




# BMJ Open Healthcare professionals' priorities for training to identify and manage distress experienced by young people with a stoma due to inflammatory bowel disease: a consensus study using online nominal group technique

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## ABSTRACT

**Objectives** Young people with a stoma due to inflammatory bowel disease (IBD) commonly experience distress; however, this is not always well managed in clinical settings. More effective support may/is likely to reduce the possibility of individuals experiencing sustained distress, which may engender depression or anxiety. This study aimed to gain consensus among a multidisciplinary group of healthcare professionals (HCPs) on priorities for training in the identification and management of distress in this population. One of the authors is a young person with a stoma.

**Design** Participants were recruited through Twitter (X) and the researchers' clinical/research contacts. Two consensus group meetings were conducted using Nominal Group Technique, involving participants generating, discussing and rating on a Likert scale, topics for inclusion in an HCP training package.

**Setting** Online video conferencing. Participants were located across England, with one based in the USA.

**Participants** Nineteen HCPs participated: three general practitioners, three stoma nurses, two IBD nurses, nine clinical psychologists and two gastroenterologists.

**Results** Twenty-five topics were generated by participants; 19 reached consensus of ≥80%, that is, a mean of ≥5.6 on a 7-point Likert scale. These included: recognising and validating different levels of, and variation in, distress; tackling stigma and normalising having a stoma; everyday practicalities of stoma management, including food and sleep; opening and holding conversations about stoma-related distress; considering the impact of different cultural beliefs on adaptation after stoma surgery; training in simple techniques for gauging the patient's distress during clinical encounters; having conversations about body image; and myth-busting common fears, such as odour.

**Conclusions** This study is the first to identify HCP training priorities for managing stoma-related distress in young people. Consensus was reached for 19 topics, reflecting

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The Nominal Group Technique method used is a strength of the study, enabling a systematic approach to identification and rating of topics, with each participant's views given equal weighting.
- ⇒ We were able to bring together multidisciplinary healthcare professionals in online consensus group meetings, allowing for the inclusion of a range of clinical perspectives and expertise.
- ⇒ A limitation is the gender imbalance in the participant sample; 18 female healthcare professionals participated and only 1 male.
- ⇒ Nearly half of the participants were clinical psychologists (9), which may have led to a preference towards psychological therapies; however, a wide range of areas for managing stoma-related distress reached final consensus.

the varied needs of young people with a stoma. Findings will inform development of a training package for HCPs treating young people with IBD and a stoma.

## INTRODUCTION

Inflammatory bowel disease (IBD) refers to a group of inflammatory conditions affecting the gastrointestinal tract, the major types of which are ulcerative colitis and Crohn's disease. Both conditions follow a relapse–remission pattern and can cause similar symptoms, including abdominal pain, vomiting, bloody diarrhoea and weight loss. While medical therapy for IBD has advanced in recent years with the widespread international use of biological therapies, stoma surgery may still be required for



individuals with severe symptoms, or those who do not respond to medical management.<sup>1</sup> This involves removal of the inflamed bowel and creation of an opening in the abdomen through which faeces are collected in a bag attached to the skin.

IBD is commonly diagnosed between the ages of 15 and 25, and given that the need for stoma surgery for IBD is highest in the first 10 years after diagnosis,<sup>2</sup> living with a stoma is a possibility faced by many people between the ages of 16 and 35<sup>3</sup> (from here on throughout this paper, people within this age-range will be referred to collectively as 'young people'). Adapting to the bodily and lifestyle changes associated with a stoma can cause distress for young people. In this context, we consider distress as a broad spectrum of emotional or psychological responses that includes worries and concerns that may initially be considered normative in the context of stoma surgery, but which can also persist over time, with high levels of distress potentially indicating depression or anxiety.<sup>4,5</sup>

Several clinical guidelines highlight the need for ongoing healthcare support for individuals to manage the emotional and psychological impact of stoma surgery.<sup>6-8</sup> However, in our previous qualitative research with young people with an IBD stoma and healthcare professionals (HCPs) who manage these patients (general practitioners (GPs), IBD nurses, stoma nurses, gastroenterologists, colorectal surgeons), we found that stoma-related distress in this population was often not identified and discussed and/or was suboptimally managed in clinical settings.<sup>9</sup> For instance, when concerns were communicated young people felt that these concerns were not taken seriously or appropriately addressed.

