Italian Consensus Statement for Promoting Psycho-Social Wellbeing and Engagement in the Care of Inflammatory Bowel Disease Patients

Guendalina Graffigna

Università Cattolica del Sacro Cuore Milan

Caterina Bosio (✉ caterina.bosio@unicatt.it)

Università Cattolica del Sacro Cuore Milan

Francesco Pagnini

Università Cattolica del Sacro Cuore Milan

Eleonora Volpato

Università Cattolica del Sacro Cuore Milan

Enrica Previtali

Amici Onlus

Salvatore Leone

Amici Onlus

Ferdinando D'Amico

Humanitas University

Alessandro Armuzzi

Fondazione Policlinico Universitario A. Gemelli IRCS

Silvio Danese

Humanitas University

Research Article

Keywords: patient engagement, IBD, psychological needs, quality of life, psychological support

Posted Date: July 1st, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-587615/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Inflammatory bowel diseases (IBD) are remitting and relapsing diseases that mainly interest the gastrointestinal tract. This is associated with a condition of psycho-social discomfort that prevents the affected person from living normally and deeply compromises the quality of life in terms of personal, work, and interpersonal well-being. Management of IBD patients should include not only clinical but also psychosocial aspects not only clinical but also psychosocial aspects in order to improve patients' wellbeing and quality of life. The promotion of patient engagement is an effective strategy to achieve a better patient's quality of life. Although the undoubted role of patient involvement in the decision making process, to date there is no standardized approach to promote the engagement between physicians and patients and little attention is paid to social and psychological needs of subjects with IBD.

To fill this gap, a consensus conference has been organized involving both gastroenterologists, healthcare professionals expert in IBD care and IBD patients in order to define the psychosocial needs of IBD patients and to promote their engagement in daily clinical practice.

1. Introduction

Inflammatory bowel diseases (IBD) are remitting and relapsing conditions that mainly interest the gastrointestinal tract. IBD include two heterogeneous diseases, ulcerative colitis (UC) and Crohn's disease (CD)¹. It is estimated that in Italy about 200,000 people are affected by IBD². CD and UC can occur in every age of life but the highest incidence is documented between 20 and 40 years³. IBD are chronic diseases requiring multiple interventions and continuous monitoring and adaptation processes by patients and family members². This is associated with a condition of psycho-social suffering that prevents the affected person from living normally and deeply compromises the quality of life in terms of personal, work, and interpersonal well-being². Management of IBD patients should include not only clinical but also psychosocial aspects not only clinical but also psychosocial aspects in order to improve patients' wellbeing and quality of life⁴. In this perspective, the promotion of patient engagement has proven to be an effective strategy to achieve a better patient's quality of life in various chronic care contexts (e.g. diabetes, kidney disease)⁵ and in different phases of life (e.g. childhood or adolescence)⁶. Although the undoubted role of patient involvement in the decision making process, to date there is no standardized approach to promote the engagement between physicians and patients and little attention is paid to social and psychological needs of subjects with IBD⁷.

To fill this gap, *A.M.I.C.I. association* (the Italian association of IBD patients), the *Higher Institute of Health and EngageMinds HUB - Consumer*, and the *Food & Health Engagement Research Center of the Catholic University of Milan* organized a consensus conference (see Materials and methods) involving both gastroenterologists, healthcare professionals expert in IBD care and IBD patients in order to define the psychosocial needs of IBD patients and to promote their engagement in daily clinical practice. Here, we report the literature evidence and practical recommendations emerged from the consensus process.

2. Materials And Methods

The consensus conference was conducted in accordance with the Consensus Development Program of the United States’ National Institutes of Health⁸ and was aimed to draft recommendations to answer the following three questions a priori determined by the project coordinators:

- What are suggested strategies for engaging pediatric IBD patients in their care?
- What are suggested strategies for engaging IBD adult patients in their care?
- What e-health technologies should be preferred to improve the engagement of IBD patients?

The consensus conference was held on 23rd and 24th of June. It was divided into three steps: 1) literature review on published evidence about life experiences, engagement, and psychosocial needs of IBD patients (see appendix 2 for literature review details and Volpato et. al, 2020⁹); 2) workshops with IBD experts and patients representatives; 3) drafting of statements and voting.

2.1 Participants

A purposive selection of participants was made by following two steps. 1) identification of the categories of stakeholders/actors relevant to IBD management (see Table 1) 2) identification and enrollment - for each category - of prototypical representatives (bearers of experience in the field and/or opinion leaders in the context of reference). Due to the goal of ensuring multidisciplinary in the selection of experts, no fixed criteria were a priori settled to define the extent of expertise. However we followed a broad inclusive concept of expertise such as the possess of the relevant knowledge, skills and experience in the management of IBD care. Furthermore, experts have been defined as relevant key opinionist in their field of scientific expertise. In order to guarantee the scientific standards of the process the stakeholders involved in the project were asked to sign a conflict of interest statement and to accept the Consensus conference regulation. As an assurance of the respect of the ethics and academic standards of the process the participants had to subscribe a conflict of interest statement and the regulation of the Consensus conference. The Research Team payed close attention to guarantee the equal chance for everyone to express his/her own opinion in the workshops and meetings to discuss the collected evidences. Participants had to accept the consensus conference regulation signing a document and disclosing potential conflict of interest with the aim of guaranteeing the methodological reliability of the process. Furthermore, according to the methodology of Consensus Conference approach, an organizational structure for the Consensus Process was set up as described in table 2¹⁰. A detailed list of participants in the different roles is provided in the Appendix 1.

Table 1. Participants to the consensus conference

Stakeholders	N (%)
Medical doctors*	27 (37)
Pediatricians	10 (14)
Psychologists	13 (18)
Nurses	5 (7)
Patients	11 (15)
Healthcare political decision makers	7 (9)
Total	73 (100)

*10 women and 17 men

Table 2: The role in the Consensus Conference

ROLE	RESPONSIBILITIES
Organizing Committee	Was responsible for: - defining the aims of the conference; - finding financers; - identifying members of the Technical-Scientific Committee (TSC); - writing the protocol with the TSC; - promoting the conference; - organizing the different phases of the program; - identifying members of the Panel Jury; - formulating, in agreement with the Technical-Scientific Committee, the queries for the Panel Jury; - giving directions and methodological support to the Experts for the preparation of the reports to present to the Panel Jury; - defining the distribution and measuring strategies of the impact of the recommendations produced
Technical-Scientific Committee	Was composed of members with recognized experience and representativeness identified and invited by the Organizing Committee and was responsible for: - collaborating with the Organizing Committee for the writing of the Consensus Conference protocol; - formulating the queries for the Panel Jury, in accord with the Organizing Committee; - internally designating its Experts and the eventual work groups needed to prepare and present to the Jury the reports of the single queries during the conference; - providing the Experts and the work groups with the necessary methodological directions to write the assigned reports and make sure that a common method is used to analyse data and present it to the Jury.
Panel Jury	Had the authority to: - write a regulation of discussion in which the methods and procedures that the Jury will apply internally are defined a priori, including the composition of the Writing Committee; - read and evaluate the documents produced from the work groups; - assist to the presentation and discussion of the reports during the meetings of the Consensus Conference; - discuss, review and approve the preliminary consensus document to present at during closing time of the conference; - review and approve the final consensus document according to the modalities and times provided by the regulation.

