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## Identification of research priorities for Inflammatory Bowel Disease nursing in Europe: a Nurses-European Crohn's & Colitis Organisation Delphi survey

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**Short title: Research priorities for European IBD nursing**

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**Lesley Dibley:** none; **Palle Bager** has served as a speaker, compensated by Pharmacosmos and Takeda. He has received research grants from Takeda and AbbVie.

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## **Abstract**

### ***Background***

Robust research evidence should inform clinical practice of inflammatory bowel disease (IBD) specialist nurses, but such research is currently very limited. With no current agreement on research priorities for IBD nursing, this survey aimed to establish topics to guide future IBD nursing research across Europe.

### ***Method***

An online modified Delphi survey with nurse and allied health professional members of the Nurses European Crohn's and Colitis Organisation (n=303) was conducted. In round one, participants proposed topics for research. In round two, research topics were rated on a 1-9 scale and subsequently synthesised to create composite research questions. In round three, participants selected their top five research questions, rating these on a 1-5 scale.

### ***Results***

Eighty-eight, 90, and 58 non-medical professionals, predominantly nurses, responded to rounds one, two and three respectively, representing 13 European countries. In round one, 173 potential research topics were suggested. In rounds two and three, responders voted for and prioritised 125 and 44 questions respectively. Round three votes were weighted (rank of 1 = score of 5), reflecting rank order. The top five research priorities were: interventions to improve self-management of IBD; interventions for symptoms of frequency, urgency and incontinence; the role of the IBD nurse in improving patient outcomes and quality of life; interventions to improve IBD fatigue; and care pathways to optimise clinical outcomes and patient satisfaction.

### ***Conclusion***

The prioritised list of topics gives clear direction for future IBD nursing research. Conducting this research has potential to improve clinical practice and patient-reported outcomes.

**Keywords:** Delphi, IBD nursing, inflammatory bowel disease, research priorities

## Introduction

The role of the inflammatory bowel disease (IBD) nurse has become increasingly recognised for the significant contribution made to the patient experience, including complex decision-making regarding patient care, and the role is now well established across Europe and Canada<sup>1-3</sup>. However there remains wide variation in the role in terms of autonomy, education and experience, with many nurses placing experiential learning above that of an academic qualification<sup>4</sup>, meaning that few may have experience in research or have a recognised specialised or research qualification. Yet the changing demands of IBD in terms of complex treatment algorithms places the IBD nurse at the centre of care to ensure patient needs are met, and there is an ongoing requirement to deliver high quality evidence-based care. The recent Nurses-European Crohn's and Colitis Organisation (N-ECCO) consensus statements on nursing roles in caring for patients with Crohn's disease or ulcerative colitis included a recommendation for IBD nurses to be involved in research related to their area of expertise<sup>5</sup>. Enabling nurses and Allied Health Professionals (AHPs) such as dieticians and physiotherapists with similar research interests to work together and, with the help of experienced researchers, develop and deliver relevant, important and influential research, has the potential to improve patient quality of life and clinical outcomes, and augment the recommendations of the IBD healthcare professional and patient priorities identified in partnership with the James Lind Alliance in the UK<sup>6</sup>.

There is a small but growing body of research to inform IBD nurses' and AHPs care for patients with IBD. Research activity amongst IBD researchers, nurses and AHPs tends to focus on service organisation, patient care, quality of life, and symptom management<sup>7-13</sup> but there is no defined framework across Europe to develop IBD nursing and AHP research capacity, nor a collaborative process to enable this.

As part of the multi-disciplinary team caring for patients with IBD, specialist nurses and AHPs need to be able to refer to a body of robust research evidence, to inform their practice. The N-ECCO Survey identified the importance of the clinical aspect of the IBD nurse role

and so one of the challenges facing IBD nurses and AHPs is achieving research activity alongside the clinical demands which take priority<sup>4</sup>. Getting started, or getting involved in, research teams and contributing to ongoing projects is a challenging prospect for many, as is identifying feasible projects which match nurse and AHP interests, and which have potential to improve patient care. IBD nurses and AHPs who have no research experience need opportunities to initiate, participate in, contribute to, and lead on research projects which are likely to benefit patient care. Nurses and AHPs can be proactive in this process by taking the initiative to propose and develop projects for research, and by working together with research-active teams within and across healthcare and academic organisations, locally and internationally.