There are several possible reasons for this lack of attention to stoma-related distress in the healthcare setting. Several HCPs can be involved in the management of young people with a stoma across the care pathway, including GPs, practice nurses, specialist IBD nurses and stoma nurses, as well as consultant gastroenterologists and colorectal surgeons. Our qualitative findings revealed some equivocation from young people with a stoma and HCPs as to which of these professional groups is best placed to address mental health needs related to living with a stoma.<sup>9</sup> Some HCPs also reported lacking training and knowledge—for GPs, this related to knowledge about stomas; while stoma nurses reported a lack of formal training in identifying distress or other mental health needs.<sup>9</sup> Additionally, the increased time and resource pressures faced in healthcare settings mean that the practical aspects of stoma care may be given priority, such as proficiency in changing the stoma bag. These factors combined indicate a range of barriers to effective management of stoma-related distress in young people.

It is clear from the evidence that more effective support for distress in young people with IBD and a stoma is needed at any early stage,<sup>10</sup> to improve their quality of life and reduce the possibility that distress, which may initially be normative, could persist or worsen, and potentially lead to a diagnosis of depression.<sup>11</sup> In the current UK National Institute for Health and Care Research (NIHR)-funded Stoma Support Study, we are co-designing with young people and HCPs an intervention to support the management of stoma-related distress in young people with IBD, aged 16–35. The proposed intervention will comprise two parts: (1) an online resource to help young people to self-manage distress and (2) a brief information and training package for HCPs involved in the care of this group, to enhance the identification and management of stoma-related distress. This paper focuses on part 2 of the planned intervention, the information and training package. Part 1 is the focus of a separate, linked paper.<sup>12</sup>

The need for improved identification and management of stoma-related distress in clinical settings has also been identified elsewhere in the literature<sup>10 13 14</sup>; however, no previous studies have explored ways to address this need in relation to young people. To address this gap, this study aimed to gain consensus among a multidisciplinary group of HCPs on the priority areas for HCPs to receive training in to identify and manage distress experienced by young people, aged 16–35, with IBD who are living with stoma. This relates to any HCPs involved in treatment throughout the young person's stoma surgery journey, including the preoperative, perioperative and postoperative periods.

## METHODS

### Study design

In this study, we used a consensus groups method, an approach that can 'identify and measure areas where incomplete evidence exists for decision-making',<sup>15</sup> and which has increasingly been used in developing healthcare interventions. The consensus groups method adopted was Nominal Group Technique (NGT).<sup>16</sup> This is a systematic approach to building consensus through structured meetings with groups of individuals (commonly between 9 and 12 per group<sup>17</sup>), who have expertise on a particular topic. NGT follows a set of stages that involves participants initially generating topics on a defined issue in the meeting, which they then share with the rest of the group. All topics are then anonymously rated by participants. Following this, the results of the ratings are discussed among the group and can then be re-rated individually, with participants given the opportunity to change their ratings based on the group discussions. We aimed to include a geographically diverse group of professionals, therefore the NGT method was adapted for online data

collection, with meetings hosted on the Microsoft Teams videoconferencing platform. Consensus group meetings were videorecorded using the Microsoft Teams recording function. Online NGT methods have been used successfully in other recent studies to develop health interventions.<sup>18</sup> The stages of the NGT process are described in detail below.

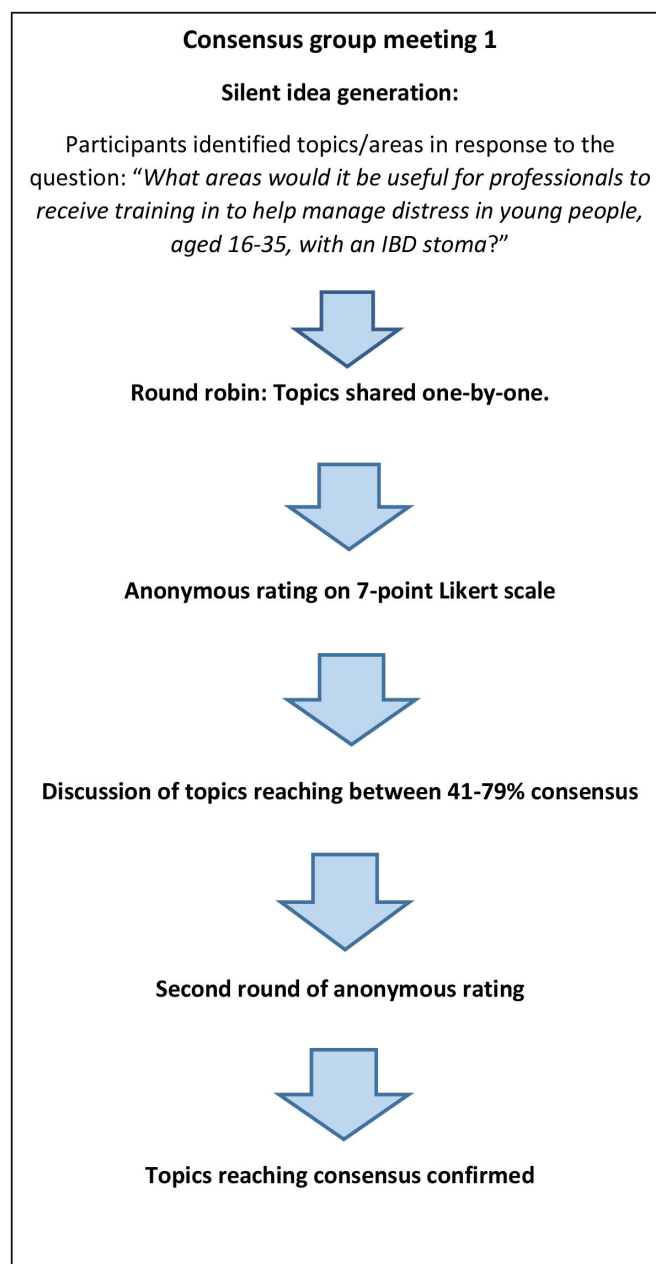
### Patient and public involvement and engagement (PPIE)