President of the Jury	Had the authority to: - write the work regulation and get the Jury's members to approve it; - verify that all the members of the Jury promptly receive the materials produced by the experts and work groups; - coordinate the Jury and the Writing Committee until the writing of the final consensus document; - regulate the unfolding of the Jury's discussions, ascertain the poll results and countersign the meeting's reports; - maintain the relationships with the Organization Committee and act as a conduit for communications directed to the Jury; - take part in the celebration of the Consensus Conference; - publicly communicate, at the end of the Jury's discussion, the conclusions reported in the approved preliminary consensus document.
Writing Committee	Formed by members selected from the Jury, this Committee reflects the competences and characteristics of the Panel's multidisciplinary, provided the newsroom with the final consensus document, following the modalities established and described in the Jury regulation. This document is an integration of the preliminary document that the Jury will produce in the hours following the Consensus Conference with a synthesis of the tasks that the Panel based itself on to formulate the recommendations. Moreover, the Writing Committee verified the coherence between the conclusions and the accompanying texts.
Scientific Secretariat	coordinated the collected and exchanged material and information between the different participants involved
Organizational Secretariat	coordinated the operative organization of the conference
Members of the Expert Meetings	Held the role of assessing and synthesizing the evidence present in literature that were pertinent to the queries of the Consensus Conference. Particularly, they had the following jobs: - preparing a synthesis of the scientific evidence available on the subject; - preparing a synthesis of the information available to the public that comes from different sources, regarding the subjects of interest in the conference; - handing the reports made to the Jury, within the stipulated times; - presenting the data collected during the celebration of the conference and participate in the discussion.

2.2 Literature Review

A systematic search of the scientific literature was conducted in electronic databases from January 2009 to October 2019 in accordance with the approach defined by Arksey and O'Malley¹¹ and the PRISMA extension for scoping reviews¹². A detailed description of the literature review process is provided in the appendix 2⁹(See appendix 2 for a detailed description of the literature review process).

2.3 Workshops

Five workshops were organized. The theme of technology was developed in one workshop, while the themes of needs and interventions were each articulated in two workshops (one focused on the developmental age and one on the adult age). All workshops involved a balanced mix of IBD experts and patients' representatives following the maximum variety coverage criterion. The workshops – moderated in a non-directive approach ¹³– had a scheduled duration of 4 hours. The moderators ensured the engagement and equal participation of patients and caregivers advocates in all the meetings. The documents generated during the workshops were discussed, revised, enriched and consensualized by the Panel of Jury participants in order to reach a collegial approval.

2.4 Consensus statements

Finally, the jury panel (to see the composition of the jury panel see appendix 1) revised the workshop reports in order to elaborate the final statements of the consensus. The jury panel, discussed, drafted, voted and approved the final document. The statements included in the paper were selected on the basis of a twofold criterion of 1) being approved by the majority of the panel members; 2) having received no overt expression of dissent.

3. Results

Seventy-three participants were involved in the consensus conference including IBD experts from different scientific and professional fields and representatives of patient associations (Table 1).

The available literature evidence on this topic has also been previously reported more broadly by Volpato and colleagues ⁹.

3.1. Psycho-social needs and methods to improve the engagement of pediatric IBD patients in their management

3.1.1 Literature Evidence

Psychosocial needs of pediatric patients with IBD include three main topics: transmission of information/knowledge, psychological/psychotherapeutic interventions, and promotion of psychosocial support¹⁴. An adequate communication of information to the patient (literacy) is associated with a better disease management with possible positive effects on coping competences, perception of self-efficacy, and satisfaction with the services received^{14,15}. On this point, there are problems of continuity in the flow

of information related to organizational dysfunctionality¹⁶, especially in the moment of transition between structures dedicated to pediatric and to adult age. Pediatric IBD patients experience a higher rate of psychological problems (e.g. depression, sense of helplessness, anxiety, family problems, and school difficulties) compared with the general population, requiring more psychological support¹⁷⁻²². Several validated psychodiagnostic tools are available for the management of IBD, including the Pediatric Quality of Life (PedsQL) Family Impact Module²³, the KidScreen-10²⁴, the IBD Specific Anxiety Scale (IBD-SAS)²⁵, and the Children's Depression Inventory (CDI)²⁶. Interestingly, most psychotherapeutic treatments showed to be effective in terms of clinical management of disease and psychological support to the patient²⁷⁻³⁰. Finally, attention should be paid to the psychosocial support to the pediatric IBD patient³¹. This could be done in various methods such as narrative exchange of experiences, self-help groups, mapping strengths and weaknesses of patients and their network of social support, development of coping and problem-solving skills, integration of peers/family contexts/care settings³². In this patient associations can play a big role³³. The transition in the management of IBD from childhood to adulthood should also be considered, supporting the integration between these phases both in terms of patient's personal identity and health organization and coordination of the operators involved^{34,35}. Importantly, the cooperation between physicians and nurses in this transition period is crucial to ensure an optimal management³⁶⁻³⁸. In addition, the connection between health care professionals and school/life contexts has been associated with improved patient care³⁹⁻⁴⁵. Of note, an uncomfortable social context could lead to negative behaviors such as personal isolation, feelings of embarrassment/humiliation in relationships, and difficulty in formulating requests for help^{46,47}. The role of family and caregivers is relevant in the management of IBD patients during childhood, but to date it is still poorly explored⁴⁸. On the other hand, appreciable results on caregivers' quality of life and disease management capabilities were reported after psychological and social support interventions^{49,50}. The coordination between different professional figures (e.g. health professional, psychologist, nutritionist, and social worker) could improve the synergy in responding to specific psycho-social needs of patients and support patient engagement in the care process⁵¹⁻⁵⁴.

