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ORIGINAL ARTICLE

Gastroenterology: Inflammatory Bowel Disease

Implementing routine medical and mental health screening in children and adolescents with inflammatory bowel disease

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Abstract

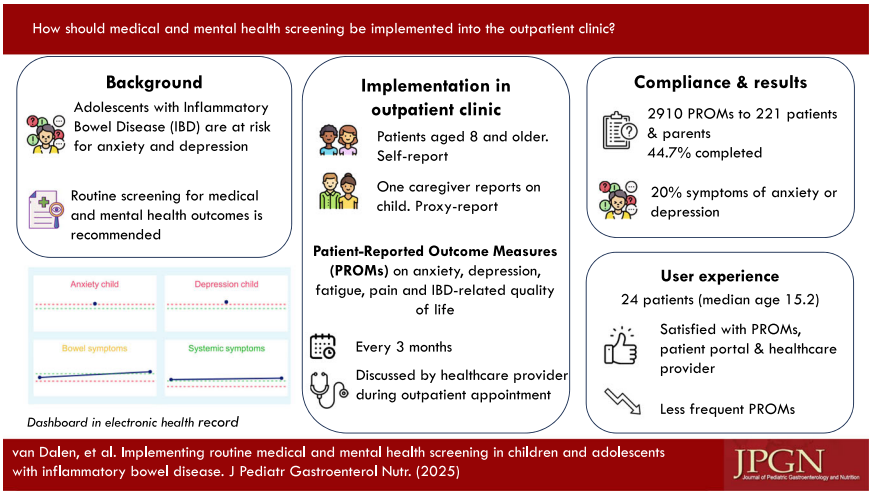
Objectives: Living with inflammatory bowel disease (IBD) can have a significant impact on children. Many children with IBD experience symptoms of anxiety or depression. Routine screening for mental health has been recommended. This preregistered study aimed to describe the implementation of patient-reported outcome measures (PROMs) in routine healthcare at an outpatient IBD clinic, as well as assess its feasibility.

Methods: Before every outpatient clinic appointment, PROMs were distributed to all patients aged 8 and older, as well as their parents. PROMs related to anxiety, depression, fatigue, pain and IBD-related quality of life were selected by a paediatric gastroenterologist and psychologist, and integrated into electronic health records. Patients who completed PROMs on two occasions were invited to complete a user experience survey, focussing on their experiences with the PROMs.

Results: A total of 2910 questionnaires were distributed. Adherence was 44.7%, with 175 patients or parents completing at least one questionnaire. User experience results of 24 patients showed they were satisfied with both the patient portal and the discussion with the healthcare provider. Five patients perceived the length of the questionnaires as too long, or as having to complete the questionnaires too frequently. Outcomes of 114 patients with 187 sets of questionnaires, described in the supplement, showed that up to 82% reported pain and/or fatigue. About 20% of patients reported symptoms of anxiety and/or depression.

Conclusions: Implementation of PROMs is feasible, but the length and frequency of PROMs can be improved. Healthcare professionals wanting to work with PROMs should carefully decide which PROMs to select.

Trial Identification: This study was registered prospectively on the Open Science Framework (OSF), https://osf.io/ef8wm/?view_only=67b4d7e55f684364b8a338fb1898e841.



KEYWORDS
anxiety, depression, feasibility studies, patient-reported outcome measures

1 | INTRODUCTION

Paediatric and adolescent patients with inflammatory bowel disease (IBD) can experience adverse psychosocial outcomes. For instance, they frequently encounter stigmatisation, regularly leading to social withdrawal.[1] Paediatric-onset IBD has been associated with mood disorders in childhood and adulthood.[2] Specifically, meta-analyses showed that 4.2%–6% of adolescents with IBD are diagnosed with an anxiety disorder and 3.4%–4% with a depressive disorder.[3,4] Symptoms of anxiety and depression occur in 16.4% and 15.0% of adolescents, respectively.[3] These psychological problems are likely to have a bidirectional relationship to IBD-related physical problems,[5,6] although large, prospective, high-quality studies are currently lacking. Adolescents with IBD are also at increased risk of suicidal ideations and suicide attempts.[7]

As symptoms of anxiety and depression may lead to poor treatment adherence, higher morbidity and higher mortality,[8] screening for these symptoms at least once a year has been recommended both in research[9] and in clinical guidelines[10] to ensure early detection of psychosocial problems.