A group of nine young people who have previously had stoma surgery, recruited via social media advertising, provided ongoing advice and input on the study. PPIE members are aged between 18 and 37; six of whom are female and three male, located across England and Wales. Eight have an ileostomy and one has a colostomy. Time since stoma surgery among the group ranged from 2 and half months to 10 years (average 3 years). One of the PPIE group members, MM-H, is a coauthor on this article. The PPIE group met with the research team for four 2-hour virtual meetings, giving input on the aims and purpose of the study, recruitment methods and interpretation of the NGT findings. This allowed us to gain the perspectives of individuals who have been patients in IBD and stoma care services on the priorities for training identified by the HCPs.

### Participant recruitment

HCPs in various roles related to caring for young people with IBD and a stoma (including GPs, clinical psychologists, stoma care nurses, IBD nurses and gastroenterologists) were eligible to participate in the study. HCPs were also eligible if they worked in mental health services and had worked with young people across the 16–35 age-range, even if they had not worked in gastroenterology/IBD services. HCPs were eligible to take part irrespective of the country in which they worked. As far as possible, we intended to recruit HCPs who had worked in their clinical role for at least 5 years, to ensure a good level of experience in managing distress and/or stoma-related issues experienced by young people. However, as explained in the Results section, later, a pragmatic recruitment decision was made in relation to three participants who had under 5 years' clinical experience, but who had personal experience of IBD and/or a stoma. Following discussion among the research team, it was felt that these participants could bring unique insights that could be beneficial to the identification of training priorities, and the decision was therefore made to include these participants.

Participants were recruited through a flyer posted on *Twitter (X)*, as well as through the research team's existing clinical and research contacts, which involved asking contacts to share information about the study on staff mailing lists and with relevant professional and research groups. We did not recruit any participants who we knew personally or worked with. HCPs interested in participating contacted the research team directly, via email or *Twitter (X)*, following which they were sent a participant



**Figure 1** Outline of stages of Nominal Group Technique group 1.

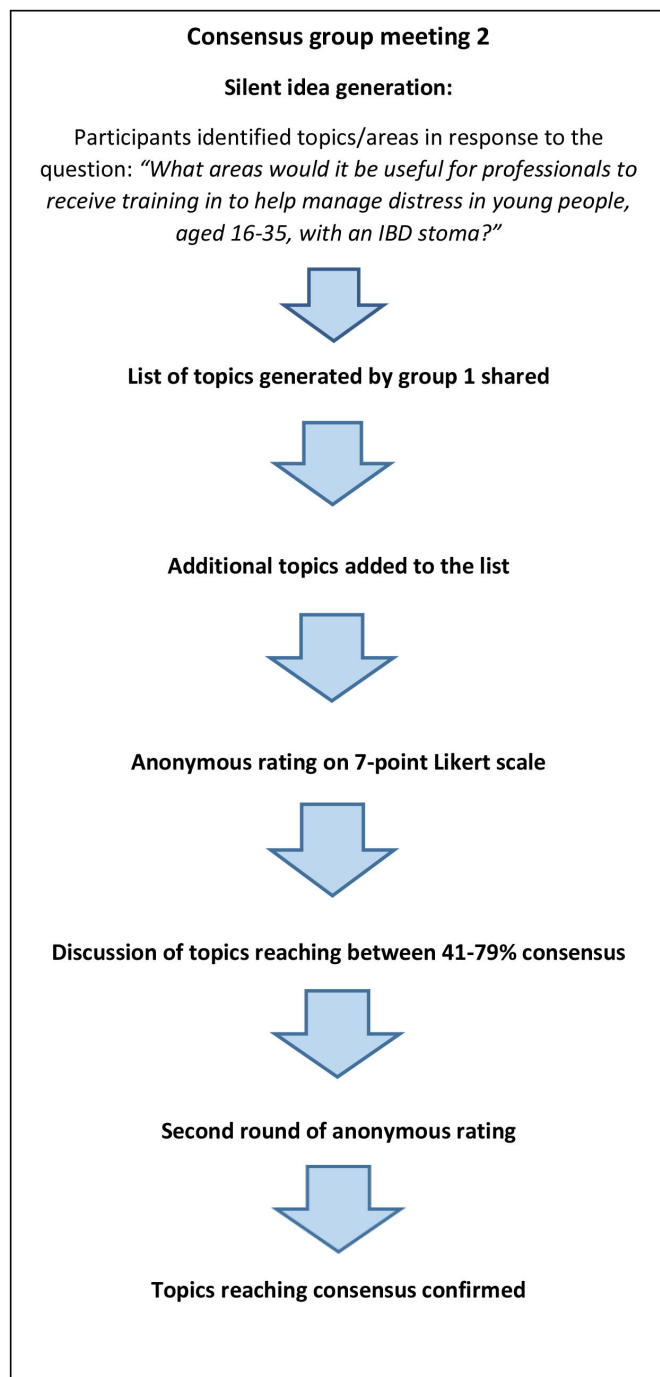
information sheet and consent form via email. Having confirmed participation, HCPs were later emailed to arrange a convenient date and time for the consensus group meeting. Written consent was given via email prior to meetings and reaffirmed verbally at the beginning of the consensus group meeting.

