

## Supplementary file 1. Search strategy

<p><b>CINAHL</b></p> <p>((TI crohn*) OR (TI ibd) OR ((TI "inflammatory bowel"))) AND (((TI "self care" OR AB "self care")) OR ((TI self-care OR AB self-care)) OR ((TI "self- management" OR AB "self- management")) OR ((TI "self management" OR AB "self management")))</p> <p>12-17-2024 N= 131</p>
<p><b>EMBASE</b></p> <p>(crohn*:ti OR ibd:ti OR 'inflammatory bowel':ti) AND (((self:ti AND (care:ti OR care:ab OR 'care'/exp) OR self:ab) AND (care:ti OR care:ab OR 'care'/exp) OR 'self care':ti OR 'self care':ab OR 'self-management':ti OR 'self-management':ab OR self:ti) AND (management:ti OR management:ab OR 'management'/exp) OR self:ab) AND (management:ti OR management:ab OR 'management'/exp)</p> <p>12-17-2024 N= 1089</p>
<p><b>PUBMED</b></p> <p>(crohn*[ti] OR ibd[ti] OR ("inflammatory bowel"[ti])) AND (("self care"[tiab]) OR (self-care[tiab]) OR ("self- management"[tiab]) OR ("self management"[tiab]))</p> <p>12-17-2024 N= 261</p>
<p><b>SCOPUS</b></p> <p>( TITLE ( crohn* ) OR TITLE ( ibd ) OR TITLE ( "inflammatory bowel" ) ) AND ( ( TITLE ( self ) AND ( TITLE ( care ) OR ABS ( care ) ) ) OR ( ABS ( self ) AND ( TITLE ( care ) OR ABS ( care ) ) ) OR TITLE ( "self care" ) OR ABS ( "self care" ) OR TITLE ( "self-management" ) OR ABS ( "self-management" ) OR ( TITLE ( self ) AND ( TITLE ( management ) OR ABS ( management ) ) ) OR ( ABS ( self ) AND ( TITLE ( management ) OR ABS ( management ) ) ) ) )</p> <p>12-17-2024 N= 639</p>
<p><b>Web Of Sciences</b></p> <p>(TI=crohn* OR TI=ibd OR (TI="inflammatory bowel" )) AND (((TI="self care" OR AB="self care")) OR ((TI=self-care OR AB=self-care)) OR ((TI="self- management" OR AB="self- management")) OR ((TI="self management" OR AB="self management")))</p> <p>12-17-2024 N= 287</p>

**Supplementary Table II.** Data extraction

Reference, year and country	Methodology/Study design	Aim	Population/Sample characteristics	Educational intervention	Self-care dimension	Barriers and facilitators for the Educational Intervention	Outcomes and Key Findings
[19], 2019, UK	RCT	To assess the feasibility and initial estimates of potential efficacy of a CBT intervention for the management of fatigue in people with IBD	n= 31 adults (≥18 years) with a diagnosis of IBD and self-reported fatigue were recruited from a tertiary outpatient clinic	CBT manual for IBD-fatigue: Printed, user-friendly manual adapted from MS-fatigue CBT. Included 8 structured, color-coded sessions with homework tasks. Content tailored to IBD-fatigue in collaboration with clinicians, patients, and communication experts	Maintenance, monitoring and management	HCPs deemed the intervention applicable, but identified time, financial, and training barriers to implementation	The intervention was acceptable to participants and feasible for clinical implementation. Reduced fatigue and improved QoL at 3, 6, and 12 months (complete case analysis)
[22]., 2009, UK	Comprehensive review	The aim of this review is to identify interventions aimed at promoting self-management of inflammatory bowel disease (IBD) and to identify their efficacy.	23 studies included. These were conducted between 1986 and 2007, most of which were in the UK (n = 6) and Canada (n = 6). The remaining studies were conducted in the USA (n = 4), Germany (n = 4), Chile (n = 1) and Sweden (n = 2).	The purpose and content of the intervention varied, with 1 study targeting coping strategies, or attempting to deal with thoughts and emotions through relaxation or group therapy. Another approach were intervention to improve doctor-patient communication or promote recognition and	Self management	Barriers reluctance to give IBD patients control over treatment changes, especially for steroids; difficulty in offering open-access clinics; and the preference of some IBD patients for a model in which all decisions are made by their healthcare providers.	The health outcomes of educational interventions are varied as is the quality of life (only 3 studies out of 13 included show an improvement). Only a few studies also show a reduction in relapses, disease activity and pain and therefore a reduction in hospital visits. Only 5 studies

				management disease. The interventions were mainly provided in the form of booklets, computers or CDs and one intervention was carried out directly from home, with the contribution of a multi-professional team.			report a better knowledge of the disease without any impact in terms of health.
[21], 2016, Germany	Randomized Controlled Trial	The aim of the study was to evaluate manualized education program in out-patients with long-lasting IBD.	The study excluded participants not meeting inclusion criteria: two due to group size limitations, 79 who withdrew for health reasons, seven who didn't complete the baseline questionnaire, and 19 who attended only one study day. The final sample included 181 participants.	The intervention followed a protocol created by gastroenterologists and a psychologist, incorporating input from experts and IBD patients. It consisted of two parts: medical information and coping/self-management skills. The program, held over a weekend, encouraged active participation and included discussions, worksheets, and relaxation techniques. Two pilot sessions were conducted for feedback.	Self Management	Not reported	The patient education program proved effective, reducing concerns and fears in participants. Improvements were seen after 2 weeks and 3 months on the IBDPC scale. It reduced fear of progression, improved anxiety management, and enhanced coping with IBD and related issues.

