

What are the Top 10 Research Questions in the Treatment of Inflammatory Bowel Disease? A Priority Setting Partnership with the James Lind Alliance

Hart et al. (2017)
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For which topic were research priorities identified?

inflammatory bowel disease

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

These diseases are increasing in incidence and carry a burden of symptoms including abdominal pain, diarrhoea and sometimes faecal incontinence, fatigue, extra-intestinal symptoms including joint pains, skin lesions and eye symptoms, and an increased risk of cancer. Treatment of IBD involves a multidisciplinary approach to management, with medical therapies and surgery playing important roles. Research priorities are often set by academics or by the pharmaceutical industry; however, are these groups best placed to ensure that resources for research are focused on the clinically-relevant and meaningful issues for clinicians and patients? JLA partnership has the goal of bringing together clinicians, patients and other stakeholders to set research priorities.

What was the objective?

to identify and prioritize unanswered questions about treatments for inflammatory bowel disease

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: initiation and setting up committee. Step 2: collection of treatment uncertainties: via survey, participants were asked to submit up to five treatment uncertainties, 1636 uncertainties submitted. Step 3: data processing of treatment uncertainties: indicative questions formulated, then checked by steering group, suggested uncertainties that could already be resolved by published systematic reviews were removed. Step 4: interim ranking: survey consisting of a list of 70 uncertainties: participants were asked to select a maximum of 10 uncertainties that they considered to be the most important and to rank them, results of ranking exercise then reviewed by steering group, agreed priority list established based on overall rank order. Step 5: final prioritization: workshop: 25 topics brought forward to workshop, small group discussions and small group ranking, aggregate ranking in plenary session

Which stakeholders took part?

Healthcare professionals, patients and their support groups. Survey: 531 participants: 113 healthcare professionals (6 dietitians, 3 general practitioners, 13 nurses, 13 surgeons, 70 gastroenterologists) or researchers and 406 patients, carers or patient organization representatives. Workshop: 16 participants: 3 patients with IBD, 2 carers, 3 gastroenterologists, 1 colorectal surgeon, 2 IBD specialist nurses, 2 dietitians, 1 Crohn's and Colitis UK Charity representative, 1 information specialist, 1 James Lind Alliance Facilitator.

How were stakeholders recruited?

The survey was advertised through a combination of direct emails and newsletters to members of the partner organizations, including Crohn's and Colitis UK, and through links on relevant websites.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 2 patients with IBD, 2 gastro-enterologists, 2 inflammatory bowel disease specialist nurses, 2 colorectal surgeons, 2 dietitians, 1 representative from the UK inflammatory bowel disease charity organization Crohn's and Colitis UK, 1 representative of the James Lind Alliance and an administrator. The members defined the scope of the partnership and developed the protocol detailing the methods to be used