problems of substance use are suspected but not confirmed.

CURRENT

Here risks/vulnerabilities for poor health care outcomes, related to the child/youth's current living situation, family situation, and parenting supervision are described.

Residential Stability (CF1)

Providing stable housing and adequate financial resources is critical to meeting children's personal growth, and health care needs. The absence of stable housing situation and adequate financial resources is often associated with significant stress impacting on children and families, and potentially placing them at risk. If a youth is living independently, then the rating on this item applies to the financial assets available to the youth, and the stability of their current residence. A rating of '3' indicates problems of recent homelessness, and insufficient resources to meet the child's immediate needs (e.g., adequate nutrition). A '1' indicates some concerns related to changes in residence, and mild financial stressors, but overall stability for the child. A situation where a child has had to move due to parent employment or financial issues would be rated as '1'. Similarly, a family having difficulty paying utilities, rent or a mortgage might be rated as a '1'.

Caregiver/Family Support (CF2)

This variable describes the social support network available to parents/caregivers to assist them in their roles, responsibilities and activities as parents, particularly when their children have specific health issues and needs. The assessment of this item considers support available form extended family members, friends, and/or acquaintances, employers and work colleagues.

Family Stress (CF3)

This item addresses the extent to which the child's current health care needs and situation is having a stressful impact on the family as a whole, and on individual family members. For example, this would be reflected in a recent increase in marital conflict between spouses, or a sibling of a chronically ill child who is depressed and anxious and unable to attend school.

Parenting Skills (CF4)

This item addresses the caregiver's ability to consistently provide the level of monitoring and discipline required by the child/youth, and to adequately supervise their health care needs. Discipline is defined in the broadest sense of all of the things that parents/caregivers can do to promote positive behaviour in their children. A mother who reports frequent arguments with her teenage son, who is not following house rules, is staying out all night and who may be using drugs or alcohol may be rated as a '2'. A parent who battles with a child to have him take his required medications in the evening, although eventually succeeds would be given a rating of '1. A parent of a child with severely reduced lung functioning due to poorly managed Cystic Fibrosis, who does not monitor whether the youth completes daily physiotherapy treatments and has no awareness of whether the child is taking her medications, despite being asked to do so by the CF team, would be rated as a '3'.

ANTICIPATED NEEDS/VULNERABILITIES

Caregiver/Family System Vulnerability (VF2)

This item addresses the extent to which the child's health condition is anticipated to put a strain on caregivers and healthy family functioning over the next 3 to 6 month, adversely impacting child/youth health outcomes. It taps whether the caregivers, or family require external supports to cope and manage with the situation during the next 3-6 months. Based on the information collected for the "History" and "Current State" items, one determines the caregiver/family needs ("Vulnerability/Prognosis), including their capacity to meet the child/youth's health care needs and to promote the child's healthy functioning.

HEALTH SYSTEM DOMAIN

HISTORICAL/DEVELOPMENTAL

Items in this domain address the child and his/her family's experience in trying to access health care services, their level of trust in health care professionals, and their ability to navigate an increasingly complicated delivery and reimbursement environment in the process.

Access to Health Care (HHS1)

This item addresses impairment of access to health care due to problems with insurance, the distance to care facilities, and linguistic and cultural barriers.

Treatment Experience (HHS2)

This variable describes the experienced quality of the relationships with health care providers. Simply put, past experience is a good predictor of the quality of future relationships with health care personal. Negative experiences with health care personnel may have any impact on the outcome of care, including future non-adherence and failure to pursue treatment for existing health problems. These feelings/experiences may also have resulted from previous misdiagnoses or the feeling of not having been treated respectfully or with understanding by a health care professional. It is important to note that this item captures the child/youth's own experiences, but may also reflect the experiences of parents and other family members, or friends.

CURRENT

These items address the nature and level of health care services/facilities involved in the child/youth's care and the level of coordination between health care providers.

Organization of Care (CHS1)

This variable addresses risks related to the number of types of care professionals involved with the child/youth and the care system that they are receiving services from (i.e., primary care, tertiary care (hospital), community based mental health care, school support services, substance abuse care). The more professionals and services involved in the treatment (care) of the child/youth, the more important coordination and communication among providers and services becomes. Patients often report the absence of linkages and integration of care. Further, the fragmentation of health into medical care, mental health care, and substance care facilities increases this problem. Lack of coordination and integration may also occur not only across levels and location of care but also between the different medical specialties involves in the child/youth's care.

Coordination of Care (CHS2)

This item addresses the extent to which different providers working with the child/youth are in communication with each other, and have access to information about the other's respective provision of care to the child/youth. Risks related to poor coordination of care include lack of access to each other's documentation, including mental health issues and treatments, or lack of or inadequate coordination of care, including the need for case management. If providers are not aware of what others are doing, duplication and/or gaps in service can occur, increasing risk of conflicting treatments and/or drug interactions.

ANTICIPATED NEEDS/VULNERABILITY

Health System Impediments (VHS1)

This item addresses the risks as described in the "historical" and "current" state that interfere with good access to needed services and coordinated care and related care system needs. This variable should be rated from the perspective of the anticipated future need for services and coordinated care.

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