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A Self-led Self-management Intervention Supporting Teens with IBD (ASSIST-IBD): protocol for a feasibility study of a novel digital treatment adherence intervention

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ABSTRACT

Introduction Treatment non-adherence is common in young people with inflammatory bowel disease (IBD), yet support is lacking. A self-led self-management intervention supporting teens with IBD (ASSIST-IBD) is a new theory-based digital treatment adherence intervention, co-developed by young people living with IBD. ASSIST-IBD includes 10 short modules supporting adolescents to feel confident to follow their treatment plan, develop skills to overcome adherence obstacles, feel confident when talking to others about IBD and feel positive about the future. This research aims to determine the feasibility of implementing and measuring the effectiveness of ASSIST-IBD, using a single-arm mixed-methods feasibility trial.

Methods and analysis 24 young people (aged 13–17) with IBD identified as being ≤80% adherent, and their parents, will use ASSIST-IBD for 6–12 weeks. For the primary endpoint of progression to randomised controlled trial, qualitative and quantitative data will be collected on; number of eligible members of the target population; number of recruited participants; reasons for non-participation and ineligibility; retention and follow-up rates; reasons for early withdrawal; completeness and utility of outcome measures; as well as further data on intervention acceptability, user experiences and user engagement. Secondary outcomes of preliminary effectiveness will include pre-intervention and post-intervention measures of treatment adherence (MARS-5), quality-of-life (IMPACT-III) and well-being (WEMWBS), and self-reported behaviour change success. Quantitative data will be analysed using descriptive statistics; qualitative data will be analysed thematically. An active patient and public involvement and engagement group will advise on the research throughout, including the development of the protocol.

Ethics and dissemination The study has been granted ethical approval by Aston University's Health and Life Sciences Research Ethics Committee (ref:#HLS2112) and NHS Research Ethics Committee, Nottingham 1 Board (IRAS:#344918). Findings will be disseminated via peer-reviewed publications and lay summaries.

Registration details This protocol is registered on the Open Science Framework (https://doi.org/10.17605/OSF.IO/KC649).

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A self-led self-management intervention supporting teens with IBD is the first treatment adherence intervention for young people with inflammatory bowel disease that includes behaviours beyond medication-taking (eg, symptom monitoring, attending medical appointments and following lifestyle advice).
⇒ Involving and engaging young people throughout the feasibility study will facilitate depth in our understanding of participants' experiences and support us to identify user-led modifications.
⇒ While the digital intervention format and social media recruitment will reach a wider sample of participants, it is possible that our recruitment methods may not reach those who are disengaged from clinical care or online support.

INTRODUCTION

Affecting approximately 25 per 100 000 young people aged 10–16, in the UK,[1] inflammatory bowel disease (IBD) is common in childhood and adolescence, with disease activity typically more severe and progressive than in adults.[2–6] IBD is a collective term used to describe gastrointerological conditions including ulcerative colitis and Crohn's disease, both of which involve inflammation of the digestive system, causing debilitating symptoms including abdominal pain, fatigue and diarrhoea.[5] To successfully manage this condition, young people are required to perform a range of complex health behaviours including taking medication, symptom monitoring, attending medical appointments and following lifestyle advice.[7] Adolescence, however, is known to be a challenging stage of life, as young people learn to navigate growing independence and peer relationships.[8] Given this developmental context, it is unsurprising that

adolescents are at high risk of treatment non-adherence,[9] with rates reported as high as 93% for those with IBD.[10] The relapsing and remitting nature of IBD may further encourage non-adherence during periods of wellness.[11 12] Other reported barriers include forgetting, lack of time, treatment routine interfering with social activities, fatigue, families' views on the effectiveness of prescribed medications and embarrassment of administering medication in front of friends.[13–17]

Failing to follow a prescribed treatment plan can lead to significant clinical consequences, including poor health outcomes (eg, greater experiences of pain, fatigue and urgency; more inflammation of joints), unnecessary escalation in therapy, increased need for surgical procedures, resistance to therapy, unplanned hospitalisation and increased healthcare costs.[12] Interventions that support young people to identify their own adherence barriers and to develop action plans to overcome these barriers are needed to ensure development of key self-management behaviours in the formative years and throughout the life course. Despite this need, there is a significant lack of successful interventions to support treatment adherence in young people with IBD.[18]