In recent years, screening for mental and medical health outcomes has been implemented in the context of value-based healthcare.[11,12] In outpatient clinics with adults, implementation of patient-reported outcome measures (PROMs) has led to significantly fewer endoscopies, surgeries, hospitalisations, emergency department visits and imaging studies.[13] Overall, IBD-related healthcare costs were 16% lower than expected.[14] In paediatric IBD patients, the Patient-Reported Outcomes Measurement Information System (PROMIS) Paediatric domain questionnaires have been shown to be responsive to changes in disease activity and quality of life.[15,16] These questionnaires assess symptoms of anxiety and depression, as well as health-related quality of life.

There is currently no gold standard for PROM implementation in paediatric IBD healthcare. We provide an example and use case of how PROMs could be implemented in clinical care. We aimed to (1) describe the implementation of PROMs in routine outpatient healthcare for children and adolescents with IBD in an academic children's hospital, and (2) assess the feasibility of implementing PROMs on mental health and quality of life and its associated outcomes. We defined feasibility as asking 'whether something can be done, should we proceed with it, and if so, how'.[17] Exploratory results on the PROM outcomes of 114 patients and referrals to psychological care can be found in the supplemental materials.

What is Known

- Children and adolescents with inflammatory bowel disease (IBD) commonly experience symptoms of anxiety and depression.
- Routine screening for mental and medical outcomes has been recommended, but not often implemented.

What is New

- Routine screening can be implemented into daily practice.
- Screening for mental and medical health in children with IBD is shown to be feasible, both by patients as well as through compliance measures.

2 | METHODS

2.1 | Ethics statement

This study was registered prospectively in the Open Science Framework (OSF; https://osf.io/ef8wm). The Medical Research Ethics Committee of the Erasmus MC rated this study as exempt research (MEC-2022-0222). This study was conducted in accordance with the Declaration of Helsinki.[18]

2.2 | Implementation

From May to November 2022, the PROMs were implemented into standard healthcare procedures. PROMs on mental and medical health outcomes were selected by a paediatric gastroenterologist and a psychologist. Patients reported on their own functioning, while parents reported on their child's functioning. The distribution of PROMs was automated and linked to electronic health records. This allowed patients and parents to complete the PROMs through the patient portal and allowed healthcare providers to view the patient's results directly in the electronic health record. A dashboard was built, with the colours green, orange and red aiding the interpretation of the scores as normal, slightly elevated (+1 SD) and highly elevated (+2 SD), respectively. An example of the dashboard is shown in Figure 1. This dashboard was also designed to be used to discuss the results with patients and parents and decide together if referral to psychological healthcare is necessary.

As part of routine care, patients and their parents received PROMs 7 days before their scheduled appointment at the outpatient clinic, with a time interval of 3 months. This was done through an automated process. Patients or parents received an email notification that there were questionnaires for them to complete. They could then log into the electronic patient portal to complete the questionnaires in a secure environment.

Patients aged 8 and older completed all PROMIS measures, but not the IMPACT-III. Patients aged 9 and older completed all the PROMIS measures and the IMPACT-III.

To aid healthcare providers in the discussion of possible symptoms of anxiety and depression, a flowchart and pocket cards were created. The flowchart showed possible actions to be taken in the case of a green, orange or red score. The pocket cards detailed information on symptoms of anxiety and depression in children and adolescents, and possible questions to ask the patient and parents. This way, an informed decision could be made on whether to refer to psychological healthcare or not.

