| | nflammatory Bowel Disease (IBD) Research Priorities from IBD Priority-Setting Partnership 2015 | |
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| Group rank | Original Questions (voted on) | |
| | J: Are combinations of immunomodulators and biologics safe, and which will be most effective in IBD management? K: Which immunomodulators or biologics are most effective in IBD Management? What is the optimal treatment strategy: selecting / stratifying for the 'right patient group' at the 'right stage of disease' / potential for withdrawal)? | |
| 1 | COMBINED INTO What is the optimal treatment strategy considering efficacy, safety and cost-effectiveness (immunomodulators, biologics, surgery, combinations) in IBD management: selecting the right patient group, right stage of disease, and assessing potential for withdrawal? | |
| | Important because: it is unknown what the optimal algorithm of care is taking into account efficacy and safety for the patient and cost-effectiveness for any given society | |
| 2 | O: What are the optimal markers (clinical, endoscopic, biomarkers, genetics) that stratify patients with regards to disease course and treatment response? N: What are the optimal methods of monitoring disease activity in both active and quiescent IBD? | |
| | COMBINED INTO What are the optimal markers/ combinations of markers (clinical, endoscopic, imaging, genetics, other biomarkers) for stratification of patients with regards to a) disease course and b) monitoring disease activity and c) treatment response? | |
| | Important because: it is unknown how to gauge how the disease behaves over time; what predictors are there to define individuals with poor prognosis versus good prognosis disease course. This information will assist in directing the best treatment strategy for a given patient | |
| 3 | What role does diet have in the management of mildly active or inactive ulcerative colitis or Crohn's Disease to achieve normal daily activities and symptom control? | |
| | Important because: Real importance for patients in terms of need for information; promoting self-management | |
| 4 | How can pain be most effectively managed in people with IBD? | |
| | Important because: Usual analgesia does not work; over investigation for cause of pain; clinicians don't know what to do | |
| 5 | What is an optimal treatment strategy for perianal Crohn's Disease and what individual factors determine this? | |
| | Important because: need to prevent progression to fistula; there is currently no clear medical surgical combination and timing of intervention; no ongoing studies, or relevant and reliable systematic reviews | |

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| | What is the best treatment for controlling diarrhoea and/or incontinence symptoms in people with IBD, including novel pharmacological and non- pharmacological options? Is high-dose Loperamide safe and effective in the treatment of diarrhoea in IBD? |
| 6 | Important because: Clinicians are cautious about using these agents in the presence of active IBD; diarrhoea is often the most troublesome symptom with active IBD. |
| 7 | What is the optimal dietary therapy (liquid enteral diet and/or reintroduction diet) and duration to achieve mucosal healing in active IBD and/or remission either as a primary or adjunctive treatment? Is there a difference between adults and children? |
| | Important because: Dietary therapy using a liquid diet is potentially an effective treatment option with minimal long term side effects and should be considered alongside other treatment options for patients with IBD. It is important that each IBD patient is on the right treatment and a liquid diet is often not considered. Patients seek alternatives to medical therapy, and need information on which to base their decisions on treatment options. There are no relevant and reliable systematic reviews (only a pilot study) |
| 8 | What is the association between IBD and fatigue and how should it be managed? |
| | Important because: Fatigue is a major problem and research so far has failed to identify anything to improve it. (a) Many patients who receive B12 report marked reduction in fatigue that cannot be related to correction of a low B12. This is the informal experience of (probably) a majority of specialists. Consider mechanisms related to free radicals (B12 is a scavenger) See https://www.caymanchem.com/app/template/Article.vm/article/2156 (b) Sport England has an initiative to fund exercise programmes for patients with chronic diseases. |
| | M: What are the relative roles of surgery and/or medication in the treatment of terminal ileal Crohn's in terms of clinical and cost effectiveness in quality of life? What factors are important in decision making? W: Is step up or step down treatment (bottom up / bottom down) more effective in IBD management and which is safer? |
| 9 | COMBINED INTO Does early surgery or later surgery for terminal ileal Crohn's disease result in better outcomes (quality of life, cost-effectiveness)? |
| | Important because: it is unknown whether early surgery can achieve a longstanding remission and chance of drug-free period |

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| | A: What is the role of antimicrobial approaches such as antibiotics in the management of IBD? Is faecal transplantation effective in patients with IBD and how can it be optimised (delivery/donor)? |
| | B: Are probiotics useful in the management of active or inactive IBD to achieve symptom control and normal daily activities? |
| 10 | COMBINED INTO Does influencing the gut microbiota influence the course of IBD? |
| | Important because: no ongoing studies, or relevant and reliable systematic reviews. This is a very important area for patients particularly in improving living with IBD |

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