During the nurses' research networking forum at the European Crohn's and Colitis Organisation congress in 2015, the need to build research capacity amongst members by developing research skills and enhancing research involvement was discussed. As a result of that and follow-up discussion, the authors aimed to identify and agree the priorities for European IBD nursing and AHP research.

### **Materials and Methods**

An online modified Delphi survey of IBD nurse and AHP members of N-ECCO was conducted in order to identify research priorities. A Delphi survey is generally considered to be the optimal technique when seeking expert opinion on a specific topic, particularly where the intention is to identify priorities<sup>14</sup>. A modified approach is adopted when participants are provided with a 'starter set' of questions or topics, rather than being given a 'blank sheet'. Eligible participants are invited to offer their opinion on a specific issue, results are collated and then redistributed to participants when a request to prioritise can be made. The process of collation, redistribution and prioritising is repeated until a consensus is reached<sup>15</sup>.

## Sample

Participants were recruited from a convenience sample of all European-based nurse and AHP current members of ECCO in 2015 (n=303).

## Data collection and analysis

Three rounds of data collection took place from June – Dec 2015 [Figure 1]. All nurse and AHP members of ECCO were invited to participate by the ECCO office personnel, on behalf of the study team. All members received an email invitation to participate in each round, the study information leaflet (round one only) and an electronic link to the online survey platform. A single email reminder was sent two weeks before the deadline for each round.

In Round One the themes of *Service organisation*, *Patient care*, *Quality of life*, *Symptom management* and the *Role of IBD nursing and AHP practice* were proposed for participants to suggest research questions. These themes were derived from the combined reports of the UK National IBD Audits, the N-ECCO Consensus Statements, the N-ECCO survey and the Royal College of Nursing IBD Nurse Audit<sup>2-5,16</sup>. A sixth category of 'Other' allowed research suggestions from participants which did not align with the previous five categories. The research team then grouped the suggestions based on similarity and formulated 125 research topics for Round Two.

In Round Two, the same 303 members were invited to mark the importance of each of the 125 research topics, using a nine-point Likert-type scale (1= Not Important – 9 = Very Important). Most topics were scored 7, 8 or 9 by most respondents, preventing clear priorities for research from being established. The research team therefore agreed to merge similar questions (those which addressed different aspects of the same issue), generating 44 composite research questions for Round Three. Examples of the development of research questions over the three rounds are provided in Table 1.

In Round Three, participants were asked to select, from the list of 44 composite research questions, the five questions they felt were most important and rank these in their priority order (1 = most important, 5 = least important). The results were initially calculated for number and percentage of voters for each question. To calculate the ranking for each research question, scores were given a weighting as follows: 1<sup>st</sup> place = 5 points; 2<sup>nd</sup> place = 4 points; 3<sup>rd</sup> place = 3 points; 4<sup>th</sup> place = 2 points; and 5<sup>th</sup> place = 1 point. Total weighted scores reflected the ranking given by each participant.

### **Ethical Statement**

The study was reviewed and approved by the research ethics committee at King's College London, England [Reference Number: LRS-14/15-0876; 12.06.2015]. Return of the completed online survey implied consent to participate. The research team had no access to participants' personal contact details.