2.3 | Participants

Recruitment for the feasibility study took place from November 2022 to the end of August 2023. Patients were eligible for participation if they (1) had an IBD diagnosis (Crohn's disease, ulcerative colitis or IBD

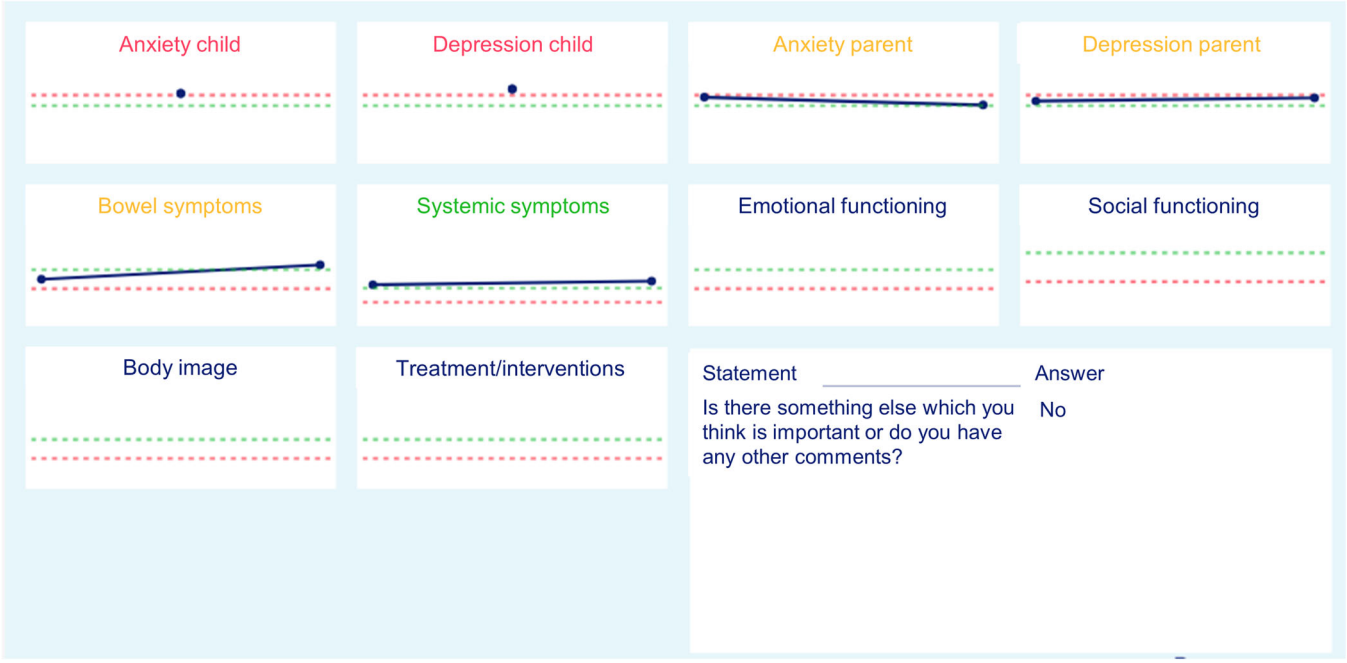


FIGURE 1 Example of a dashboard integrated into the electronic health record. Each blue dot in the dashboard represents a point of measurement. A single dot indicates one point of measurement; two dots indicate that a patient has completed two measurements. An absence of dots indicates that the patient has not provided any data related to this construct.

unclassified [IBD-U]), (2) were 8–18 years old, (3) were able to read and answer Dutch questionnaires and (4) completed PROMs on two occasions. Patients with an intellectual disability were excluded.

2.4 | Instruments/materials

2.4.1 | Patient demographics

Patient characteristics were extracted from their electronic health records. These characteristics were: sex, age, medical diagnosis (Crohn's disease, ulcerative colitis or IBD-U), age at diagnosis, current medication use and disease activity. Medication use was categorised into the following categories: Oral 5-aminosalicylates, immunomodulators, biologics, corticosteroids, nutritional treatment and no current treatment. Disease activity was divided into remission, mild, moderate and severe, based on a Physician Global Assessment.[19] Disease duration was calculated based on the age at diagnosis and the age of completing the first PROM.