Evidence suggests that digital self-management approaches can improve adherence in adolescents living with chronic conditions (eg, type 1 diabetes, asthma[19 20]), and that online interventions are as effective and more cost-effective than in-person interventions for improving well-being in young people.[21 22] While no such interventions exist in the UK for young people with IBD, a recent systematic review[18] shows that including behaviour change techniques is more effective than providing education alone for improving treatment adherence in young people with IBD. Synthesising this evidence with in-depth qualitative research findings,[18] and mapping to behaviour change theory (following a Behaviour Change Wheel approach), we have created a new digital intervention targeting key determinants of adherence in this group.

A self-led self-management intervention supporting teens with IBD (ASSIST-IBD) is an evidence-based and theory-driven, digital treatment adherence intervention co-developed by, and designed for young people (aged 13–17) living with IBD. Based on extensive qualitative research and co-production work,[18] a novel definition of treatment adherence is used within the intervention, to include three groups of behaviours: medication taking, health communication and following lifestyle advice. As directed by outcomes identified as important to young people, it incorporates behaviours associated with adherence and well-being, as well as those required for a successful transition to adulthood and adult health services. The intervention is delivered via a web-app which participants can access using user profiles provided by the research team. It contains interactive modules covering a range of topics inclusive of strategies for supporting young people in their treatment adherence behaviour (eg, education and training, problem solving, goal setting and action planning). Within each module, young people are supported to create a user-centred action plan to overcome their adherence barriers. To support transition to adulthood/services, a parental version of the intervention has also been developed. Young people will be advised to discuss their intended action plan with their parent/caregiver prior to officially setting their goal within the ASSIST-IBD programme.

While a prototype intervention has been judged by young people and parents as acceptable and beneficial, further research is needed to formally assess intervention feasibility in preparation for a definitive randomised controlled trial (RCT). A feasibility study asks whether something can be done, should we proceed with it, and if so, how. As outlined by the Medical Research Council and National Institute of Health Research, feasibility testing is an essential next step in the development of complex intervention development and evaluation.[23]

This research aims to assess the feasibility of implementing and measuring the effectiveness of ASSIST-IBD, a novel, theory-driven and evidence-based digital intervention to support treatment adherence in young people (aged 13–17) with IBD.

Objectives are:

1. To implement and evaluate the feasibility of ASSIST-IBD as a new intervention for improving treatment adherence in young people with IBD.
2. To test the feasibility of proposed methods for a definitive RCT, including identification of participants, recruitment and retention rates, acceptability, sample size, follow-up rates and outcome measurement tools.

METHODS AND ANALYSIS

Methods are reported in accordance with the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) statement[24] and the template for intervention description and replication (TIDieR) checklist.[25] The review protocol is registered on the Open Science Framework (https://doi.org/10.17605/OSF.IO/KC649).

Design

The research has a mixed-method, non-comparative design. The research will be conducted between March 2024 and December 2024. Participants will have access to the full ASSIST-IBD intervention, including 10 modules addressing self-management behaviours in young people with IBD. Following baseline measures of adherence, eligible young people (and parents) will be given up to 12 weeks to work through the intervention, at their own pace and in a way that is meaningful to their own adherence needs. Participants will be encouraged to create a profile on the web-app and to interact with intervention content, keeping a note of things they like, things that are helpful and areas for improvement. Qualitative and quantitative evaluation techniques will be used to assess acceptability and preliminary effectiveness.

Participants

Based on considerations of participant flow, budgetary constraints and number of participants required to reasonably evaluate feasibility goals,[26] 24 young people (aged 13–17) with IBD, who are identified as being ≤80% adherent to their treatment plan, will be recruited. Parents of these young people will be invited to assess the ASSIST-IBD parental resources. Recruitment and attrition rates will be monitored to inform the recruitment strategy and sample size for a subsequent RCT.