### Ethics

Ethical approval for the study was granted by the Faculty of Medicine and Health Sciences Research Ethics Committee at Keele University (0038).

### NGT meetings

Two online NGT meetings were held in June and July 2022 with a different group of HCPs attending each meeting.



**Figure 2** Outline of stages of Nominal Group Technique group 2.

Each group was run by three researchers with experience in using NGT and similar methods. The ‘pre-elicitation technique’<sup>19</sup> was used, that is, providing participants with a summary of existing evidence to inform their decision-making. This can facilitate participants in beginning to think about the subject area prior to the meeting, as well as a way to supplement and reinforce (or challenge) their thinking based on their own clinical practice. Prior to the meetings, participants were emailed evidence maps

summarising findings from our qualitative research with young people and HCPs, mentioned earlier<sup>9 20</sup> (online supplemental files A and B); and a summary of clinical guidelines on managing IBD- and stoma-related distress and psychological concerns.

In meeting 1, following an overview of the study and NGT process, participants were asked to spend 5 min silently generating topics in response to the question: ‘What areas would it be useful for professionals to receive training in to help manage distress in young people, aged 16–35, with an IBD stoma?’. It was explained to participants that this referred to current, qualified HCPs working in practice, as well as future HCPs. Participants were then asked to choose one to two topics to share with the group in ‘round robin’ fashion.

The researchers transferred the list of topics to an online voting platform (www.mentimeter.com). Participants used their mobile phones to access this platform and rated each topic on a 7-point Likert scale, in terms of the perceived importance of each for managing stoma-related distress (7=extremely important; 1=not at all important). Ratings given by each participant were kept anonymous. Ratings were displayed live as mean averages across the group, and those topics reaching  $\geq 80\%$ , that is, an average of  $\geq 5.6/7$  on the Likert scale, were considered as reaching consensus. Those with lower than 40%, that is,  $\leq 2.8/7$ , were discarded.

Topics with 41–79% agreement (2.9–5.5/7) were then discussed further among the group, followed by a second round of rating to allow for changes of opinion in light of these discussions. This discussion allowed for the exchange of views and debate on the relative merits and demerits of these topics, with participants given the opportunity to rerate these topics in light of these discussions. Discussion data were used to supplement and contextualise the ratings data but were not formally analysed. Participants consented to use of their quotations from the discussion as part of their consent to take part in the study.

Those topics not reaching 80% consensus were then discarded after the second round of rating. The 80% consensus threshold used was based on existing NGT literature which argues that a higher threshold, signalling a stronger level of agreement, indicates more robust evidence for intervention or policy development.<sup>21</sup>

Meeting 2, which was with a different group of HCPs, followed a similar structure, except following the silent topic generation phase participants were shown the full list of topics from meeting 1, and asked to add anything to the list that they felt was missing. Therefore, at the anonymous rating stage the group rated the topics from meeting 1 as well as the additional topics they had proposed. The stages of the two NGT meetings are displayed in figures 1 and 2.