2.4.2 | Quality of life

Quality of life was assessed using both a generic and a disease-specific questionnaire. Generic quality of life was measured using the PROMIS Paediatric Scale v1.0 – Global Health 7+2 and the PROMIS Parent Proxy Profile v1.0 – Global Health 7+2. Both forms consist of nine questions and are completed by patients and their parents/caregivers, respectively. Questions are rated on a 5-point Likert scale covering two domains (physical and mental health) and one question on general quality of life. Higher scores indicate better functioning. The forms have internal consistencies of $\alpha = 0.88$ for the paediatric form and $\alpha = 0.84$ for the parent proxy.[20]

Disease-specific quality of life was measured using the IMPACT-III questionnaire[21] completed by patients. The IMPACT-III contains 35 questions that are rated on a 5-point Likert scale. Higher scores indicate a better quality of life. Answers were summed up to create scores in several domains: bowel symptoms, systemic symptoms, emotional functioning, social functioning, body image, and treatment/interventions. Internal consistency in these domains ranges from $\alpha = 0.57$ to $\alpha = 0.85$.[22]

2.4.3 | Anxiety

Anxiety was assessed using the PROMIS Paediatric Short Form v2.0 – Anxiety 8a and the PROMIS Parent Proxy Short Form v2.0 – Anxiety 8a.[23] Both forms consist of eight questions and were completed by the patient and parent/caregiver, respectively. Questions were rated on a 5-point Likert scale and higher scores indicate more symptoms of anxiety. Internal consistencies are $\omega = 0.89$ for the paediatric form and $\omega = 0.87$ for the proxy form.[24]

2.4.4 | Depression

Depression was assessed using the PROMIS Paediatric Short Form v2.0 – Depressive symptoms 8a and the PROMIS Parent Proxy Short Form v2.0 – Depressive symptoms 6a.[23] The forms were completed by the patient and the parent/caregiver respectively. The patient form consists of eight questions and the proxy form of six questions. Questions were rated on a 5-point Likert scale and higher scores indicate more depressive symptoms.

2.4.5 | Cognitive functioning

Cognitive functioning was assessed using the PROMIS Paediatric Short Form v1.0 – Cognitive Function 7a and the PROMIS Parent Proxy Profile v1.0 – Cognitive Function 7a.[25] Both forms contain seven questions and are completed by the patient and the parent/caregiver, respectively. Questions are rated on a 5-point Likert scale and higher scores indicate better cognitive functioning.

2.4.6 | Peer relationships

The perceived quality of peer relationships was measured using the PROMIS Paediatric short Form v2.0 – Peer Relationships 8a and the PROMIS Parent Proxy Short Form v2.0 – Peer relationships 7a.[26] The forms were completed by the patient and the parent/caregiver, respectively. The patient form consists of eight questions, and the parent form consists of seven questions. Questions were rated on a 5-point Likert scale, and higher scores indicated a better-perceived quality of peer relationships.

2.4.7 | Feasibility and user experience

A survey was created by a psychologist (MvD) and a paediatric gastroenterologist (JE). The survey measures user experience related to the PROMs, the way the PROMs were discussed with patients during their hospital appointment and their experiences with the patient dashboard. The survey consisted of a mix of open-ended questions (e.g. 'What was it like for you to complete the questionnaires?') and statements with a 5-point Likert scale ranging from completely disagree to

completely agree (e.g. 'It was easy to complete the questionnaires'). The survey consisted of 26 questions. The full survey is available in the Supporting Information.

2.5 | Procedure

Patients and their caregivers were informed of the feasibility study by their treating clinician. They received information letters through e-mail and gave electronic informed consent. If the patient was younger than 16 years old, informed consent was obtained from both legal parents/caregivers and assent was obtained from the patients. For patients aged 16 or older informed consent was obtained from the adolescent. Parents also signed informed consent for their data (i.e., answers to PROMs) to be used in the current study. Participants did not receive incentives upon participation.