Eligibility

Inclusion criteria for young people (n=24):

- Age 13–17
- Diagnosis of IBD
- ≤80% adherent to treatment plan (determined using MARS-5)
- Able to provide assent (if aged 13–15)/consent (if aged 16–17)
- Living in the UK

Inclusion criteria for parents:

- Parent of child who meets young person inclusion criteria
- Able to provide consent for own participation
- Able to provide consent for child participation (if aged 13–15)

Intervention

Based on health behaviour theories relating to self-efficacy,[27] self-regulation[28] and resilience,[29] ASSIST-IBD consists of 10 short interactive modules that support young people to feel confident in following their treatment plan, develop skills to overcome adherence obstacles, feel confident when talking to others about their IBD and feel more positive about the future. Modules facilitate behaviour change through a mix of behaviour change techniques, education and training, social support, tailored support and action planning. Content of the modules can be tailored to meet an individual's need (eg, inputting individual treatment recommendations, identifying personal challenges). Modules contain strategies for young people to practise, delivered via short videos of other young people sharing their experiences, podcasts of young people talking about ways to overcome challenges and interactive activities (eg, quizzes). Each module concludes by guiding participants to form a user-led action plan to overcome an experienced adherence barrier. ASSIST-IBD parental resources focus on how parents can support their child to develop autonomy in managing their health and well-being.

Recruitment

Multiple recruitment strategies will be used to identify potential participants. First, the Gastroenterology team at a specialist Children's Hospital will review medical records of patients and identify those who meet the eligibility criteria relating to their age and IBD diagnosis. The Gastroenterology team will provide eligible young people and their parents with an invitation letter containing a QR code link to an age-dependent online study information pack inclusive of age-appropriate participant information sheets. Each participant information sheet includes the contact details of the research team, whom potential participants can contact to express an interest in taking part in the study and/or to ask any questions.

Second, the study will be advertised online by a specialist Children's Hospital, relevant charities (eg, Crohn's and Colitis UK) and other online support groups/social media pages for young people living with IBD. Posters advertising the study will also be placed in the Gastroenterology department at a specialist Children's Hospital. Interested young people and parents will be directed to contact the research team, after which they will be sent further information about the study, including an online study information pack (letter of invitation and age-appropriate participant information sheets). If the potential participant does not contact the research team within 1 week of receiving the information pack, the research team will contact interested families once, offering to answer any questions and asking whether they are still interested in taking part in the research. No further proactive contact will be made, but the participant will be able to contact the researcher at any time with any questions or to request to take part.

Regardless of the recruitment strategy, young people and their parents who have read the information sheets and wish to participate in the research will be asked to provide written consent/assent to take part via completion of an online form. Parental consent will also be obtained for all young people aged 13–15. Self-reported demographic information, relating to participants' age, gender, age at diagnosis, current medication routine and severity of illness, will be collected following the provision of informed consent. To determine eligibility, all young people will complete the Medication Adherence Report Scale-5 (MARS-5),[30] a self-report medication adherence screening questionnaire, validated for use in those living with IBD. As previously validated,[30] young people will be deemed 'non-adherent' and therefore eligible to take part in the research, if they report ≤80% adherence to their treatment plan. Those who are deemed ineligible at this point will be thanked for their time but not proceed into the study. Young people who are eligible will be given access to all 10 ASSIST-IBD modules (see figure 1). Participants will be given a unique username (rather than their real name) to login to the programme, ensuring participant anonymity. Young people will be able to work through the digital web-app at their own pace, for 6–12 weeks. Parents of young people participants, who also wish to participate in the research, will be given access to the online ASSIST-IBD parental resources for usage during the same 6–12-week period as their child.

Data collection

To achieve the primary endpoint of progression to an RCT, primary outcomes will include quantitative and