**Table 1** Participant characteristics

Consensus group 1		Consensus group 2	
Healthcare role	1 IBD nurse 3 Stoma care nurses 2 GPs 1 Gastroenterologist (paediatrics) 3 Clinical psychologists (2 worked in gastroenterology/stoma services; 1 worked in community mental health with young people)	Healthcare role	1 IBD nurse 1 GP 1 Gastroenterologist 6 Clinical psychologists (2 worked in gastroenterology/stoma services; 4 worked in community or acute mental health with young people)
Gender	10 females 0 males	Gender	8 females 1 male
Length of time in role	1–21 years (mean 8 years, 4 months)	Length of time in role	1–19 years (mean 7 years, 4 months)
Geographical location	3 South East England 1 South West England 3 North West England 3 Midlands of England	Geographical location	1 USA, East Coast 5 North West England 2 East of England 1 South East England

Following meeting 2, the participants from meeting 1 were recontacted and asked to give ratings via email for the additional topics generated in meeting 2, on the same 7-point scale. This ensured that participants from both groups had rated the same list of topics. The ratings for all topics were then averaged across all participants, and the final percentage of consensus calculated for each topic. Those topics receiving a final mean rating of  $\geq 80\%$  across both groups were confirmed as the priorities for HCPs to receive training in to manage stoma-related distress in young people with IBD.

In what follows we present the characteristics of the participant sample followed by results of the consensus group meetings.

## RESULTS

### Participant characteristics

Nineteen HCPs took part in one of two online NGT meetings (group 1=10 participants; group 2=9). Six were recruited from Twitter (X) and 13 via existing clinical and research networks. The sample included three GPs, three stoma care nurses, two IBD nurses, nine clinical psychologists and two consultant gastroenterologists, one of whom worked in paediatric gastroenterology. Of the nine clinical psychologists, four worked in gastroenterology or stoma care services and five worked in acute or community mental health settings and had experience of working with patients across the 16–35 age-range. Eighteen participants were female and one male (a gastroenterologist), and most participants had over 5 years' experience in their current clinical role. Three of the participants who had worked in their roles for less than 5 years also had IBD and/or a stoma themselves and therefore brought experiential as well as professional expertise. The length of time in their clinical role ranged from 1 to 21 years (mean:

8 years). Eighteen participants were located in different regions across England; one IBD nurse was based in the USA. **Table 1** displays characteristics of the participants, separated into groups 1 and 2.

### Priorities identified through the NGT process

#### NGT group 1 results

In meeting 1, 16 topics were generated for HCPs to receive training in to help manage young people's distress. Following the initial round of anonymous rating, 11 topics reached the  $\geq 80\%$  consensus threshold. These were:

- ▶ Recognising and validating different levels of, and variation in, distress
- ▶ Understanding key points/crucial junctures in the IBD stoma patient journey
- ▶ Information about physical issues related to stoma surgery and understanding what is 'normal' in terms of function
- ▶ Tackling stigma and 'normalising' having a stoma
- ▶ Information about referral/signposting to mental health support
- ▶ Opening and holding conversations about stoma-related distress with young people (ie, broaching this area with patients and having the confidence to hold these conversations without ending them or moving the subject on too quickly)
- ▶ Active listening techniques: not trying not to 'fix' worries
- ▶ Exploring with patients the role of family and peer support
- ▶ Considering the impact of different cultural views and beliefs on adaptation after stoma surgery
- ▶ Managing patients' expectations about surgery and adaptation to living with a stoma

- ▶ ‘Top tips’ to help young people with emotional regulation
- ▶ Recognising own distress and emotional reaction to patients
- ▶ Everyday practicalities of stoma management, for example, food and sleep hygiene
- ▶ Information on the roles of different members of the multidisciplinary team
- ▶ General lifestyle advice for young people, for example, drugs, alcohol and sex
- ▶ Information about different types of stoma surgery

These topics were taken forward for further discussion. There were no topics at  $\leq 40\%$ , which meant that none were discarded at this stage.

During the discussion of items rated between 41% and 79%, some participants explained that they had rated certain topics lower than others because these were not seen to directly relate to the management of distress, but to stoma management more broadly. This included ‘information on the roles of different members of the multidisciplinary team’ and ‘information about different types of stoma surgery’. It was also suggested that these areas are likely to be already covered through other clinical training for some HCP groups. However, there was some debate on this, as one GP participant proposed that for professionals who are not specialists in stoma care, understanding the physical and practical aspects related to different types of stomas would enable them to feel confident in having conversations about stoma-related distress with young people.

Following the second round of rating, the five topics were again rated between 41% and 79% and were therefore not considered to have reached consensus. The full ratings data are displayed in [table 2](#).