3.1.2 Final Consensus Statement

Based on literature evidence, attention should be given to the psychological needs of pediatric IBD patients. In this scope, the experts claimed for the following recommendations.

Patients should be managed through a multidisciplinary approach

Different professionals should be involved in the management of pediatric IBD patients including physicians (Gastroenterologists, radiologists, surgeons, pediatricians, rheumatologists, dermatologists, ophthalmologists, and general practitioners), nurses, psychologists, nutritionists, and social workers.

Patients with IBD should be provided with early psychological screening and psychosocial support

Patient psychology should be investigated already at the time of IBD diagnosis to promptly identify patients at risk of psychological and social distress⁵⁵. The assessment should consider the social and psychological status of the patient in order to intervene on targeted psychotherapeutic plan and/or on a psychosocial plan to promote adaptation and self-management, as well as to build a proactive role (engagement) in the management of disease impacting on quality of life. Patient's distress should be evaluated at each follow-up visit and/or hospital access⁵⁶.

Psychosocial support should be provided to the patient's family / caregiver

There is little evidence about the distress of family and caregivers of IBD patients⁵¹. More studies are needed to deepen the interventions dedicated to them, as well as to define their role in the management of pediatric IBD patients.

Connection with the school

It is necessary to provide an adequate information on IBD at school and to promote collaboration between health care givers and teaching staff to prevent disease-related stigma and the loss of educational continuity during relapses or hospitalizations.

Awareness of IBD in the general population should be increased

Greater awareness of IBD in the general population are necessary to limit the formation of social stigma and contain its negative effects on patient life⁵⁷. A recent survey conducted by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) found that patient organizations play a key role in reducing fears and worries of IBD patients.³³ For this reason, close cooperation between physicians and patient associations is desirable in order to promote the dissemination of information to IBD patients and to ensure an optimal management.

Patients transitioning from pediatrics to adulthood should be managed through the combined work of pediatric and adult experts (transitional ambulatory)

Pediatric and adult professionals should be involved in the management of patients with intermediate age to guide therapeutic decisions⁵⁸.

3.2 Psycho-social needs and methods to improve the engagement of adult IBD patients in their management

3.2.1 Main Evidence

A higher proportion of psychological distress (e.g. anxiety and depression) is detected in adult IBD patients than in both general population and patients with other diseases^{59,60}. IBD patients may have an altered perception of their body image, resulting in a negative impact on subjective well-being^{61,62}. In addition, IBD-related fatigue is associated with a decrease quality of life⁶³. Regarding human

relationships, adult IBD patients tend to social withdrawal and experience considerable difficulties in adapting to daily and working life due to the unpredictability of the disease course^{64,65}. Several psychotherapeutic and psychosocial interventions are available to achieve adequate levels of well-being and quality of life. In this context, different initiatives have been proposed including a focus on diet, physical activity, sleep⁶⁶⁻⁷⁰, and restoration of a good social relationship^{68,69,79,80,71-78}. Effective clinical and social management of IBD requires the active involvement of health care stakeholders and health care organizations implicated in this condition^{81,82}. To date, there is a gap between the level of information on disease provided by health professionals and that required by patients^{83,84 85}. An appropriate transmission of information is a prerequisite for the development of patient engagement⁸⁶. Interestingly, engagement programs should involve not only the patient but also the family, caregivers, and care team^{81,82}. With regard to the care team, programs were developed to improve communication skills strengthening the physician-patient relationship^{40,83,87}. Similarly to pediatric patients, the psychosocial needs should be taken into account in a multidisciplinary perspective also in adult IBD patients in order to integrate the performances of health professional (doctors, nurses...) and lay people (family members, caregivers, and patients' associations)⁸⁸. Consequently, the involvement of non-medical personnel in the management of patients and caregivers should be enhanced^{71-74,89}. Growing evidence shows that the physician should be accompanied by a figure (case manager) who coordinates the interactions between patient, hospital, and any other parties⁹⁰. This multidisciplinary strategy should be associated with organizational changes leading to the development of IBD unit including physicians, nurses, and psychologists to meet patient needs^{88 91} and ensure continuity of care⁹².

3.2.2 Final Consensus Statement

Based on the indications offered by the literature, the experts formulated seven recommendations for the management of IBD patients.

Integrated approach to the adult IBD patient

A multidisciplinary approach is needed to take care of psycho-socio-assistential-existential needs of IBD patients. Dedicated and specialized nurses and psychologists should be integrated in the IBD team leading to the construction of IBD units.

Active patient involvement (engagement)

Effective response to patient's psychosocial needs requires the engagement of patients, family members/caregivers, and care providers through appropriate information and support interventions.

Physician-patient communication

Specific attention should be paid to physician-patient communication through communication and empathy training programs to improve the effectiveness of the therapeutic relationship. Communication

should be flexibly modulated in relation to critical moments and specific phases of the patient journey (diagnosis, pre and post-surgical phases, worsening of the condition..).

Continuity of care

It is necessary to ensure a therapeutic continuity to achieve an effective response to the psycho-social needs of patients.

Adult patient support

For the adult patient, psychological (and, if necessary, psychotherapeutic) support should be planned and implemented, to overcome critical moments and achieve/maintain good levels of quality of life.

Family and caregiver support

More attention should be paid to family members and caregivers implementing psychological/psychosocial initiatives dedicated to them⁹³.

Connections with institutions, stakeholders, and public opinion

Communication interventions should be implemented in order to improve knowledge of IBD, its psycho-social impact on quality of life, and reduce the negative effects of social stigma related to IBD⁹⁴.

3. What e-health technologies are available for engaging IBD patients?

3.3.1 Main evidence

The usefulness of e-health technologies in IBD is still under study, but some research directions are already identified, such as the possibility of sharing stories and experiences to support the emotional management of one's pathology⁹⁵. E-Health is a wide term, and is referred to the utilization of information and communications technologies in the healthcare world⁹⁶. Digital technologies are an effective support to maintain therapeutic continuity and promote the physician-patient relationship even in "remote" settings⁹⁷, giving the chance to communicate without being effectively together. Moreover, they prevent the spread of fake news. In fact, patients, often use social media and apps to search for information on the pathology they suffer from with the risk of using unreliable or inaccurate sources⁹⁸.