2.6 | Preregistered statistical analysis

In this study, we defined adequate feasibility as favourable feedback ratings (>3 on a 5-point Likert scale) by patients and a completion rate of ≥50% of scheduled measurements.

Quantitative data were analysed using descriptive statistics. Medians and interquartile ranges were calculated for the closed questions of the user experience survey.

Qualitative data were analysed using inductive content analysis[27] at a manifest level. Two researchers (MvD and MvG) read and reread the responses to familiarise themselves with the data. They simultaneously developed codes on a manifest level. These codes were discussed during a consensus meeting, and code sheets were developed. A total of 41.7% of the data was coded independently. Intercoder reliability was 81.1%. One of the researchers (MvD) used these code sheets to code the remainder of the data.

All analysis scripts and corresponding output are publicly available on the OSF repository (https://osf.io/p2gjk/).

3 | RESULTS

3.1 | Implementation

Between 7 November 2022 and 25 July 2023, a total of 2910 questionnaires were sent to 221 patients and their parents. Of these, 1609 (44.7%) were completed. A total of 175 patients or parents completed at least one questionnaire. For children, depending on the age and PROM category, 25%–50.4% of questionnaires were completed. For the proxy measures, the number of completed questionnaires ranged from 40% to 44.6%.

3.2 | Feasibility

A total of 72 patients were approached to complete the user experience questionnaire. One person was not approached due to time constraints. Of these 72 patients, 16 declined participation, 26 received the user experience questionnaire and 30 did not respond to the request. Due to the online recruitment process, reasons for nonparticipation are unknown. One person received the questionnaire, but did not complete it, resulting in a completion rate of 96.2%. One additional questionnaire was excluded from the analysis, as this had been completed by a parent. Of the remaining 24 completers, the median age was 15.2 years (interquartile range [IQR] = 13.9–16.8), and 37.5% were male. Fourteen patients were diagnosed with Crohn's disease, nine with ulcerative colitis and one with IBD-U.

3.2.1 | User experience relating to PROMs

All closed questions were rated from 0 (*completely disagree*) to 5 (*completely agree*). Patients were fairly neutral when rating whether they had to complete questionnaires too often (median = 3, IQR = 2–3) or whether the questionnaires were too long (median = 3, IQR = 2–4).

Results of content analysis are shown in Figure 2A. Patients reported both negative and positive experiences related to the PROMs. The majority of negative responses related to perceiving the questionnaires as too long or having to complete them too often ($n = 5$). The most often reported positive experiences related to the clarity of the questions ($n = 8$) or were positive in general (n = 12; i.e., participants reporting the questionnaires as 'ok to complete'). When asked for changes, three patients reported wanting more room for their own comments, or an option 'other' with questions that were not applicable to them. Explanation of the codes is available in Table 1.

3.2.2 | User experience relating to the patient portal

The patients thought the invitation e-mail they received was clear (median = 4, IQR = 4–5) and everyone agreed or totally agreed that it was easy to log in (median = 4, IQR = 4–5). No one thought it was unclear which questionnaire was intended for the parent and which questionnaire was intended for the patient (median = 4, IQR = 4–5).

Open questions were asked to those rating the statements with disagree or totally disagree. One person did not like the fact that their parents received the invitation e-mail. Another person thought it was hard to login with their digital identification (*DigiD*). No other feedback was provided by participants.