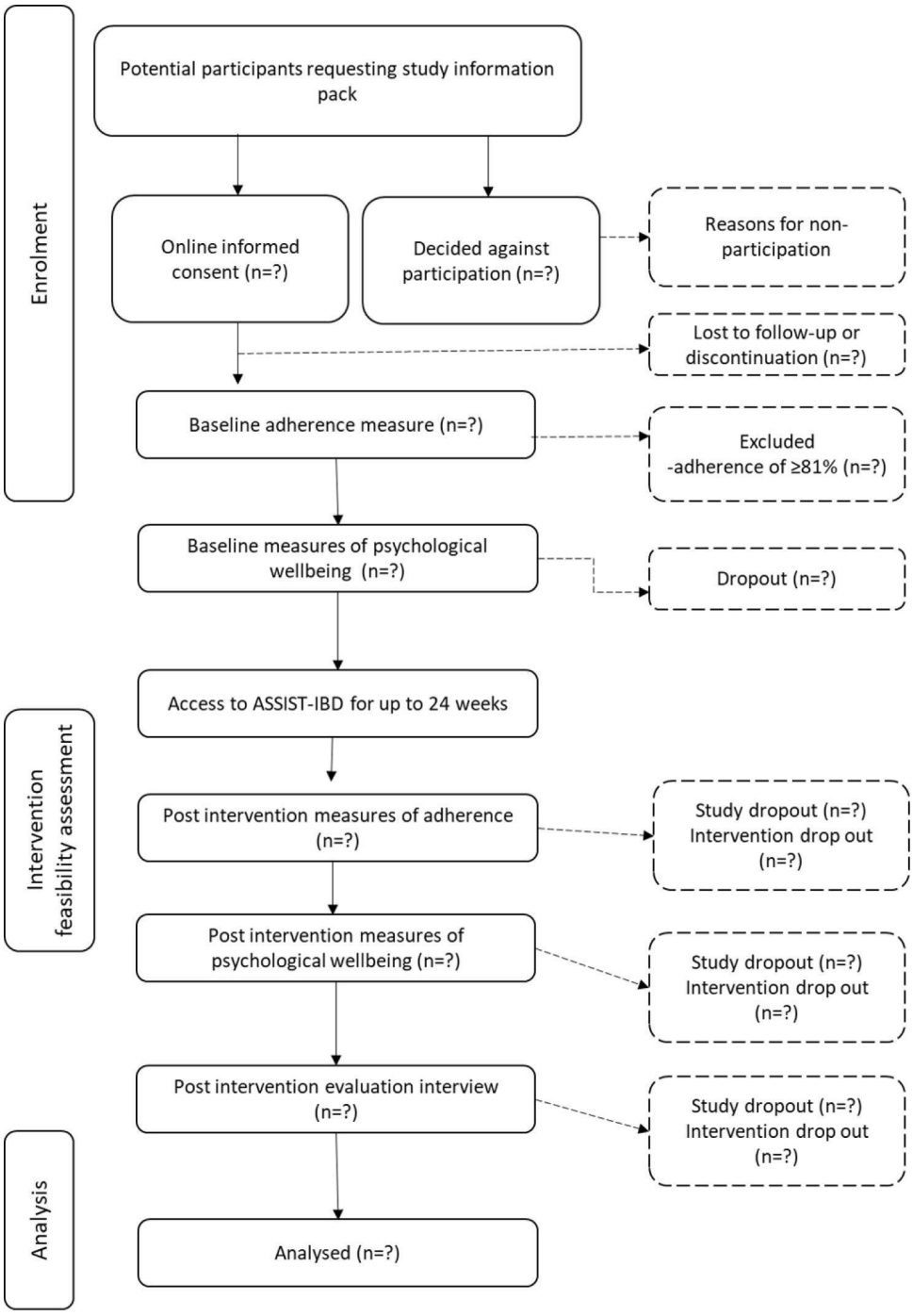

Figure 1 Participation flow diagram.

qualitative data on the key parameters for a definitive RCT, acceptability, user experiences and user engagement. Secondary outcomes will be obtained using validated self-report measures of medication adherence and well-being administered to young people at baseline (before access to the intervention) and post-intervention (following up to 12 weeks usage), as well as real-time data collected within the ASSIST-IBD online materials.

Primary outcome

Key parameters for a definitive trial

Quantitative data will be collected on number of eligible members of the target population, number of recruited participants, reasons for non-participation and ineligibility, retention and follow-up rates, reasons for early withdrawal, completeness and utility of outcome measure data, and time/resources required to collect and analyse data. Data on willingness to be randomised in a future RCT, acceptability of more objective measures of treatment adherence (eg, pill counts, clinical notes, biomarkers) and opportunities for patient and public involvement in

future studies will be collected within post-intervention qualitative interviews.