### **Results**

#### **Round One**

Eighty-eight of the 303 (29%) invited members of ECCO participated. Of these, 76 (86.4%) were female, modal age 41-50 years; 73 (82.9%) were IBD, gastrointestinal or other specialist nurses; 18 (20.4%) were IBD researchers, research nurses or academics; six (6.7%) were AHPs. Participants had worked in the field of IBD for less than three years (n=21, 23.8%), four to six years (n=21, 23.8%), seven to 10 years (n=21, 23.8%), 11 – 15 years (n=20, 19.3%), or over 16 years (n=8, 9.1%), and represented 13 European countries. In total, 161 research topics were suggested under the five proposed themes of: (i) *Service organisation* (n=32); (ii) *Symptom management* (n=32); (iii) *Quality of life* (n=30); (iv) *Patient care* (n=29); (v) *Role of the IBD Nurse and AHP Practice* (n=26). A further 12 topics were offered under the *Other suggestions* option.



Examples of suggested topics for each theme included:

(i) *Service organisation*: the role and value of the multi-disciplinary team (MDT) and the IBD Nurse's role within the MDT; determining the best patient reported outcome measures (PROMS) which evaluate nurse impact on delivery of IBD care and outcomes; identifying how to personalise the service offered to the patients.

(ii) *Symptom management*: the ways in which arthralgia can best be managed in patients with IBD; providing medical treatment education for patients so that they can self-medicate with their prescribed medication to best treat their symptoms; addressing incontinence in IBD.

(iii) *Quality of Life*: determining whether paediatric IBD patients with access to an IBD nurse have better school attendance; exploring quality of life issues for the IBD patient's whole family unit; confirming which quality of life PROMs are the most appropriate for use with IBD patients.

(iv) *Patient Care*: identifying what patients want from their IBD service in order to optimise IBD care delivery; developing a patient 'information pathway' for newly-diagnosed IBD patients; developing IBD-specific assessment tools which address psychological, psychosocial and quality of life issues.

(v) *Role of the IBD Nurse and AHP Practice*: determining how the role of the IBD Nurse can or should be extended or developed further to meet the wider needs of patients whilst maintaining a quality service; exploring the role of diet in development of and management of IBD; evaluating the role of the IBD pharmacist in delivery of care, and the impact on services.

(vi) *Other suggestions*: investigating the value of peer support / patient organisations; how to establish an international IBD-nursing education programme / certificate; addressing

the legal considerations for IBD nurses relating to tele-health services, such as telephone triage, and giving health information and laboratory results over the telephone.

All 173 suggestions were reviewed and synthesised by the project team, resulting in 125 refined suggestions organised into 19 groups of related topics [Table 2].

### **Round Two**

Ninety of the 303 (29.7%) invited members participated. All research statements were rated by at least 96% of participants. Most statements were scored 7, 8 or 9 on the Likert-type scale so no clear indication of priorities emerged. Consequently, the research team reviewed and combined similar statements to produce fewer, broader, research questions. For example, the research statements 'Symptom Management in IBD', 'Prevalence and inter-relationship of symptoms', 'Symptoms occurring together', 'The relationship between physical and psychological symptoms', and 'The impact of emotional stress on physical symptoms' were combined to generate the broader research question: 'What is the prevalence and inter-relationship of different symptoms in IBD?' Application of this strategy to the 125 research topics from Round Two resulted in 44 broader, composite research questions for Round Three.

### **Round Three**

Fifty-eight (19%) of the 303 members participated. Of the 44 questions, participants ranked their top five research priorities from 1 – 5 (1 most important, 5 least important). Scores were then calculated twice. First, using descriptive statistics, questions were ranked according to the percentage of votes each question received. In the second calculation, scores were weighted to reflect the ranking given by each participant.

The top ten research priorities identified as a result of each method of calculation, are shown in Table 3. Regardless of scoring method, the top priority addresses patient education

interventions to improve self-management of IBD. The top three research priorities - improving self-management of IBD, the role of the IBD nurse in improving patient outcomes and quality of life, and interventions to improve bowel symptoms in IBD, are the same, albeit in a slightly different order. Seven of the top ten priorities appear in both ranking lists.

## Discussion

After three modified Delphi rounds, the top ten research priorities were identified by IBD nurses and AHPs. A range of clinical, symptom, service delivery and quality of life issues have been prioritised, providing staff working with IBD patients with a list of research topics for future research.