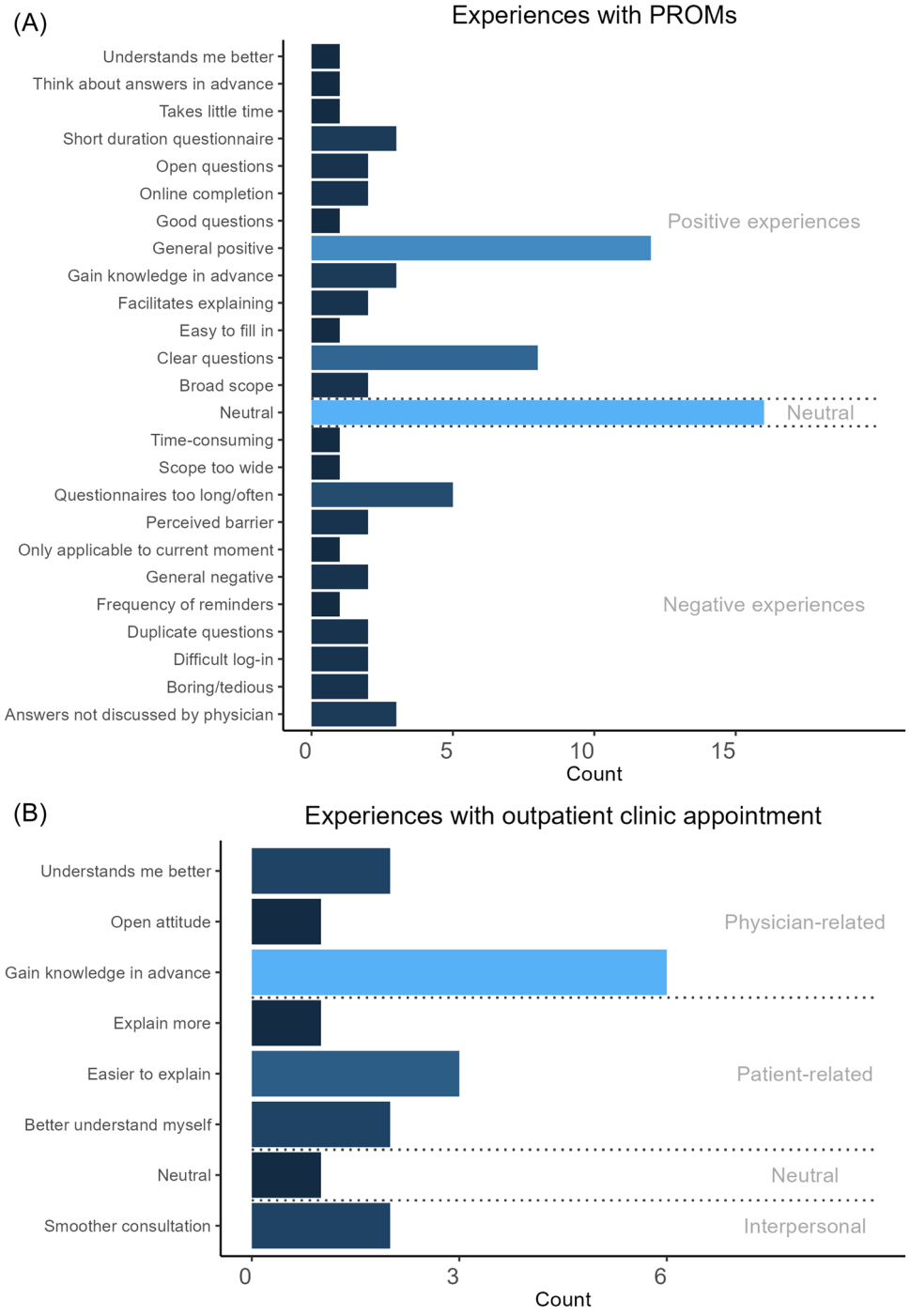


FIGURE 2 Barcharts showing the results of the content analysis on user experience. The length of the bars indicates the frequency of the code. Barchart A shows results relating to questions on positive and negative experiences with the PROMs. Barchart B shows results relating to questions on positive and negative experiences with the discussion with the healthcare provider during the outpatient clinic appointment. PROM, patient-reported outcome measure.

3.2.3 | User experience relating to the healthcare provider

On average, patients were neutral when asked if the questionnaires allowed their healthcare professional to better help them (median = 3, IQR = 3–4) or to better understand them (median = 3, IQR = 3–4).