#### NGT group 2 results

In meeting 2, 9 new topics were generated, which were added to the list of those generated in meeting 1, making a total of 25 topics. Following the initial round of anonymous rating, 15 topics reached  $\geq 80\%$  consensus. Ten of the 11 topics that had reached consensus in group 1, reported above, also reached consensus in group 2, except for ‘considering the impact of different cultural views and beliefs on adaptation after stoma surgery’ which was rated 75.7% (5.3/7) in group 2. An additional five topics reached consensus in group 2:

- ▶ General lifestyle advice for young people, for example, drugs, alcohol and sex
- ▶ Training in simple techniques/tools for gauging the patient’s level of distress at the specific moment in the time
- ▶ Training in self-soothing and grounding techniques to teach patients
- ▶ Having conversations with young people about body image

- ▶ Myth-busting of common fears patients may hold, for example, odour or the bag coming off
- The remaining 10 topics fell between 41% and 79%, and again no topics were rated  $\leq 40\%$ .

During the discussion of topics rated between 41% and 79%, one of the topics focused on was ‘everyday practicalities of stoma management’. One of the gastroenterologists reported having rated this highly and argued that the effect that food and sleep hygiene has on the stoma can, in turn, have an impact on young people’s distress. They proposed that young people’s distress related to practical concerns about the stoma can often ‘be allayed with simple things’. One of the GPs, who also had a stoma themselves, put forward a case for the importance of the topic: ‘talking to patients about disclosure’. They argued that this is a particularly salient issue for young people, who may experience uncertainty about disclosing to friends and peers, and proposed that it ‘can have a massive impact on reducing distress if people have the tools for how to approach this’.

Following the second round of rating, the following three topics moved above the  $\geq 80\%$  consensus threshold:

- ▶ Having early conversations with young people when stoma surgery first becomes an option
- ▶ Talking to patients about disclosure and sharing information about the stoma
- ▶ Everyday practicalities of stoma management, for example, food and sleep hygiene

The remaining seven topics fell between 41% and 79% and were therefore discarded. The full ratings data are displayed in [table 2](#).

#### Calculating consensus across all participants

Following meeting 2, the additional nine topics generated were sent to participants from group 1 to provide ratings remotely via email. All 10 participants from meeting 1 responded and provided ratings. Six of these topics reached consensus of  $\geq 80\%$  across this group: exploring with patients the role of family and peer support; having early conversations with young people when stoma surgery first becomes an option; managing mixed emotions patients may experience; talking to patients about disclosure and sharing information about the stoma; having conversations with young people about body image; and myth-busting of common fears patients may hold, for example, odour or the bag coming off (see [table 2](#)).

The mean scores and percentage consensus for each topic across all 19 participants in the two groups were then calculated. This resulted in 19 topics reaching final consensus, which were confirmed as priorities for HCP training. The average ratings and percentage consensus for each topic in consensus groups 1 and 2, and across all participants are displayed in [table 2](#), with those topics reaching final consensus in bold and shaded.

**Table 2** Mean ratings and percentage consensus for each topic in consensus groups 1 and 2, and across all participants