Several tools are available^{98,99}. Web-apps can provide the patient with useful information for self-management and symptom monitoring¹⁰⁰. In adult patients, Web Apps have been recognized as valid instruments for patient education, monitoring of disease and side effects, as well as for therapeutic decisions^{97,101}. Telemedicine is defined as a communication channel between patient and physician outside the routine clinical practice (e.g.: unexpected events, need for unscheduled consultations in the

presence of unpredictable flare-ups)⁹⁷. In young and adolescent patients, a telemedicine-based approach could be useful to support the achievement of skills and competencies (self-management, adherence, therapeutic relationship satisfaction...) in the transition to adulthood, saving time, costs and ensuring disease monitoring¹⁰². Finally, social media play an elective role in sharing experiences and promoting social support¹⁰². Finally, groups and disease-related web pages represent an important "place" for the creation of a lay network of sharing and support, in particular when physical participation is not possible or complicated¹⁰³.

3.3.2 Consensus Statement

Based on the available evidence, three statements were approved with reference to new technologies.

Further studies on usability and effectiveness of e-health technologies should be promoted

The use of e-health technologies requires further research with respect to usability and effectiveness.

Personalized interventions should be planned according to the characteristics of the target audience

The e-health technologies to be used should be chosen on the basis of available tools, patient targets, and combination between target and tool specificity (e.g.: a too sophisticated technology for an old patient could not work because too difficult for him to use).

Interventions should be planned according to the demonstrated utility

The choice of specific e-health technologies should be justified by its proven usefulness (e.g. sharing of experiences among patients, therapeutic continuity, and prevention of fake news).

4. Discussion

IBD disease has an undoubted impact on patients' quality of life with important consequences at psychosocial level¹⁰⁴. However, psychosocial support for IBD care is still underestimated and there is no clear consensus on priorities for interventions. In addition, although patient engagement is a crucial target in chronic care, often this appears to be an abstract principle and it is not applied to clinical practice¹⁰⁴. Based on these considerations, we conducted a consensus conference to animate a scientific, multidisciplinary, and inclusive debate in which IBD patients could participate together with scientists and healthcare professional aimed at improving psycho-social wellbeing and engagement of IBD patients. This project was the occasion to bridge expertises, visions, and concerns from multiples scientific disciplines and with the peculiar and crucial expertise of the patients about their needs and priorities. So, a democratic, constructive and collaborative endeavor was enabled along the whole consensus process and this in itself constitute a best practice for innovation of IBD care practices. The consensus statements emerged offer a complex and integrated framework aimed to track the

specificities of the psycho-social unmet needs of patients along their life-cycle and in the different phases of the patient journey. Early detection of psycho-social needs of patients is the first priority for achieving a truly patient centered and participative approach to IBD care. A second crucial step concerns the design and implementation of an organic approach to the promotion of patient and caregiver/family engagement. This approach requires not only the development of an effective information activity (literacy), but also of adequate psychological and psychosocial initiatives aimed at fostering active involvement in the management of IBD. To this end (third step), it is also necessary to educate and sensitize all the different healthcare professionals involved in the IBD care in order to support not only the Engagement of the patient/caregiver but also of the healthcare organizations in charge of the management of the disease (with specific attention to the hospital-territory connection). Fourth, a better sensitive and personalized use of the different digital health technologies today available can contribute to achieve these goals, but in the light of further education activities about a more proficient and aware use of such devices. Finally, an intervention on public opinion, stakeholders and health policy makers is important to improve the representation and management of IBD in society, free from the prejudices of stigma. In this perspective, the role of patient associations may play a fundamental role in such transformation process as a catalyst of the cultural shift required both from the healthcare professionals and the IBD patients side. This Consensus Conference happened in Italy, but the experts involved have a international clinical and scientific know how on the Conference's theme and they ground their affirmations on scientific evidences. These recommendations should be seen as inspirational principles to promote an enhanced awareness about IBD patients' unmet needs and priorities in their healthcare and as a potential starting point to a paradigmatic shift in the treatment of IBD diseases aimed at a truly patient centered and participative medicine approach. Although preliminary and needing further cross-cultural validation and consolidation, we are confident that this contribution can be taken as a reference framework -on a cultural, theoretical and operational level- by health policy makers for the design of services able to ensure the best health outcomes and the highest levels of quality of life for IBD patients.

5 Limitations

Even if the consensus Statement process has been broad, deep and inclusive there were a few limitations. First, any generalizations from the literature review or workshops must be done carefully being that they represent the specific experience and perspectives of the individuals included in the process, and a forthcoming replica of the consensus process in a wider international scenario would be useful to also include the experiences of other scientists on the topic. Another limitation is connected to the national nature of this Consensus Conference. The habits of clinical practice of IBD may change in different countries and local communities. Nonetheless, although this consensus was set up in Italy, the participating experts reputable international clinical and scientific know how on the theme of the conference and elaborated their recommendation accordingly to international scientific evidence. Finally, these recommendations are not meant to be rigorous standards of practice. They are a scientific systematization of best practices in the IBD sector. These recommendations should be taken as inspiring concepts to promote an effective engagement eco-system in IBD.

Of course, the most important passage of the process is the transposition of this principles inoperative day by day practice through use of validated scientific instruments and practices to be applied in educative interventions and in medical care in IBD scenario. Furthermore, the Consensus Conference process needs to be intended as a psycho social intake process itself: patients and their caregivers have been thoroughly included during the whole process of gathering evidence, discussion, and prioritization. So, this Consensus Conference is on its own an Engagement process in order to establish criteria and standards for effective psychosocial care of the IBD patient and to enable more successful transfer of the findings of research into real-world medical practice. The transition to a true culture of psychosocial care at all levels of the health care system will be the essential basis for a concrete realization of new best practices capable of enhancing the role of patients and their caregivers throughout the care pathway.

Abbreviations

A.M.I.C.I. Onlus: Associazione Nazionale per le Malattie Infiammatorie Croniche dell'Intestino

IBD: inflammatory bowel disease

IG-IBD: Italian Group for Chronic Inflammatory Bowel Diseases

ISS: Istituto Superiore di Sanità

Declarations

Ethics approval and consent to participate

Each expert, patient and caregiver freely participated in the consensus conference. No sensitive patient data were collected.

Consent for publication

All the authors reviewed and approved this paper.

Availability of data and material

All the data and materials are provided or referenced in the paper.