[23], 2016, USA	Systematic review	the aim of this study is describe self-management skills in the interventions and describe the effects of the interventions on the health-related outcomes measured	Six reports were included in this article, published between 2001 and 2014. All were randomized controlled trials (total 1815 participants for six article)	Three self-management programs included personalized plans for self management of IBD, when and how to self-start prednisone for active disease, education about when and how to contact the clinic and the system change of open-access clinics with no regular appointments and same day appointment scheduling. One intervention taught self-management skills through gut-directed self hypnosis. This intervention included two self-management skills focus on: how to solve problems around stress, how to recognize and take action around disease activity.	Self Management	Not reported	Self-management interventions show improvements in active disease. The results may depend on the disease trajectory, according to the studies. It has been observed that interventions improve quality of life in four out of five studies on disease activity. Some studies have shown improvement in depression, while others have not shown improvements in anxiety and depression scores.
[24], 2023, Japan	Systematic Review	To identify effective self-management interventions for improving patient outcomes in IBD, including symptom severity and healthcare	n= 50 study included in the synthesis (31 IBD studies; 19) on ulcerative colitis	Self-management interventions encompassed symptom monitoring, patient education, and personalized, participatory approaches.	Maintenance and management	Not reported	Symptom- and information-based self-management interventions may improve psychological well-being and reduce healthcare use in IBD patients.

		resource utilization.		Effective interventions were commonly tailored to individual needs and delivered by multidisciplinary teams, often involving non-physician HCPs.			Given the individualized nature of IBD, personalized delivery by specialized professionals with coordinated team communication is essential
[26], 2024, Iran	RCT	To compare the effect of the TB method and a smartphone application on treatment adherence in patients with IBD	n=80 individuals with IBD. Patients' mean age and duration of disease were $38.73 \pm 10.32$ and $8.93 \pm 3.68$ years, respectively. The majority of patients had ulcerative colitis (81%) and were married (67%)	TB group: Two individual teaching sessions on two different days were held for patients in this group. App group: The app was installed for patients in this group and they were taught how to use its different sections. Control group: No education was provided to patients in this group at the time of intervention	Maintenance, monitoring and management	The smartphone application was considered more cost-effective given limited healthcare resources and personnel. Its potential for continuous, updatable patient education aligns well with the chronic nature of IBD.	Both the teach-back method and the smartphone application were similarly effective in improving treatment adherence among patients with IBD, highlighting the importance of self-care education in disease management.
[25], 2016, USA	Narrative review	The aim of the review was to adopt a novel conceptualization of self-management that focused on these possible mechanisms for improving self-	Not reported	Problem solving skills training (PSST) focus on enhancing medication adherence, the quality of the patient-healthcare professional relationship, and the availability of adequate social support.	Self management, self efficacy- self maintenance	Not reported	Interventions targeting these areas have shown improvements in treatment adherence, psychosocial adjustment, and quality of life.

		management in patients with IBD of all ages					
[27], 2024, Cina	Systematic Review	To summarize high-quality evidence on mobile health-based self-management support in IBD, with the goal of informing healthcare professionals and promoting its implementation to enhance patients' self-management abilities.	n=15 record included in the synthesis	Mobile health systems—including apps, remote management tools, and social media platforms—offer portable and intelligent solutions to support self-management in IBD.	Maintenance, monitoring and management	Facilitators: Pre-use training enhances patient readiness and acceptance of mobile health systems. Training includes IBD education and system navigation, delivered via video modules or in-person sessions. Specialized nutritional support is essential to reduce malnutrition risk and improve outcomes in IBD management. Mobile health systems promote peer support and experience sharing, enhancing patient self-efficacy. Barriers: Lack of patient nutrition knowledge and limited availability of clinical staff hinder effective nutritional support for IBD patients in outpatient settings.	These systems enhance patient-provider interaction, enable remote monitoring, and provide personalized health interventions. Patients benefit from functions such as self-management support, health data tracking, and access to medical information, while providers gain tools for automated follow-up and clinical decision-making.
[32], 2022, USA	Pilot study	To test a self-management SMS text messaging intervention for	n= 105 (mean age of the participants was 29 years (range 19-53 years). Most	Text4IBD delivered 14 daily SMS messages over 2 weeks to	Maintenance and management	Not reported	The SMS-based support intervention for IBD was feasible

