

Engaging Patients and Caregivers in Research for Pediatric Inflammatory Bowel Disease: Top 10 Research Priorities

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For which topic were research priorities identified?

pediatric inflammatory bowel disease

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

Including individuals with lived experience in pediatric inflammatory bowel disease (IBD) is essential to establishing a research agenda that is mutually impactful to both those treating and those experiencing the disease.

What was the objective?

to solicit the 10 most important research uncertainties in the management of pediatric inflammatory bowel disease from the point of view of patients, caregivers, and clinicians

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: collecting uncertainties: via survey and focus groups, questions submitted via survey then combined with focus group responses and questions abstracted from a review of clinical practice guidelines, 1209 research uncertainties reported. Step 2: data processing: thematic analysis: grouping questions, total of 626 unique questions which were subsequently divided into 17 themes, forming indicative questions by combining similar questions and removing redundant items or questions out-of-scope, check against evidence base, resulting 105 unanswered indicative uncertainties within scope. Step 3: interim ranking: via survey participants were asked to rank their top 20 research questions, collective rank was used to determine the most highly ranked items resulting in 27 highly ranked questions along 12 out of 17 topics, steering group met to review the top 27 uncertainties: after deliberating 5 uncertainties combined and 2 new added resulting in 18 uncertainties moving forward to workshop. Step 4: final prioritization: workshop with nominal group technique: small group discussions deliberating on rank order, large group ranking, final top 10 questions by consensus

Which stakeholders took part?

Patients, caregivers, and clinicians. Survey: 111 patients who developed IBD before 18 years, 133 caregivers, and 46 interdisciplinary health professionals, along with an additional 73 participants. Interim ranking: patients (n=25), caregivers (n=20), and interdisciplinary health professionals (n=30). Workshop: steering committee and 2 additional patients, 4 caregivers, 1 sibling, and 5 clinicians (3 gastroenterologists, 2 nurses, 2 dietitians, a social worker, and a psychologist who all worked directly with pediatric patients with IBD).

How were stakeholders recruited?

This survey was advertised through local networks (i.e., IBD-specific Facebook groups, community organizations involved in IBD support), pediatric IBD clinics, and national IBD organizations. The prioritization survey was disseminated across Canada.

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 10 members: current and former pediatric patients with IBD, caregivers, and clinicians. The members created survey, were involved in data processing, reviewed the top 27 uncertainties before the workshop and participated in the workshop.