Competing interests

S Danese has served as a speaker, consultant, and advisory board member for Schering-Plough, AbbVie, Actelion, Alphawasserman, AstraZeneca, Cellerix, Cosmo Pharmaceuticals, Ferring, Genentech, Grunenthal, Johnson and Johnson, Millenium Takeda, MSD, Nikkiso Europe GmbH, Novo Nordisk, Nycomed, Pfizer, Pharmacosmos, UCB Pharma and Vifor.

Funding

This project has been funded by AMICI Onlus.

Authors' contributions

GG and CB drafted the paper with the contribution of FP and EV. All the authors reviewed and approved the final draft of the paper before the submission.

Acknowledgements

The authors would like to thank AMICI Onlus and IG-IBD (Italian Group for Chronic Inflammatory Bowel Diseases) and ISS (Istituto Superiore di Sanità) for their support to the project.

References

1. Giulia R, Siew CN, Kotze PG, et al. Crohn's disease (Primer). *Nat Rev Dis Prim*. 2020,6(1).
2. Kawalec P, Malinowski KP. Indirect health costs in ulcerative colitis and Crohn's disease: A systematic review and meta-analysis. *Expert Rev Pharmacoeconomics Outcomes Res*. 2015. doi:10.1586/14737167.2015.1011130
3. Torres J, Mehandru S, Colombel J-F, Peyrin-Biroulet L. Crohn's disease. *Lancet*. 2017,389(10080):1741-1755.
4. Lönnfors S, Vermeire S, Avedano L. IBD and health-related quality of life—discovering the true impact. *J Crohn's Colitis*. 2014,8(10):1281-1286.
5. Van den Bos G, Triemstra A. Quality of life as an instrument for need assessment and outcome assessment of health care in chronic patients. *Qual Heal care QHC*. 1999,8(4):247.
6. Eiser C, Morse R. A review of measures of quality of life for children with chronic illness. *Arch Dis Child*. 2001,84(3):205-211.
7. Mikocka-Walus A, Massuger W, Knowles SR, et al. Psychological distress is highly prevalent in inflammatory bowel disease: A survey of psychological needs and attitudes. *JGH Open*. 2020,4(2):166-171.
8. Wortman PM, Vinokur A, Sechrest L. Do consensus conferences work? A process evaluation of the NIH consensus development program. *J Health Polit Policy Law*. 1988,13(3):469-498.
9. Volpato E, Bosio C, Previtali E, et al. The Evolution of IBD Perceived Engagement and Care Needs Across the Life-Cycle: A Scoping Review. 2020.
10. Graffigna G, Barelllo S, Riva G, et al. Recommendation for patient engagement promotion in care and cure for chronic conditions. [Promozione del patient engagement in ambito clinico-Assistenziale per le malattie croniche: raccomandazioni dalla prima conferenza di consenso italiana]. *Recenti Prog Med*. 2017,108(11):455-475. doi:10.1701/2812.28441
11. O'Malley L. Scoping studies: towards a methodological framework AU-Arksey, Hilary. *Int J Soc Res Methodol*. 2005,8:19-32.

12. Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med.* 2018;169(7):467-473.
13. Tynan AC, Drayton JL. Conducting focus groups—a guide for first-time users. *Mark Intell Plan.* 1988.
14. Moradkhani A, Kerwin L, Dudley-Brown S, Tabibian JH. Disease-specific knowledge, coping, and adherence in patients with inflammatory bowel disease. *Dig Dis Sci.* 2011. doi:10.1007/s10620-011-1714-y
15. Gumidyala AP, Plevinsky JM, Pouloupoulos N, Kahn SA, Walkiewicz D, Greenley RN. What teens do not know can hurt them: An assessment of disease knowledge in adolescents and young adults with IBD. *Inflamm Bowel Dis.* 2017;23(1):89-96. doi:10.1097/MIB.0000000000000974
16. Benchimol EI, Fortinsky KJ, Gozdyra P, Van Den Heuvel M, Van Limbergen J, Griffiths AM. Epidemiology of pediatric inflammatory bowel disease: A systematic review of international trends. *Inflamm Bowel Dis.* 2011. doi:10.1002/ibd.21349
17. Greenley RN, Hommel KA, Nebel J, et al. A meta-analytic review of the psychosocial adjustment of youth with inflammatory bowel disease. *J Pediatr Psychol.* 2010. doi:10.1093/jpepsy/jsp120
18. Fuller-Thomson E, Sulman J. Depression and inflammatory bowel disease: Findings from two nationally representative Canadian surveys. *Inflamm Bowel Dis.* 2006. doi:10.1097/00054725-200608000-00005
19. Graff LA, Walker JR, Bernstein CN. Depression and anxiety in inflammatory bowel disease: A review of comorbidity and management. *Inflamm Bowel Dis.* 2009. doi:10.1002/ibd.20873
20. Neuendorf R, Harding A, Stello N, Hanes D, Wahbeh H. Depression and anxiety in patients with Inflammatory Bowel Disease: A systematic review. *J Psychosom Res.* 2016. doi:10.1016/j.jpsychores.2016.06.001
21. Bokemeyer B, Hardt J, Hüppe D, et al. Clinical status, psychosocial impairments, medical treatment and health care costs for patients with inflammatory bowel disease (IBD) in Germany: An online IBD registry. *J Crohn's Colitis.* 2013. doi:10.1016/j.crohns.2012.02.014
22. Jelenova D, Prasko J, Ociskova M, et al. Quality of life and parental styles assessed by adolescents suffering from inflammatory bowel diseases and their parents. *Neuropsychiatr Dis Treat.* 2016;12:665-672.
23. Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL™ family impact module: preliminary reliability and validity. *Health Qual Life Outcomes.* 2004;2(1):55.
24. Ravens-Sieberer U, Erhart M, Rajmil L, et al. Reliability, construct and criterion validity of the KIDSCREEN-10 score: a short measure for children and adolescents' well-being and health-related quality of life. *Qual life Res.* 2010;19(10):1487-1500.
25. Reigada LC, Moore MT, Martin CF, Kappelman MD. Psychometric evaluation of the IBD-specific anxiety scale: a novel measure of disease-related anxiety for adolescents with IBD. *J Pediatr Psychol.* 2018;43(4):413-422.
26. Sitarenios G, Kovacs M. Use of the Children's Depression Inventory. 1999.