Only two of the priorities identified in this project map onto those reported through a partnership with the James Lind Alliance (JLA)<sup>6</sup>. Whilst the latter clearly focuses on basic science, and medical and surgical management of IBD, only management of bowel symptoms (diarrhoea / incontinence) and of fatigue appear in both the JLA partnership and the currently-reported priority lists. The JLA partnership also prioritises the role of diet in managing IBD, and the issue of pain management. Although both these topics were included at the Round Three stage of our study, questions addressing dietary issues and pain in IBD did not score high enough to enter the top ten (20<sup>th</sup> and 24<sup>th</sup> position respectively). The under-prioritising of dietary issues may have been influenced by the low numbers of dieticians participating in the survey.

Differences in priorities reported in this study compared to the JLA partnership may also be a reflection of the type of participants involved in each project. Our findings are heavily driven by IBD nurses, who appear to express a different set of priorities to the doctors, nurses, AHPs and patients participating in the JLA partnership project. Rather than placing these in opposition, we suggest that our findings augment and expand the understanding of the wide range of issues which, for different clinical groups, are considered priorities for research.

### *Limitations*

There were methodological challenges within this study. Firstly, the number of participants reduced between rounds. The potential for participants to withdraw is well-documented<sup>18-21</sup>. There are no guidelines on acceptable panel size, although there is a suggestion that more than 30 is unnecessary<sup>21</sup>. Factors which influence panel size include the geographical spread of participants, and availability of pre-existing evidence relating to the subject under review. It can be argued that a larger participant panel may be required to gain consensus across several countries, and where there is no existing evidence on the topic. Loss of participants can introduce response bias, since those contributing to the process at the start may differ from those involved at the end<sup>20</sup>. In this study, surveys were administered on the team's behalf to nurse and AHP members of ECCO, and it is not known whether the 58 participants involved in the final round had all participated in the preceding rounds. It is therefore not possible to comment on any actual or potential response bias. However, as there is no requirement for participant panels to be representative samples<sup>18</sup>, any alterations in panel membership may be mitigated by the quality of the remaining respondents.

A further challenge refers to the use of between-round feedback. The Delphi technique indicates that when surveys are returned, panellists may also receive their own previous feedback and the anonymous responses of other panellists, enabling them to amend their original responses in light of the overall feedback, if they desire<sup>19,20</sup>. The technique can be criticised for facilitating regression towards the mean – panellists whose opinions differ from those of the majority, may feel co-erced to change their responses to come in line with the majority opinion. In this study, we provided a summary of the responses gathered in the previous round, when sending out the survey for the subsequent round, and always provided the opportunity for panellists to make additional comments, allowing expression of issues not addressed in each survey. We did not know the identity of our panel members, could not link responses to panel members, and by not providing inter-round feedback enabled independent and unbiased responses. This strategy adds credibility to the results since

without influence from others responses, similar topics were initially suggested and ultimately ranked with comparable importance<sup>22</sup>.

A further point refers to whether panellists are equal in experience. When a study is concerned with clinical intervention, specialists in that clinical area are considered appropriate<sup>23</sup>. Recruiting participants from varied backgrounds to create a heterogeneous group (in the case of this study, different professional groups delivering IBD care, with a range of years of experience) enhances credibility and transferability of results. The diversity within the panel leads to consensus based on a greater variety of perspectives<sup>24</sup>.

The identification of research topics may be influenced by those with specific interests responding to the survey, and favouring certain topics. The majority of current members of N-ECCO and registered AHP members of ECCO did not participate. The provision of the survey in English only, and online, may have precluded participation. AHPs and some European countries were under-represented. Nurses dominated the survey and so the priorities may not be representative of AHP groups. Involvement of patients via the European Federation of Ulcerative Colitis and Crohn's Associations (EFCCA) may have enhanced the results.

## Conclusion

The identification of the list of research priorities can guide and support the development of research projects to provide evidence in the areas most needed to support the delivery of patient centred care by IBD nurses. The identified list of priorities should augment the work of EFFCA<sup>17</sup> and the partnership work with the James Lind Alliance<sup>6</sup> in establishing healthcare professional and patient priorities, to support the delivery of evidence-based patient care, and to guide the future research programmes of the nursing membership of N-ECCO.