Acceptability and user experience

Post-intervention evaluation interviews will explore participants' views and experiences of the acceptability and satisfaction with ASSIST-IBD's content and mode of delivery. Interviews will provide a deep, nuanced and contextual understanding of participants' experiences of using ASSIST-IBD and their views on acceptability.[31] Semi-structured interviews lasting approximately 60 min will be carried out separately with all young people and parents. Questions will be guided by the theoretical framework of acceptability (TFA) of healthcare interventions,[32] a framework for exploring acceptability as 'a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses' (p.1). Questions will reflect the seven component constructs of the TFA, including affective attitude (towards the intervention itself and associated measures), burden (amount of effort needed to engage with the intervention, including reasons for discontinuation or dropout), perceived effectiveness (extent to which participants believe the intervention is able to achieve its aims; perceived benefit of intervention components), ethicality (fit with the participants' value system, side-effects of the intervention), intervention coherence (extend to which participants understand the intervention and how it works, including comprehension and utility of its components), opportunity costs (extent to which participants have to forfeit other valued aspects of their lives to engage with the intervention) and self-efficacy (participants' confidence to engage with the intervention and behaviours it requires). Interviews will be conducted remotely using video calling (eg, Microsoft Teams). This approach has been tried and tested by the research team. It is judged as acceptable by parents and young people, benefiting from increased convenience, reduced travel time and costs and increased diversity pools. All interviews will be transcribed and anonymised prior to analysis.

User engagement

To assess satisfaction and engagement with the intervention content, real-time data will be captured at the end of each module using a star-rating system, and anonymised free text comments boxes. Self-reported ratings of user motivation to continue with other modules will also be collected. Data regarding movement through the intervention materials (eg, number of logins, clicks on components, completeness of activities, time using it) will be collected via data capture tools built into the digital programme.

Secondary outcomes

Changes to adherence behaviour

MARS-5

MARS-5 is a self-report adherence questionnaire, validated for use with young people living with IBD.[30] MASR-5 contains five items, using a five Likert response, to assess medication adherence behaviours. Scores across each item are combined to produce an indication of an individual's adherence behaviours, previously a score of ≤80% has been validated as an indication of poor adherence.[30] An increase in the MARS-5 score between pre-intervention and post-intervention will measure preliminary effectiveness.

Measures of well-being

IMPACT-III

IMPACT-III is a quality-of-life measure validated for young people with IBD aged 9–17 years.[33] IMPACT-III contains four domains: well-being (n=12), emotional functioning (n=7), social functioning (n=11) and body image (n=4). Each item (n=35) uses a five Likert response to determine quality-of-life. Scores for each domain and an additional general quality-of-life question are added together and divided by the number of items (n=35) to produce a total IMPACT-III score. A higher score reflects a better quality-of-life.

An increase in the IMPACT-III score between pre-intervention and post-intervention will measure preliminary effectiveness.

WEMWBS

WEMWBS 14-item is a validated measure to assess mental well-being over the last 2 weeks.[34 35] Each item (n=14) uses a five Likert response to determine well-being. Scores for each question are combined to produce an indication of an individual's mental well-being, with a higher score indicating a greater level of well-being. An increase in the WEMWBS 14-item score between pre-intervention and post-intervention will measure preliminary effectiveness.

Overcoming adherence barriers

Interactive activities within each intervention module (eg, self-reported goal success, changes to confidence ruler scores) will assess the user's self-reported success in overcoming their adherence barriers.

Data analysis

Quantitative data will be analysed when all data collection, entry and validation are completed. Statistical analyses will be descriptive and will provide estimates of key parameters for a definitive RCT. The number of participants missing (from treatment, follow-up or both) will be reported (see figure 1). Differences in pre-post measures of treatment adherence (MARS-5), quality-of-life (IMPACT-III) and well-being (WEMWBS 14-item) will be reported and analysed in relation to participant's health and demographic information, movement through the intervention materials, as well as evaluative information collected within each ASSIST-IBD module.

Data collected during the qualitative evaluation interviews will be analysed thematically.[36] Thematic analysis is a theoretically flexible approach to identifying and reporting patterns (themes) within qualitative data that describe the underlying semantic and latent meanings, including people's beliefs, perspectives and experiences.[32] Data analysis will be carried out in accordance with the six stages of thematic analysis outlined by Braun and Clarke[36]: familiarisation through reading and re-reading transcripts, generating and assigning codes to data, constructing themes from the codes, reviewing themes, defining and naming themes, and writing up the analysis. A subset of transcripts will be independently coded by two researchers and then discussed with the research team, thus, ensuring validity. To further support research reflexivity, the research team will engage with reflective journalling.