Topic generated	Consensus group 1		Consensus group 2		Mean rating across the 19 participants
	Rating round 1	Rating round 2	Rating round 1	Rating round 2	
Recognising own distress and emotional reaction to patients	5.4–77.1%	5.4–77.1%	4.8–68.6%	5.3–75.7%	5.3–75.7%
<b>Recognising and validating different levels of, and variation in, distress</b>	6.5–92.9%	n/a	6.7–95.7%	n/a	<b>6.6–94.3%</b>
<b>Understanding key points/crucial junctures in the IBD stoma patient journey</b>	6.4–91.4%	n/a	6.2–88.6%	n/a	<b>6.3–90%</b>
<b>Information about physical issues related to stoma surgery and understanding what is ‘normal’ in terms of function</b>	6.2–88.6%	n/a	6–85.7%	n/a	<b>6.3–90%</b>
<b>Tackling stigma and ‘normalising’ having a stoma</b>	6.1–87.1%	n/a	5.8–82.6%	n/a	<b>5.9–84.3%</b>
<b>Everyday practicalities of stoma management, for example, food and sleep hygiene</b>	5.5–78.6%	5.5–78.6%	5.4–77.1%	5.9–84.3%	<b>5.6–80%</b>
Information on the roles of different members of the multidisciplinary team	5.3–75.7%	5.3–75.7%	4.7–67.1%	3.1–44.3%	4.2–60%
<b>Information about referral/signposting to mental health support</b>	6.5–92.9%	n/a	6.1–87.1%	n/a	<b>6.3–90%</b>
<b>Opening and holding conversations about stoma-related distress with young people</b>	6.3–90%	n/a	6.7–95.7%	n/a	<b>6.5–92.9%</b>
<b>Active listening techniques: not trying not to ‘fix’ worries</b>	6.7–95.7%	n/a	6.3–90%	n/a	<b>6.5–92.9%</b>
<b>Exploring with patients the role of family and peer support</b>	5.7–81.4%	n/a	6.1–87.1%	n/a	<b>5.8–82.9%</b>
General lifestyle advice for young people, for example, drugs, alcohol and sex	5.3–75.7%	5.3–75.7%	5.7–81.4%	n/a	5.4–77.1%
<b>Considering the impact of different cultural views and beliefs on adaptation after stoma surgery</b>	6.2–88.6%	n/a	5.3–75.7%	5–71.4%	<b>5.6–80%</b>
Information about different types of stoma surgery	5.5–78.6%	5.5–78.6%	4.8–68.8%	5.2–74.3%	5.4–77.1%
<b>Having early conversations with young people when stoma surgery first becomes an option</b>	6.1–87.1%	n/a	5.2–74.3%	5.6–80%	<b>5.8–82.9%</b>
<b>Managing patients’ expectations about surgery and adaptation to living with a stoma</b>	6.4–91.4%	n/a	6.2–88.6%	n/a	<b>6.3–90%</b>
<b>‘Top tips’ to help patients with emotional regulation</b>	5.9–84.3%	n/a	6.1–87.1%	n/a	<b>6–85.7%</b>
<b>Training in simple techniques/tools for gauging the patient’s level of distress at the specific moment in the time</b>	5.5–78.6%	n/a	6.2–88.6%	n/a	<b>5.8–82.9%</b>
<b>Managing mixed emotions patients may experience</b>	6.4–91.4%	n/a	4.8–68.8%	5.3–75.7%	<b>5.9–84.3%</b>
<b>Training in self-soothing and grounding techniques to teach patients</b>	5.4–77.1%	n/a	6.9–98.6%	n/a	<b>6.1–87.1%</b>
<b>Having conversations with young people about body image</b>	6.1–87.1%	n/a	6.2–88.6%	n/a	<b>6.1–87.1%</b>
<b>Talking to patients about disclosure and sharing information about the stoma</b>	5.6–80%	n/a	5.4–77.1%	6.2–88.6%	<b>5.9–84.3%</b>
<b>Myth-busting of common fears patients may hold, for example, odour or the bag coming off</b>	6.6–94.3%	n/a	6.2–88.6%	n/a	<b>6.4–91.4%</b>
Recognising the impact on the patient’s family	5–71.4%	n/a	5.1–72.9%	4.6–65.7%	4.8–68.6%

Continued



Table 2 Continued

Topic generated	Consensus group 1		Consensus group 2		Mean rating across the 19 participants
	Rating round 1	Rating round 2	Rating round 1	Rating round 2	
Case-finding questions, for example, to identify symptoms of anxiety and depression	5.9–84.3%	n/a	5.2–74.3%	4.6–65.7%	5.5–78.6%

## DISCUSSION

In this study, we were able to gain consensus from a multidisciplinary group of HCPs on the priority topics for professionals to receive training in to manage distress in young people, aged 16–35, with an IBD stoma. The majority (n=19) of the topics generated by participants reached the  $\geq 80\%$  consensus threshold, with eight of these reaching consensus of 90% or more. The highest rated topic was ‘recognising and validating different levels of, and variation in, distress’ which reached 94.3% consensus. This strong level of consensus across the topics generated may be surprising given that multidisciplinary groups of HCPs have been found to reach generally lower levels of consensus due to the heterogeneity in disciplinary background and clinical perspectives.<sup>22</sup> However, there are a few possible reasons for this not being the case in our findings. First, the majority of participants worked in gastroenterology and stoma care services, and two of the participants who did not work in these services had personal experience of having IBD and/or a stoma. Therefore, the participants may have similar understandings of the needs of this patient population. Additionally, participants were asked to rate topics for training that could be provided to any HCP groups who treat young people with an IBD stoma, prompting them to think broadly and with wide applicability. If they had instead been asked to identify training priorities for only one HCP group, for example, stoma nurses, it is likely that fewer topics would have reached consensus. These findings may also indicate that there are many areas that need to be prioritised in managing distress in this population, given the complexity involved in adapting to living with a stoma during this life stage.<sup>20</sup>

Previous research exploring the experiences of young people with IBD and those who have had stoma surgery has identified some similar issues that cause distress. This suggests that the priorities agreed by HCPs for the management of stoma-related distress closely align with the concerns identified by young people themselves, which is encouraging. This includes previous studies that have identified young people’s concerns about body image, odour and experiencing stigma from others.<sup>23 24</sup> Young people with IBD, some of whom had a stoma, have also reported difficulties in deciding who to disclose information to about their condition.<sup>25</sup> Addressing the mixed emotions that can be experienced following stoma surgery, which reached consensus among HCPs in the present study, was also identified in our previous qualitative research. Young people reported that following surgery they felt ‘liberated’ from IBD symptoms, yet they

also experienced negative emotions and low mood, which was not fully addressed by their healthcare team.<sup>20</sup> These similarities in the perspectives of young people with IBD and HCPs differ from research in people with a stoma due to rectal cancer, which identified a number of disparities in the perspectives of people with a stoma and HCPs towards the impact of surgery on quality of life.<sup>26</sup>