27. Szigethy E, Kenney E, Carpenter J, et al. Cognitive-behavioral therapy for adolescents with inflammatory bowel disease and subsyndromal depression. *J Am Acad Child Adolesc Psychiatry*. 2007;46(10):1290-1298. doi:10.1097/chi.0b013e3180f6341f
28. Keerthy D, Youk A, Srinath AI, et al. Effect of psychotherapy on health care utilization in children with inflammatory bowel disease and depression. *J Pediatr Gastroenterol Nutr*. 2016. doi:10.1097/MPG.0000000000001207
29. Levy RL, van Tilburg MAL, Langer SL, et al. Effects of a Cognitive Behavioral Therapy Intervention Trial to Improve Disease Outcomes in Children with Inflammatory Bowel Disease. *Inflamm Bowel Dis*. 2016;22(9):2134-2148. doi:10.1097/MIB.0000000000000881
30. van den Brink G, Stapersma L, El Marroun H, et al. Effectiveness of disease-specific cognitive-behavioural therapy on depression, anxiety, quality of life and the clinical course of disease in adolescents with inflammatory bowel disease: study protocol of a multicentre randomised controlled trial (HAPPY-I. *BMJ open Gastroenterol*. 2016;3(1):e000071. doi:10.1136/bmjgast-2015-000071
31. Szigethy E, Whitton SW, Levy-Warren A, DeMaso DR, Weisz J, Beardslee WR. Cognitive-behavioral therapy for depression in adolescents with inflammatory bowel disease: a pilot study. *J Am Acad Child Adolesc Psychiatry*. 2004;43(12):1469-1477. doi:10.1097/01.chi.0000142284.10574.1f
32. Jelenova D, Prasko J, Ociskova M, et al. Psychoeducation of adolescents with inflammatory bowel diseases and their families. 2016;58(1):33-39.
33. D'Amico F, Rahier J-F, Leone S, Peyrin-Biroulet L, Danese S. Views of patients with inflammatory bowel disease on the COVID-19 pandemic: a global survey. *lancet Gastroenterol Hepatol*. 2020;5(7):631-632.
34. McCartney S. Inflammatory bowel disease in transition: challenges and solutions in adolescent care. *Frontline Gastroenterol*. 2011;2(4):237-241. doi:10.1136/fg.2010.002741
35. Gray WN, Resmini AR, Baker KD, et al. Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: Perspectives of patients, parents, and health professionals. *Inflamm Bowel Dis*. 2015. doi:10.1097/MIB.0000000000000419
36. Elkins G, Whitfield P, Marcus J, Symmonds R, Rodriguez J, Cook T. Noncompliance with behavioral recommendations after bariatric surgery. *Surg Obes Relat Dis*. 2005;1(3):287. doi:10.1016/j.soard.2005.03.186
37. Cho R, Wickert NM, Klassen AF, Tsangaris E, Marshall JK, Brill H. Identifying Needs in Young Adults With Inflammatory Bowel Disease. *Gastroenterol Nurs*. 2018;41(1):19-28.
38. Donegan A, Boyle B, Crandall W, et al. Connecting families: A pediatric IBD center's development and implementation of a volunteer parent mentor program. *Inflamm Bowel Dis*. 2016;22(5):1151-1156. doi:10.1097/MIB.0000000000000733
39. Timmer A, de Sordi D, Menke E, et al. Modeling determinants of satisfaction with health care in youth with inflammatory bowel disease: a cross-sectional survey. *Clin Epidemiol*. 2018;10:1289.
40. Mayberry JF, Lobo A, Ford AC, Thomas A, Group GD. NICE clinical guideline (CG152): the management of Crohn's disease in adults, children and young people. *Aliment Pharmacol Ther*.

2013,37(2):195-203.

41. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *J Adolesc Heal.* 1993,14(7):570-576. doi:10.1016/1054-139X(93)90143-D
42. Campbell F, Biggs K, Aldiss SK, et al. Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database Syst Rev.* 2016. doi:10.1002/14651858.CD009794.pub2
43. Cooley WC. Adolescent health care transition in transition. *JAMA Pediatr.* 2013. doi:10.1001/jamapediatrics.2013.2578
44. Afzali A, Wahbeh G. Transition of pediatric to adult care in inflammatory bowel disease: Is it as easy as 1, 2, 3? *World J Gastroenterol.* 2017. doi:10.3748/wjg.v23.i20.3624
45. Cole R, Ashok D, Razack A, Azaz A, Sebastian S. Evaluation of Outcomes in Adolescent Inflammatory Bowel Disease Patients Following Transfer from Pediatric to Adult Health Care Services: Case for Transition. In: *Journal of Adolescent Health.* , 2015. doi:10.1016/j.jadohealth.2015.04.012
46. van Tilburg MAL, Claar RL, Romano JM, et al. Psychological factors may play an important role in pediatric Crohn's disease symptoms and disability. *J Pediatr.* 2017,184:94-100.
47. Vedrana V, Bramhagen A-C, Idvall E, Wennick A. Swedish Children's Lived Experience of Ulcerative Colitis. *Gastroenterol Nurs.* 2017,00(00). doi:10.1097/SGA.0000000000000295
48. Zmeskalova D, Prasko J, Holubova M, et al. Unmet psychosocial needs in adolescents with inflammatory bowel disease. *Neuroendocrinol Lett.* 2016,37(5):395-402.
49. Guilfoyle SM, Denson LA, Baldassano RN, Hommel KA. Paediatric parenting stress in inflammatory bowel disease: Application of the Pediatric Inventory for Parents. *Child Care Health Dev.* 2012. doi:10.1111/j.1365-2214.2010.01200.x
50. Guilfoyle SM, Gray WN, Herzer-maddux M, Hommel KA. Parenting stress predicts depressive symptoms in adolescents with inflammatory bowel disease. *Eur J Gastroenterol Hepatol* 26964–971. 2014,26:964-971. doi:10.1097/MEG.0000000000000149
51. Wang Z, Zhong J, Zhou X, et al. Illness perceptions and stress: mediators between disease severity and psychological well-being and quality of life among patients with Crohn's disease. *Patient Prefer Adherence.* 2016,Volume 10:2387-2396. doi:10.2147/ppa.s118413
52. Lindström C, Åman J, Anderzén-Carlsson A, Lindahl Norberg A. Group intervention for burnout in parents of chronically ill children – a small-scale study. *Scand J Caring Sci.* 2016,30(4):678-686. doi:10.1111/scs.12287
53. Halmos EP, Gibson PR. Dietary management of IBD—insights and advice. *Nat Rev Gastroenterol Hepatol.* 2015,12(3):133.
54. García-Vega E, Fernandez-Rodriguez C. A stress management programme for Crohn's disease. *Behav Res Ther.* 2004. doi:10.1016/S0005-7967(03)00146-3
55. Parekh NK, Shah S, McMaster K, et al. Effects of caregiver burden on quality of life and coping strategies utilized by caregivers of adult patients with inflammatory bowel disease. *Ann*