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<b>Round 1:</b> suggested questions from participants	<b>Round 2:</b> refined research topics	<b>Round 3:</b> final research questions
<p>1. How can we manage fatigue in IBD? There are several tools to help us identify fatigue in patients but very little to help us manage it on a practical level</p> <p>2. Practical tips and interventions for managing fatigue in IBD</p> <p>3. How can fatigue be best managed in people with IBD? Many patients are complaining of fatigue irrespective of their disease activity; it cannot always be explained by biochemical and/or nutritional factors. It is worth looking into the cause of fatigue and ways to manage it.</p>	<ul style="list-style-type: none"> <li>• Causes of fatigue</li> <li>• Symptom management strategies for fatigue</li> <li>• Complementary therapies in the management of fatigue</li> <li>• Psychological interventions for fatigue</li> <li>• Physical interventions for fatigue</li> <li>• Relationship between fatigue and other symptoms</li> </ul>	<ol style="list-style-type: none"> <li>1. What are the causes and associations of IBD fatigue?</li> <li>2. What interventions improve IBD fatigue?</li> <li>3. How does IBD fatigue relate to other IBD symptoms?</li> </ol>

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4. Pain and fatigue are the most common problems faced by patients. How do we manage this better?

These are recurring issues that I quite often feel powerless about. It has such a huge impact on quality of life and emotional wellbeing.

5. Pain can be associated with extra intestinal manifestations of disease process. Important that pain pathways are understood and patients are treated safely and effectively

6. Symptom clusters - are there relationships between anxiety and depression, and symptoms of pain, incontinence and fatigue, for example; these directly impact on quality of life. Important to think about treating all symptoms, not just one.

- Causes of pain in IBD
- Role of nutrition in pain management
- Physical interventions to manage pain
- Psychological interventions to manage pain
- Holistic techniques to manage pain

- Prevalence and inter-relationship of symptoms
- Symptoms occurring together
- The relationship between physical and psychological symptoms

1. What are the causes and associations of pain in IBD?
2. What interventions improve IBD pain?
3. What is an efficient and effective management pathway for assessing and managing IBD pain?

1. What is the prevalence and inter-relationship of different symptoms in IBD (How often do symptoms arise, do groups of symptoms occur together, and influence each other?)

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**Table 1: Sample of topics identified in the ‘Symptom management’ theme, showing progress from initial suggestions in Round 1, through refinement of research topics in Round 2, to generation of final research questions in Round 3**

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Topic	Examples
<b>Bowel symptoms</b>	1. Interventions for managing bowel symptoms (frequency, urgency, diarrhoea); 2. Role of diet in relieving bowel symptoms; 3. Nurse-delivered interventions for incontinence
<b>Communication</b>	1. Communication (online, telephone or face to face); 2. Effectiveness of patient forums / discussion boards; 3. Value of patient support groups / IBD organisations
<b>Patient finances</b>	1. The financial cost of having IBD for the patient; 2. Loss of earnings; 3. Insurance / travel
<b>Decision-making</b>	1. Decision-making (how healthcare professionals make decisions about care); 2. Patient choice about medical and surgical treatment options for their IBD; 3. Patient involvement in decision-making about care
<b>Education</b>	1. Patient education about self-management of medical treatment, such as increasing or decreasing doses according to symptoms; 2. Information for IBD nurses and AHPs on IBD-related diet and nutrition; 3. Establish an international IBD education / certificate
<b>Fatigue</b>	1. Symptom management strategies for fatigue; 2. Relationship between fatigue and other symptoms; 3. Psychological interventions for fatigue
<b>Social and cultural factors</b>	1. Cultural diversity (people of different origins, religions and traditions, and the impact of this on the IBD experience); 2. Intellectual ability / health literacy (ability to find and understand illness / medical / hospital information and make informed choices about care)
<b>Nutrition and diet</b>	1. Role of diet in symptom management; 2. Nutrition assessment tools; 3. Patients views on the role of diet in IBD
<b>Patient care</b>	1. Organisation of IBD services; 2. Patient pathways of care; 3. Waiting times and access; 4. Meeting quality indicators
<b>Pain in IBD</b>	1. Causes of pain in IBD; 2. Pain care pathway / algorithm; 3. IBD nurses delivering pain management interventions
<b>Patient-based measures</b>	1. PROMs to evaluate the value of the IBD nurse; 2. Patient needs analysis; 3. Patient satisfaction with IBD service
<b>Psychological</b>	1. The role of psychotherapy in IBD; 2. Anxiety and depression in IBD; 3. The role