Our findings also show similarity with research literature highlighting the importance of the providing psychological support in clinical settings to help patients to adapt to living with a stoma.<sup>10</sup> This has stressed the lack of specific guidance for professionals in managing stoma-related distress, beyond the broad advice in clinical guidelines.<sup>27</sup> In relation to stoma care nurses, Burch proposed that there are ‘no optimal support system protocols ... to guide nurses in giving the best standard of care’.<sup>28</sup> This previous research literature has, however, stopped short of identifying, and gaining consensus on, priorities for training HCPs to manage stoma-related distress, as we have done in this study.

## Strengths and limitations

The NGT method used is a strength of the study, enabling a systematic approach to identification and rating of topics, with each participants’ views given equal weighting. Another strength is that we were able to bring together multidisciplinary groups of HCPs in the same online meetings, to discuss topics and bring their varying clinical perspectives and expertise.

A limitation is the lack of male participants, with only 1 of 19 identifying as male. Additionally, there were three times the number of clinical psychologists (9) when compared with any other individual HCP group, meaning there may have been preference towards psychological therapies. However, the topics that reached consensus covered several different areas for managing stoma-related distress, suggesting that this did not result in other important areas being disregarded. We also did not include any colorectal surgeons in the consensus groups, who may have added an interesting perspective given their role in performing the stoma surgery.

Another potential limitation is that, of the nine clinical psychologists, five did not work in gastroenterology/stoma services and therefore did not bring clinical knowledge of IBD/stoma care. However, these participants met the criteria for inclusion as they all worked in mental health services and had worked with young people across the 16–35 age-range; therefore, brought important



insights in managing distress in young people, although not specifically stoma-related distress.

A further limitation relates to the NGT method. There has been discussion within the methodological literature about how to combine the results from multiple NGT groups, and this represents a challenge. Key to the process in this study was that the consensus achieved was based on all participants rating all of the topics generated. This necessitated a difference in the running of the groups, whereby group 2 were shown, and given the opportunity to add to, the topics generated from meeting 1. The meeting 1 participants were then sent the additional topics generated from meeting 2 to provide their ratings following the meetings. This may represent a methodological limitation of the study. However, given that the aim of the NGT method is to reach consensus among participants, rather than gain participants' views in a neutral, objective way, sharing the topics with participants that were generated by the other groups was not problematic in terms of biasing their views.

### Conclusions and implications

This article is the first to explore the priorities of HCPs for training to identify and manage distress experienced by young people with an IBD stoma. We were able to successfully gain a strong level of consensus for 19 topics that were generated by the HCPs. These included areas related to concerns young people may have about the stoma, for example, body image, disclosure; managing expectations from an early stage in the patient journey; and upskilling HCPs to recognise and hold conversations about distress with their patients, and to deliver simple psychological techniques to reduce acute distress. As mentioned earlier, the large number of topics reaching consensus could be due to the breadth of our aims, with topics generated for any HCP group who treat this patient population across the primary and secondary care pathway. However, it is also possible the number of topics agreed on reflects the varied needs that young people with a stoma may have, indicating that training in a range of areas is required for HCPs to meet these needs.

These findings have implications for improving health-care provision for this group through raising awareness among HCPs of important areas to address in supporting young people with an IBD stoma, specifically in relation to their mental health needs. There is also potential for the findings to contribute to formal clinical guidelines on managing of stoma-related distress in this population.

The findings will directly inform the development of an information and training package for HCPs, to enhance the identification and management of stoma-related distress, that will be co-produced with young people with an IBD stoma and HCPs. In the next phase of the wider Stoma Support Study, we will convene a series of stakeholder workshops with young people with IBD and a stoma, and a multidisciplinary group of HCPs, who will work together in a single group along with the research team, to build on these consensus group findings. This will involve looking at each of the agreed topics (in addition

to our earlier qualitative findings and clinical guidelines on managing mental health needs in IBD stoma patients), and designing the content that will be included within these topics, that is, the key messages, information and advice for HCPs. We will also discuss within these workshops the format and methods of delivery for this training package, leading to the development of an intervention specification. Our PPIE group will also provide input on this, as well as research leads from key IBD/stoma charities who have advised on the broader study. The specification will act as a blueprint for future research in which we will build and evaluate the training package.

Along with the other part of our Stoma Support intervention—a digital resource to support young people to self-manage stoma-related distress<sup>12</sup>—this training package, when built, will have the potential to improve the identification and management of distress among this group, and thereby improve their quality of life.

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