- Gastroenterol.* 2017,30(1):89-95. doi:10.20524/aog.2016.0084
56. Porcell P, Leoci C, Guerra V. A prospective study of the relationship between disease activity and psychologic distress in patients with inflammatory bowel disease. *Scand J Gastroenterol.* 1996,31(8):792-796.
57. Gamwell KL, Baudino MN, Bakula DM, et al. Perceived Illness Stigma, Thwarted Belongingness, and Depressive Symptoms in Youth with Inflammatory Bowel Disease (IBD). *Inflamm Bowel Dis.* 2018,24(5):960-965. doi:10.1093/ibd/izy011
58. Goodhand JR, Greig FIS, Koodun Y, et al. Do antidepressants influence the disease course in inflammatory bowel disease? A retrospective case-matched observational study. *Inflamm Bowel Dis.* 2012. doi:10.1002/ibd.21846
59. Moser G. Should we incorporate psychological care into the management of IBD? *Nat Clin Pract Gastroenterol Hepatol.* 2006. doi:10.1038/ncpgasthep0549
60. Filipović BR, Filipović BF, Kerkez M, Milinić N, Randelović T. Depression and anxiety levels in therapy-naïve patients with inflammatory bowel disease and cancer of the colon. *World J Gastroenterol.* 2007. doi:10.3748/wjg.v13.i3.438
61. Muller KR, Prosser R, Bampton P, Mountifield R, Andrews JM. Female gender and surgery impair relationships, body image, and sexuality in inflammatory bowel disease: Patient perceptions. *Inflamm Bowel Dis.* 2010. doi:10.1002/ibd.21090
62. Pittet V, Vaucher C, Froehlich F, et al. Patient self-reported concerns in inflammatory bowel diseases: A genderspecific subjective quality-of-life indicator. *PLoS One.* 2017,12(2):1-16. doi:10.1371/journal.pone.0171864
63. Norton C, Czuber-Dochan W, Bassett P, et al. Assessing fatigue in inflammatory bowel disease: Comparison of three fatigue scales. *Aliment Pharmacol Ther.* 2015. doi:10.1111/apt.13255
64. Keefer L, Taft T. A systematic review of disease-related stigmatization in patients living with inflammatory bowel disease. *Clin Exp Gastroenterol.* 2016;49. doi:10.2147/ceg.s83533
65. Leso V, Ricciardi W, Iavicoli I. Occupational risk factors in inflammatory bowel disease. *Eur Rev Med Pharmacol Sci.* 2015,19(15):2838-2851.
66. Hood MM, Keshavarzian A. Sleep Quality in Ulcerative Colitis: Associations with Inflammation , Psychological Distress , and Quality of Life. 2018.
67. Graff LA, Vincent N, Walker JR, et al. A population-based study of fatigue and sleep difficulties in inflammatory bowel disease. *Inflamm Bowel Dis.* 2011,17(9):1882-1889. doi:10.1002/ibd.21580
68. Kakodkar S, Mutlu EA. Diet as a Therapeutic Option for Adult Inflammatory Bowel Disease. *Gastroenterol Clin North Am.* 2017,46(4):745-767. doi:10.1016/j.gtc.2017.08.016
69. Schreiner P, Yilmaz B, Rossel J-B, et al. Vegetarian or gluten-free diets in patients with inflammatory bowel disease are associated with lower psychological well-being and a different gut microbiota, but no beneficial effects on the course of the disease. *United Eur Gastroenterol J.* 2019,7(6):767-781. doi:10.1177/2050640619841249

70. Limdi JK, Aggarwal D, McLaughlin JT. Dietary Practices and Beliefs in Patients with Inflammatory Bowel Disease. *Inflamm Bowel Dis*. 2016;22(1):164-170. doi:10.1097/MIB.0000000000000585
71. Goodhand JR, Wahed M, Rampton DS. Management of stress in inflammatory bowel disease: A therapeutic option? *Expert Rev Gastroenterol Hepatol*. 2009. doi:10.1586/egh.09.55
72. Von Wietersheim J, Kessler H. Psychotherapy with chronic inflammatory bowel disease patients: A review. *Inflamm Bowel Dis*. 2006. doi:10.1097/01.mib.0000236925.87502.e0
73. McCombie AM, Mulder RT, Gearry RB. Psychotherapy for inflammatory bowel disease: A review and update. *J Crohn's Colitis*. 2013;7(12):935-949. doi:10.1016/j.crohns.2013.02.004
74. Knowles SR, Monshat K, Castle DJ. The efficacy and methodological challenges of psychotherapy for adults with inflammatory bowel disease: A review. *Inflamm Bowel Dis*. 2013. doi:10.1097/MIB.0b013e318296ae5a
75. Ewais T, Begun J, Kenny M, et al. A systematic review and meta-analysis of mindfulness based interventions and yoga in inflammatory bowel disease. *J Psychosom Res*. 2019;116(November):44-53. doi:10.1016/j.jpsychores.2018.11.010
76. Britt RK, Britt RK. Online Social Support for Participants of Crohn ' s and Ulcerative Colitis Groups Online Social Support for Participants of Crohn ' s and Ulcerative Colitis Groups. *Health Commun*. 2017;32(12):1529-1538. doi:10.1080/10410236.2016.1234539
77. Limdi JK. Dietary practices and inflammatory bowel disease. *Indian J Gastroenterol*. 2018;37(4):284-292. doi:10.1007/s12664-018-0890-5
78. Loudon CP, Corroll V, Butcher J, Rawsthorne P, Bernstein CN. The effects of physical exercise on patients with Crohn's disease. *Am J Gastroenterol*. 1999;94(3):697-703. doi:10.1111/j.1572-0241.1999.00939.x
79. Ng V, Millard W, Lebrun C, Howard J. Low-intensity exercise improves quality of life in patients with Crohn's disease. *Clin J Sport Med Off J Can Acad Sport Med*. 2007;17(5):384-388. doi:10.1097/JSM.0b013e31802b4fda
80. Klare P, Nigg J, Nold J, et al. The impact of a ten-week physical exercise program on health-related quality of life in patients with inflammatory bowel disease: a prospective randomized controlled trial. *Digestion*. 2015;91(3):239-247. doi:10.1159/000371795
81. Chrobak-Bień1ABCDEFG J, Gawor2ADF A, Paplaczky3ADF M, Małeczka-Panas4ADF E, Gąsiorowska5ADEF A. Analysis of factors affecting the quality of life of those suffering from Crohn's disease. *Pol Przegl Chir*. 2017;89(4):16-22.
82. Gregory Jr VL. Cognitive-behavioral therapy for adults with inflammatory bowel disease: A meta-analysis of randomized controlled trials with implications for clinical social work. *J Evid Based Soc Work*. 2019;16(4):363-385.
83. Bernstein KI, Promislow S, Carr R, Rawsthorne P, Walker JR, Bernstein CN. Information needs and preferences of recently diagnosed patients with inflammatory bowel disease. *Inflamm Bowel Dis*. 2011. doi:10.1002/ibd.21363

