

NCEPOD: Crohn's Disease study

Definitions

Crohn's Disease Activity Index (CDAI)	<p>The Crohn's Disease Activity Index (CDAI) is an index for describing disease activity in Crohn's disease. It is computed using laboratory data, physical exam findings, and self-reported CD symptoms for each of the prior 7 days. The index ranges from 0 to ~600. A cut-off value of <150 was selected so that most patients below this threshold would be rated by physicians as 'very well' Further information can be found at: https://doi.org/10.1016/S0016-5085(76)80163-1</p>
Harvey Bradshaw Index (HBI)	<p>The Harvey-Bradshaw Index (HBI) is a useful tool for assessing the degree of illness (activity) in patients with Crohn's disease. The index is less cumbersome to use than the CDAI and eliminates the use of the diary card (patient pre-assessment) and laboratory monitoring. Patients with Crohn's disease who scored 3 or less on the HBI are very likely to be in remission according to the CDAI. Patients with a score of 8 to 9 or higher are considered to have severe disease. Further information can be found at: https://doi.org/10.1016/s0140-6736(80)92767-1</p>
Inflammatory Bowel Disease (IBD)	<p>Inflammatory bowel disease (IBD) is a term for two conditions (Crohn's disease and ulcerative colitis) that are characterized by chronic inflammation of the gastrointestinal (GI) tract. Crohn's disease causes prolonged inflammation, which results in damage to the GI tract. It can affect any part of the GI tract (from the mouth to the anus)—Most often it affects the portion of the small intestine before the large intestine/colon.</p>
IBD Specialist hospital/ IBD service	<p>Hospital with a specialist multidisciplinary IBD service run by a multidisciplinary IBD team (e.g. including colorectal surgeons, gastroenterologists, IBD specialist nurses,) with expertise in IBD. Further information on the standards for a IBD service can be found at https://ibduk.org/ibd-standards/the-ibd-service</p>
IBD leadership team	<p>The IBD leadership team have responsibility for managing, monitoring and developing the IBD service. Further information on the IBD UK standards regarding the IBD leadership team can be found at: https://ibduk.org/ibd-standards/the-ibd-service/ibd-service-leadership-team</p>
NCEPOD Classification of Intervention	<p>IMMEDIATE – Immediate life, limb or organ-saving intervention – resuscitation simultaneous with intervention. Normally within minutes of decision to operate. Life-saving Other e.g. limb or organ saving</p> <p>URGENT – Intervention for acute onset or clinical deterioration of potentially life-threatening conditions, for those conditions that may threaten the survival of limb or organ, for fixation of many fractures and for relief of pain or other distressing symptoms. Normally within hours of decision to operate.</p> <p>EXPEDITED – Patient requiring early treatment where the condition is not an immediate threat to life, limb or organ survival. Normally within days of decision to operate.</p> <p>ELECTIVE – Intervention planned or booked in advance of routine admission to hospital. Timing to suit patient, hospital and staff.</p> <p>Whilst it is recognised that additional categories or sub-categories could be defined it is important that the classification remains as simple as possible to use. https://www.ncepod.org.uk/classification.html</p>
Levels of care	<p>LEVEL 2: (e.g. HDU) Patients requiring more detailed observation or intervention including support for a single failing organ system or post operative care, and those stepping down from higher levels of care. (NB: When Basic Respiratory and Basic Cardiovascular support are provided at the same time during the same critical care spell and no other organ support is required, the care is considered to be Level 2 care).</p>

	<p>Level 3: (e.g. ICU/ITU) Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organs. This level includes all complex patients requiring support for multi-organ failure. (NB: Basic Respiratory and Basic Cardiovascular do not count as 2 organs if they occur simultaneously, but will count as Level 3 if another organ is supported at the same time)</p>
<p>Networks of care: Formal and Informal</p>	<p>Formal network: "A linked group of health professionals and organisations from primary, secondary and tertiary care and social care and other services working together in a coordinated manner with clear governance and accountability arrangements". (Department of Health Collaborative, 2004)</p> <p>Informal network: "A collaboration between health professionals and/or organisations from primary, secondary and/or tertiary care, and other services, aimed to improve services and patient care, but without specified accountability to the commissioning organisation".</p>
<p>Patient Reported Outcome Measures (PROMs)</p>	<p>Patient Reported Outcome Measures (PROMs) assess the quality of care delivered to NHS patients from the patient perspective. Patient reported outcomes are reported directly by the patient and are powerful tools to inform patients, clinicians, and policy-makers about morbidity and 'patient suffering', especially in chronic diseases</p>
<p>Rockwood clinical frailty scale</p>	<p>1 VERY FIT - people who are robust, active, energetic, and motivated. These people commonly exercise regularly. They are among the fittest for their age.</p> <p>2 WELL - people who have no active disease symptoms but are less than fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.</p> <p>3 MANAGING WELL - people whose medical problems are well controlled but are not regularly active beyond routine walking.</p> <p>4 VULNERABLE - while not dependent on others for daily help, often symptoms limit activities. A common complaint it being 'slowed up', and/or being tired during the day.</p> <p>5 MILDLY FRAIL - these people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.</p> <p>6 MODERATELY FRAIL - people need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.</p> <p>7 SEVERELY FRAIL - completely dependent for personal care from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within 6 months of life).</p> <p>8 VERY SEVERELY FRAIL - completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.</p> <p>9 TERMINALLY ILL - approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail</p>