		individuals with IBD, assessing feasibility, acceptability, engagement, and preliminary changes in self-reported health outcomes.	participants had CD (83/114, 72.8%) or UC (22/114, 19.3%); however, a small proportion (9/114, 7.9%) self-reported other IBD diagnoses such as lymphocytic or collagenous colitis. Mean age at diagnosis was 22.32 (SD 8.32) years, and approximately half (59/114, 51.8%) of the participants had been living with IBD for ≤5 years.	participants' smartphones. Messages covered three self-management domains: Physical IBD symptoms (5 messages) IBD and mental health (5 messages) IBD and nutrition (4 messages) Each message had two components: <ul style="list-style-type: none"> <li>– Validation of a common IBD-related challenge</li> <li>– Advice/support for managing that challenge</li> </ul>			and acceptable. Participants engaged with the messages, used linked resources, and recalled key content. Improvements were observed in self-reported IBD-related distress and perceived support. The study provides preliminary evidence supporting the role of digital tools in IBD self-management.
[29], 2008, Canada	Review	Provide a framework for the use of self-management in the IBD population. Places particular emphasis on two specific concepts: the "patient passport" and the use of email.	Not reported	The <i>Patient Passport</i> is a pocket-sized card or booklet where patients record regular tests and dates, helping healthcare staff schedule them on time. <b>Email</b> serves as an effective tool for routine communication with doctors, ideal for sharing lab results, prescription details, appointments, and addressing non-urgent concerns—allowing patients to	Self-management	Low patient motivation and commitment can hinder the use of the Patient Passport, which requires consistent updating. Privacy risks arise if the passport is lost or stolen. Email use in healthcare poses challenges such as legal risks, server and device security, and the confidentiality of printed messages.	The Patient Passport improves communication among physicians, offering a clear view of care and avoiding redundant tests. It is also valuable in emergencies for efficient patient management. Doctors prefer email over phone calls due to its efficiency, traceability, and flexibility. It saves time, supports legal documentation, reduces unnecessary

				decide if a visit is needed.			appointments, and helps the environment by cutting travel-related emissions.
[30], 2017, UK	observational study	The purpose of this study is to verify the effectiveness of a flare card in the management of IBD pathology	The first consecutive 80 patients booked for routine review in January 2016 at our nurse-led clinics were sent the flare card in December 2015 before they attended.	A flare card was used: an informational leaflet given to the patient to help reduce symptoms.	Self Management	Not reported	In 53% of cases, the flare card helped control IBD; in 31% of cases, it improved adherence; in 39% of cases, it was considered effective in reducing symptoms; in 31% of cases, it led to better patient engagement in disease management. In 46% of cases, the use of an app was considered appropriate
[31], 2008, UK	Quasi experimental study (uncontrolled, non-randomized)	To evaluate the implementation of a nurse-delivered self-management education program.	Between January 2007 and January 2008, 150 patients were recruited for the self-management program (120 with ulcerative colitis (UC) and 30 with Crohn's disease).	Patients were given an outpatient appointment where they received educational intervention. Key areas of intervention were: diagnosis, treatment options, management of flares, health promotion activities (osteoporosis, smoking cessation). Materials were	Self management and self maintenance	Not reported	Reduction of follow-up appointments, greater autonomy perceived by the patient, reduction of stress in patients caused by waiting in hospital, economic savings.

				<p>provided to support them: a guide with information on IBD and a personalized plan for managing IBD and flares. Ongoing support was provided with rapid access to outpatient clinics and a telephone helpline to contact.</p>			
[20], 2022, UK	Mixed-method study	To describe the development process of a digital self-management intervention for fatigue, pain, and urgency in IBD, using theory-driven, evidence-based approaches, and stakeholder input.	n= 87 patients with IBD and 60 nurses	<p>The BOOST program is a digital intervention grounded in Cognitive Behavioral Therapy and the MRC 2008 guidance for complex interventions. It addresses fatigue, pain, and urgency in IBD through 12 web-based sessions that integrate psychoeducation with cognitive, emotional, and behavioral strategies. Participants build a personalized model of their symptom “vicious cycle” and develop skills in activity regulation, sleep hygiene, cognitive restructuring, emotional</p>		Barriers: Limited time and resources for follow-up calls; lack of adequate training for nurses.	The integration of the MRC framework with a person-based approach supported the development of a theory-informed, user-centered intervention, enhancing both content relevance and functional design.

Legend:

CBT:

				regulation, and communication. Content is tailored to IBD with patient vignettes and symptom-specific education, supporting self-care maintenance, monitoring, and management.			
[28], 2015, China	Systematic Review, Meta Analysis and Meta Regression of RCT	The purpose of this review was to identify and categorise the components of the content and structure of effective self-management interventions for patients with inflammatory bowel disease	Fifteen randomised controlled trials were included in this review	distance-based self-management, Internet-based education	Self Management, self efficacy, self maintenance	Not reported	Overall, the findings from the meta-analysis and meta-regression revealed that self-management programmes have a positive effect on the health-related quality of life (HRQoL) of patients with IBD. Notably, distance-based self-management interventions demonstrated a stronger beneficial effect.

Cognitive-behavioural Therapy; CD: Chron's disease; HCP: Healthcare Professionals'; IBD: Inflammatory Bowel Disease; MRC: Medical Research Council; MS: Multiple Sclerosis; RCT: Randomized Control Trial; TB: Teach-back; UC: Ulcerative Colitis