84. Wong S, Walker JR, Carr R, et al. The information needs and preferences of persons with longstanding inflammatory bowel disease. *Can J Gastroenterol*. 2012. doi:10.1155/2012/735386
85. Wu Q, Zhong J. Disease-related information requirements in patients with Crohn's disease. *Patient Prefer Adherence*. 2018;12:1579-1586. doi:10.2147/PPA.S169706
86. Tormey LK, Reich J, Chen YS, et al. Limited health literacy is associated with worse patient-reported outcomes in inflammatory bowel disease. *Inflamm Bowel Dis*. 2019;25(1):204-212.
87. Butcher RO, Law TL, Prudham RC, Limdi JK. Patient knowledge in inflammatory bowel disease: CCKNOW, how much do they know? *Inflamm Bowel Dis*. 2011;17(10):E131-2. doi:10.1002/ibd.21810
88. Leone D, Menichetti J, Fiorino G, Vegni E. State of the Art: Psychotherapeutic Interventions Targeting the Psychological Factors Involved in IBD. *Curr Drug Targets*. 2014;15(11):1020-1029. doi:10.2174/1389450115666140627151702
89. Ewais T, Begun J, Kenny M, et al. Protocol for a pilot randomised controlled trial of mindfulness-based cognitive therapy in youth with inflammatory bowel disease and depression. *BMJ Open*. 2019;9(4). doi:10.1136/bmjopen-2018-025568
90. Carpio D, López-Sanromán A, Calvet X, et al. Perception of disease burden and treatment satisfaction in patients with ulcerative colitis from outpatient clinics in Spain: UC-LIFE survey. *Eur J Gastroenterol Hepatol*. 2016;28(9):1056-1064. doi:10.1097/MEG.0000000000000658
91. Squires SI, Boal AJ, Lamont S, Naismith GD. Implementing a self-management strategy in inflammatory bowel disease (IBD): patient perceptions, clinical outcomes and the impact on service. *Frontline Gastroenterol*. 2017;8:272-278. doi:10.1136/flgastro-2017-100807
92. Hait E, Arnold JH, Fishman LN. Educate, communicate, anticipate—practical recommendations for transitioning adolescents with IBD to adult health care. *Inflamm Bowel Dis*. 2006;12(1):70-73.
93. Kluthe C, Isaac DM, Hiller K, et al. Qualitative Analysis of Pediatric Patient and Caregiver Perspectives After Recent Diagnosis With Inflammatory Bowel Disease. *J Pediatr Nurs*. 2018;38:106-113. doi:10.1016/j.pedn.2017.11.011
94. Khan S, Dasrath F, Farghaly S, et al. Unmet Communication and Information Needs for Patients with IBD: Implications for Mobile Health Technology. 2016;12(3):1-11. doi:10.9734/BJMMR/2016/21884
95. Carlsen K, Jakobsen C, Houen G, et al. Self-managed eHealth Disease Monitoring in Children and Adolescents with Inflammatory Bowel Disease: A Randomized Controlled Trial. *Inflamm Bowel Dis*. 2017;0(0):1-9. doi:10.1097/MIB.0000000000001026
96. Sieverink F, Kelders SM, van Gemert-Pijnen JEWC. Clarifying the concept of adherence to eHealth technology: systematic review on when usage becomes adherence. *J Med Internet Res*. 2017;19(12):e402.
97. Aguas M, Del Hoyo J, Faubel R, et al. A Web-Based Telemanagement System for Patients With Complex Inflammatory Bowel Disease: Protocol for a Randomized Controlled Clinical Trial. *JMIR Res Protoc*. 2018;7(12):e190. doi:10.2196/resprot.9639;10.2196/resprot.9639
98. Bossuyt P, Pouillon L, Bonnaud G, Danese S, Peyrin-Biroulet L. E-health in inflammatory bowel diseases: More challenges than opportunities? *Dig Liver Dis*. 2017;49(12):1320-1326.

doi:10.1016/j.dld.2017.08.026

99. Bossuyt P, Pouillon L, Peyrin-biroulet L. Primetime for e-health in IBD? *Nat Publ Gr*. 2017.
doi:10.1038/nrgastro.2017.11
100. Akobeng AK, Leary NO, Vail A, et al. EBioMedicine Telephone Consultation as a Substitute for Routine Out-patient Face-to-face Consultation for Children With Inflammatory Bowel Disease: Randomised Controlled Trial and Economic Evaluation. *EBioMedicine*. 2015;2:1251-1256.
101. Knowles SR, Mickocka-Walus A. Utilization and efficacy of internet based eHealth technology in gastroenterology a systematic review.pdf. *Scand J Gastroenterol*. 2014;49(4):387-408.
doi:doi.org/10.3109/00365521.2013.865259
102. Heida A, Dijkstra A, Groen H, Kobold AM, Verkade H, Rheeinen P Van. Comparing the efficacy of a web-assisted calprotectin-based treatment algorithm (IBD-live) with usual practices in teenagers with inflammatory bowel disease: study protocol for a randomized controlled trial Comparing the efficacy of a web-assisted calp. 2015. doi:10.1186/s13063-015-0787-x
103. George LA, Cross RK. Remote Monitoring and Telemedicine in IBD: Are We There Yet? *Curr Gastroenterol Rep*. 2020;22(3):12.
104. Baker DM, Lee MJ, Jones GL, Brown SR, Lobo AJ. The Informational Needs and Preferences of Patients Considering Surgery for Ulcerative Colitis: Results of a Qualitative Study. *Inflamm Bowel Dis*. 2018;24(1):179-190. doi:10.1093/ibd/izx026

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [APPENDIX.docx](#)