Patient and public involvement and engagement (PPIE)

A major component in the development of ASSIST-IBD was the involvement of young people with IBD and their parents. Actively involving and engaging families continues throughout this feasibility study to further facilitate depth in our understanding of participants' experiences and support us to identify user-led modifications. The study will therefore benefit from two PPIE groups: (1) a young person's advisory group of approximately 6–8 young people (aged 13–17) with IBD and (2) a parent/carer advisory group made up of parents of young people (aged 13–17) with IBD. The groups will meet online using video calls, approximately eight times over the course of the project. They will inform our recruitment strategies and advise on patient facing documents. They will also contribute to qualitative data analysis by sharing their insights into participants' experiences of using ASSIST-IBD. To facilitate this, anonymous quotes from the post-intervention interviews, as well as anonymised quantitative data, will be shared with the groups, who will be able to provide their unique insights and interpretations of the data. Finally, the groups will advise on dissemination activities.

Ethics and dissemination

Ethical approval

The project received a favourable opinion from the Aston University Health and Life Sciences Research Ethics Committee (ref:#HLS21121) and NHS Research Ethics Committee, Nottingham 1 (IRAS:#344918). The most significant ethical issues within this project relate to obtaining informed consent/assent and issues of confidentiality, anonymisation, study withdrawal and data storage.

Informed consent

Young people and parents will be provided with an online study information pack inclusive of a letter of invitation and participant information sheet. The participant information sheets will use clear age-appropriate language. Once fully informed, potential participants will be invited to contact the research team, if they are interested in taking part in the study or to ask any questions prior to consenting to join the research. Young people and their parents who are interested in participating in the study will be sent an online consent form. Parents will be asked to provide written consent for their own taking part and for their child to take part (if aged 13–15). Young people will provide written assent (if aged 13–15)/consent (if aged 16–17) for their own taking part.

Confidentiality and anonymisation

Young people and parents will be invited to login and use the intervention via a unique username rather than their own name. The impact of this anonymisation on intervention users' sense of personalisation and ownership will be explored in our PPIE work and in post-intervention interviews. Interview data will also be anonymised.

To fully interact with the online ASSIST-IBD materials, all participants will be required to link an email address to their unique username. Email addresses will be stored safely on the online ASSIST-IBD platform and will not be linked with any additional identifiable data (eg, names). Identifiable data will be stored separately in a secure online cloud storage system. Participants' email addresses will be permanently removed from the online ASSIST-IBD platform once a participant has accessed the online ASSIST-IBD materials for up to 3 months. Participants' views on the requirement to engage with the online materials via email will be explored within post-intervention interviews.

Participant withdrawal

Each participant has the right to withdraw at any time during the study and information relating to all withdrawals will be recorded. If a participant wishes to discontinue, data collected up until that point will be kept and included in the analysis.

Data storage

Electronic data will be stored on password protected secure cloud storage and only accessed by the research team.

Dissemination of findings

A dissemination strategy will be developed in collaboration with the PPIE group. This is likely to include an infographic summarising key findings disseminated to the public via the charity Crohn's and Colitis UK and via relevant social media platforms. A more detailed lay summary will be prepared for dissemination to all research stakeholders, including young people, parents and health professionals. The team will prepare academic papers (reporting the development of ASSIST-IBD and outcomes of the feasibility study) for publication in peer-reviewed open-access journals. Findings will also be disseminated via presentations at academic conferences and seminars.

DISCUSSION

ASSIST-IBD aims to empower young people to take responsibility for their health and make user-centred plans to improve their adherence behaviours based on their self-assessed needs. Overall, the intervention aims to improve young people's treatment plan self-efficacy, enhance resilience behaviours to overcome adherence barriers, foster optimism about the future and develop appropriate health communication skills. While ASSIST-IBD has been evaluated by young people and parents as being acceptable and relevant for the target population, it is necessary to formally assess the feasibility of ASSIST-IBD prior to conducting a definitive trial. The methods outlined in this protocol will enable key questions to be answered regarding implementation of the intervention including the suitability of the mode of delivery, whether the intervention materials are comprehensive and whether the intervention materials are satisfactory for the target population.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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