<b>variables</b>	of stress on symptoms
<b>Quality of life</b>	1. Use of quality of life questionnaires in clinical practice; 2. Impact of IBD surgery on quality of life; 3. Impact of IBD on quality of life for the whole family unit; 4. Impact of perianal Crohn's on quality of life
<b>Family planning and sexual activity</b>	1. Reproductive health and IBD; 2. Family planning in IBD; 3. Impact of IBD on sexual activity
<b>Role of the IBD nurse</b>	1. Value of the IBD nurse (clinical / cost-benefit); 2. Variance of the role of the IBD nurse across Europe and between hospitals; 3. Legal considerations related to tele-health services
<b>The IBD MDT</b>	1. The role and function of the MDT in IBD; 2. Impact of psychologist-care on IBD patient outcomes; 3. Patient access to a dietician for IBD
<b>Self-management of IBD</b>	1. Patient education and self-management; 2. Role of e-health (electronic sources / systems) in self-management; 3. Patient self-management and course of disease
<b>Symptom management</b>	1. Symptom Management in IBD; 2. Prevalence and inter-relationship of symptoms; 3. The relationship between physical and psychological symptoms
<b>Impact of IBD on work and school</b>	1. Impact of the IBD nurse on enabling work and school attendance; 2. Impact of symptoms on work and school attendance; 3. Factors influencing employment status (whether the patient can work fulltime, part-time or has to retire due to IBD)

**Table 2: The research topics suggested by participants, with examples developed from Round One responses for Round Two of the survey**