A total of 14 participants (58.3%) indicated that their healthcare professionals discussed the questionnaires with them. Overall, they were neutral to satisfied with the way they were discussed (median = 3.5, IQR = 3–4).

Results of the content analysis are shown in Figure 2B. The themes related to interpersonal factors,

TABLE 1 Description of codes for user experience related to PROMs.

Category name	Category description
Negative experiences	
Answers not discussed by physician	The answers to the PROMs were not discussed by the healthcare providers
Boring/tedious	The completion of PROMs was perceived as boring or burdensome
Difficult log-in	Patient-reported difficulties logging in to the patient portal
Duplicate questions	Questions in the PROMs were perceived as occurring more than once, or as slightly the same
Frequency of reminders	The frequency of reminders was not correct
General negative	Short negative comments without elaboration (i.e., patients reporting they appreciated 'nothing' about the PROMs)
Only applicable to current moment	PROMs were perceived to be a snapshot and not applicable to other moments in time
Perceived barrier	Patient experienced motivational barrier
Questionnaires too long/often	PROMs were being sent out too often or were too long
Scope too wide	The questions in the PROMs were perceived as too broad
Time-consuming	It was time-consuming to complete the PROMs
Neutral experiences	
Neutral	General neutral comments to questions
Positive experiences	
Broad scope	The wide scope of the PROMs was appreciated
Clear questions	The questions in the PROMs were worded clearly
Easy to fill in	It was easy to complete the PROMs
Facilitates explaining	Completing the PROMs facilitates explaining patients' symptoms to their healthcare provider
Gain knowledge in advance	Appreciation by the patient that the healthcare provider knows about their symptoms before the consultation in the outpatient clinic
General positive	Short positive comments without elaboration (i.e., 'fine' or 'ok')
Good questions	The questions in the PROMs were perceived as good (without further elaboration)
Online completion	Patients appreciated the option to complete the PROMs online
Open questions	Appreciation of the open questions included in the PROMs
Short duration questionnaire	The duration of the PROMs was perceived as short
Takes little time	The completion of the PROMs took little time
Think about answers in advance	Completion of the PROMs forced the patient to think about their answers before the consultation at the outpatient clinic
Understands me better	The healthcare professional understood the patient better by having access to the PROMs

Abbreviation: PROM, patient-reported outcome measure.

patient-related factors, physician-related factors and neutral responses. Overall, patients appreciated that their physician had knowledge in advance of their outpatient clinic appointment ($n = 6$). Some patients also thought it was easier to explain using the PROMs ($n = 2$) or that the PROMs helped them understand themselves better ($n = 2$). Explanation of the codes is available in Table 2.

4 | DISCUSSION

In this preregistered mixed-methods study, we aimed to describe the implementation of PROMs on mental and medical health outcomes in routine healthcare for children and adolescents with IBD in a large academic children's hospital, as well as assess the feasibility of implementing PROMs.

TABLE 2 Description of codes for user experience related to healthcare providers.

Category name	Category description
Interpersonal	
Smoother consultation	The PROMs enabled smoother consultation and easier conversation with the healthcare provider
Neutral	
Neutral	General neutral responses
Patient-related	
Better understand myself	The PROMs helped the patient to better understand themselves
Easier to explain	It is easier to explain in person
Explain more	The PROMs helped the patient to explain things more elaborately
Physician-related	
Gain knowledge in advance	The PROMs helped the healthcare provider to gain knowledge in advance, thereby being able to better help the patient
Open attitude	The healthcare provider had an open attitude, and the patient could ask questions if they did not understand something
Understands me better	The PROMs helped the healthcare provider to better understand the patient

Abbreviation: PROM, patient-reported outcome measure.