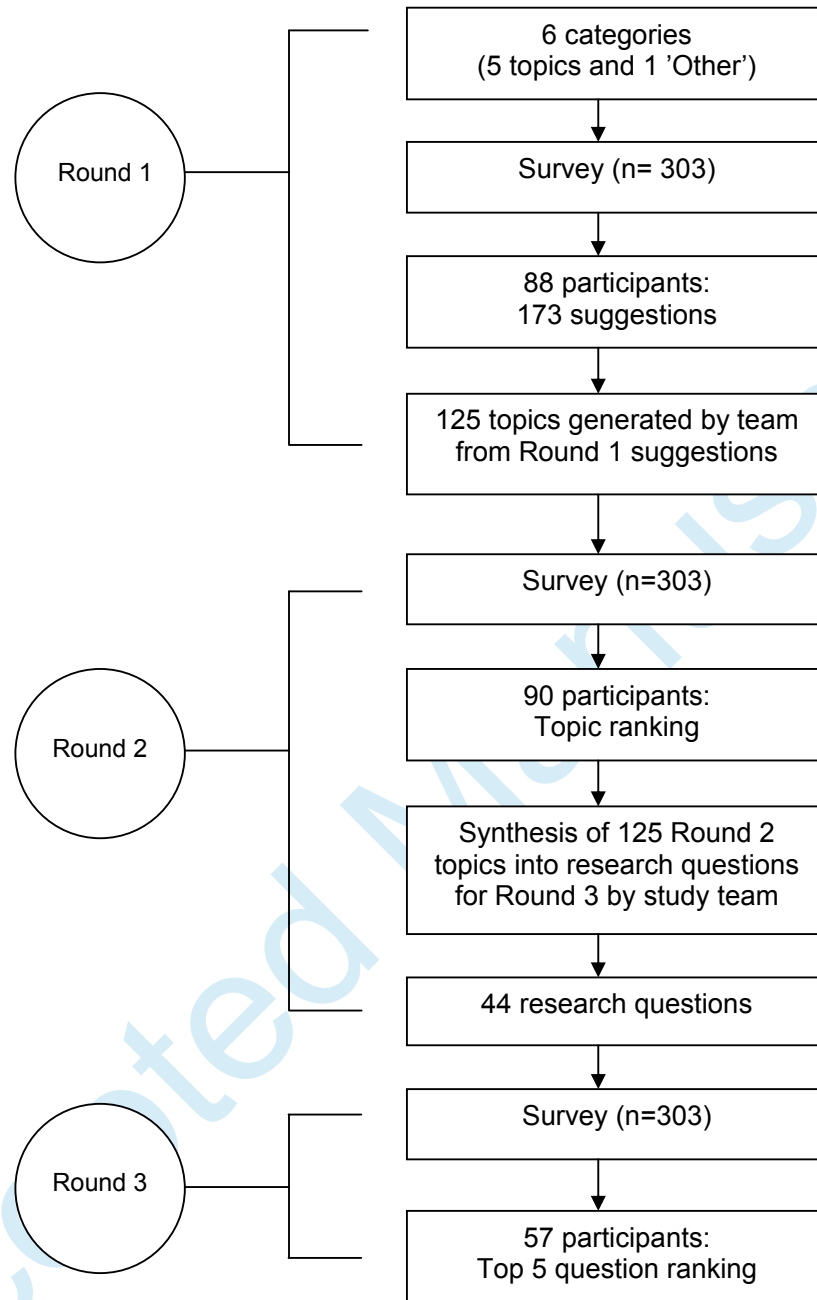
Abbreviations: IBD, inflammatory bowel disease; AHP, allied health professionals;

PROMs, Patient Reported Outcome Measures; MDT, multidisciplinary team

<b>% of votes</b>	<b>Questions by percentage of participants including each question in their top 5</b>	<b>Rank order</b>	<b>Questions ranked by calculation of weighted scores</b>	<b>Weighted score</b>
34.5	What patient education interventions improve self-management of IBD?	1	What patient education interventions improve self-management of IBD?	55
22.4	What is the role of the IBD nurse in improving patient outcomes and quality of life?	2	What interventions improve bowel symptoms (frequency, diarrhoea, incontinence) in IBD?	54
22.4	What interventions improve bowel symptoms (frequency, diarrhoea, incontinence) in IBD?	3	What is the role of the IBD nurse in improving patient outcomes and quality of life?	39
20.7	Which pathways of care produce optimum clinical outcomes and patient satisfaction in IBD?	4	What interventions improve IBD fatigue?	36
17.2	What should be the quality indicators for an IBD service?	5	Which pathways of care produce optimum clinical outcomes and patient satisfaction in IBD?	35
17.2	What is the role of psychological symptoms (anxiety, depression, stress) in exacerbating other IBD symptoms?	6	How do health care professionals make decisions about what care to offer patients with IBD?	32
17.2	What interventions improve IBD fatigue?	7	What interventions improve psychological symptoms (anxiety,	28

			depression, stress) in IBD?	
17.2	What are the relative strengths and weaknesses of different modes of communicating with patients with IBD (face to face, online, telephone)?	8	What are the education needs of health professionals relating to IBD?	27
15.5	How do health care professionals make decisions about what care to offer patients with IBD?	9	What is the cost-effectiveness of an IBD nurse?	27
15.5	What decision tools support patients in making an informed choice between treatment options?	10	What is the role of psychological symptoms (anxiety, depression, stress) in exacerbating other IBD symptoms?	25

**Table 3: Top 10 priorities for IBD nursing research according to percentage of participants ranking each in their top five (column 2), and by calculation of weighted scores (column 4)**



**Figure 1** Flow-chart outlining the processes of the three survey rounds