Although our compliance rate of 44.7% did not meet our predefined cut-off of ≥50%, we conclude that the implementation of PROMs was feasible, but improvements should be made. Several explanations exist for the lower compliance rate. First, it can in part be explained by the fact that the PROMs were distributed to all patients, including those who were unable to login to the patient portal because they did not understand Dutch or did not have access to the Dutch digital identifier (*DigiD;* f.e., expats). Second, results are comparable to other applications of PROMs in children and adolescents showing compliance rates around 50%,[28,29] although rates of 85% have also been reported.[30]

Regarding user experience, a score of 3 or higher, corresponding to at least a neutral rating, was set as the cut-off for determining feasibility. Results showed that user experience regarding the patient portal and the discussion of PROMs by the healthcare provider was above the cut-off and can be seen as feasible. Regarding the PROMs themselves, the ratings were slightly below the predetermined cut-off. Negative feedback on the PROMs primarily related to the questionnaires being too long or being sent out too often. As a result, we have adjusted the time interval between PROMs from every 3 months to every 6 months.

A topic that was not studied directly, but is of importance to our results is mental health-related stigma. Many adolescents with mental healthcare needs do not access mental health care.[31] The implementation of PROMs can help facilitate discussions around mental health.[32,33] Specifically for adolescents with IBD, it is important that they trust their healthcare provider and that the healthcare provider inquires about their mental health.[33] As our results show that up to 40% of questionnaires were not discussed by the healthcare provider, it is likely that signals of mental health problems may be missed. On the other hand, if mental health scores were indicated as orange or red, the healthcare providers made an effort to always discuss these with their patients.

The current study has some strengths and limitations. The strengths of this study include the broad sample selection, which includes a range of ages and diagnoses. Further, this study incorporated the voice of the patient group. This can increase the adherence to the PROMs.[14] The experiences and lessons learned from our work can be used by other clinicians who may want to implement PROMs into routine care.

Limitations of this study relate primarily to the sample. Only patients who completed the PROMs on two occasions were invited for the user experience questionnaire. This could have resulted in omitting patients who are not compliant and have different views on the PROMs. However, as we gathered both positive and negative feedback on the implementation of the PROMs, we believe the data are an accurate representation of the preferences of the patients. Further, a sensitivity analysis included in the Supporting Information showed that patients who completed the user experience survey were comparable to those who did not in terms of demographics (with the exception of disease duration) and PROMIS scores. A second limitation is that we were unable to extract data on ethnicity or socioeconomic status, as these are not stored within the electronic health records. We could therefore not use this data in the current paper.

Future studies should examine the acceptability and feasibility of using PROMs in the children's hospital in general. As the use of PROMs will likely increase in the near future,[34] it is important to study whether all patient groups have the same needs, or whether patients with different diagnoses report different needs and preferences. It is also important to incorporate the patient's voice into the PROMs. Many studies on PROMs have included experts,[35,36] but incorporating patients' needs and preferences could have a direct effect on compliance.

5 | CONCLUSION

Healthcare professionals who intend to use PROMs in clinical care should carefully consider which PROMs they select, as current results show that the frequency and length of the PROMs, and the content of the questions, can be perceived as burdensome. For our outpatient clinic, this meant reducing the frequency of the questionnaires from every 3 months to every 6 months. This way, we capture variability in patients' physical and mental health status, but reduce the burden placed on patients and parents. We recommend including patients and parents as early as possible and evaluating the PROMs not only by clinical outcomes but also by patient satisfaction. After implementation, an effort should be made to provide feedback based on the PROMs during each hospital appointment, as there are indications that this may motivate patients' compliance[37] and self-management.[38]

CONFLICT OF INTEREST STATEMENT

Martha van Gaalen received a research nursing grant from Erasmus MC, ECCO, and Dr Falk Pharma for a transitional care project, which did not concern the submitted work. Lissy de Ridder received institutional support from Pfizer, Medtronic, Eli Lilly, Takeda, Abbvie and Janssen, all of which were unrelated to this study. Johanna C. Escher received institutional research support from Abbvie (care project; scientific advisory committee), Janssen (scientific advisory committee) and MSD; all unrelated to this study. The remaining authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

All analysis scripts and output for this paper can be found in the following repository: https://osf.io/p2gjk/?view_only=9b9d77ad68af495ca7783fc9d0fad9c6.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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