

# Benefits of Structured Pediatric to Adult Transition in Inflammatory Bowel Disease—The TRANSIT Observational Study

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## ABSTRACT

**Objective:** To evaluate the impact of structured transition from pediatric to adult inflammatory bowel disease (IBD) services on objective patient outcomes, including disease flares, admission rates, and healthcare resource use.

**Methods:** A retrospective observational study in 11 United Kingdom gastroenterology centers. Transition patients attended  $\geq 2$  visits to the gastroenterology service with both pediatric and adult personnel jointly present; non-transition patients transferred to adult services without joint visits. Data were collected from medical records for the 12-month periods before and after the date of the first visit involving adult IBD services (index visit).

**Results:** A total of 129 patients were included: 95 transition patients and 34 non-transition patients. In the 12 months post-index visit, transition patients had fewer disease flares ( $P = 0.05$ ), were more likely to be steroid-free (71% vs 41%,  $P < 0.05$ ), and were less likely to have an emergency department visit leading to hospital admission (5% vs 18%,  $P < 0.05$ ). During this period, the mean estimated overall cost of care per patient was £1644.22 in the transition group and £1827.32 in the non-transition group ( $P = 0.21$ ).

**Conclusion:** Structured transition from pediatric to adult IBD care services was associated with positive and cost-neutral outcomes in patients with pediatric IBD.

**Key Words:** Crohn disease, healthcare, patient outcomes, ulcerative colitis

(JPGN 2022;74: 208–214)

Received January 22, 2021; accepted June 9, 2021.

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**Sources of Funding:** Financial support for this study was provided by AbbVie. AbbVie participated in the interpretation of data, funding of medical writing support, and review and approval of this manuscript.

**Conflicts of Interest:** S.M. has received honoraria for previous advisory board/meeting participation from AbbVie; and has served as a speaker, a consultant, and an advisory board member for AbbVie, Actavis, Falk, Ferring, Janssen, MSD, and Takeda. J.O.L. has served as a speaker, a consultant, and an advisory board member for AbbVie, Actavis, Ferring, Hospira, Janssen, MSD, Napp, Pfizer, Shire, Takeda, and Tillotts Pharma; and has received research funding from Hospira, MSD, and Shire. R.K.R. has served as a speaker, a consultant, and an advisory board member for AbbVie, Janssen, Pharmacosmos, Takeda, and Tillotts Pharma. D.R.G. has spoken/worked in an advisory capacity for AbbVie, Ferring, MSD, Takeda, and Vifor Pharma. I.S. has received honoraria for previous speaking/advisory board membership from AbbVie. C.D.M. has served as a speaker, a consultant, and an advisory board member for AbbVie,

## What Is Known

- The process of transferring patients with inflammatory bowel disease (IBD) from pediatric to adult care services presents several challenges to both patients and clinicians.
- However, structured transition programs involving a period of joint care have been indicated to improve disease outcomes.

## What Is New

- Structured transition from pediatric to adult IBD care services leads to significantly improved disease outcomes in patients with IBD, with minimal economic impact.
- Results from this study may inform future evidence-based recommendations for transition care in IBD.

**P**ediatric inflammatory bowel disease (IBD) affects approximately 7000 patients in the United Kingdom (UK) (1). Numerous care models are available for transitioning patients from

Falk, MSD, and Shire. T.F.-H. is an employee of AbbVie and may own AbbVie stock and/or options. S.S. has received research grants from Amgen, Ferring, MSD, Pfizer, Takeda, Tillotts Pharma, and Warner Chilcott; and has received sponsorship and advisory board and speaker honoraria from AbbVie, Celgene, Falk, Ferring, Janssen, MSD, Pfizer, Pharmacosmos, Takeda, and Warner Chilcott.

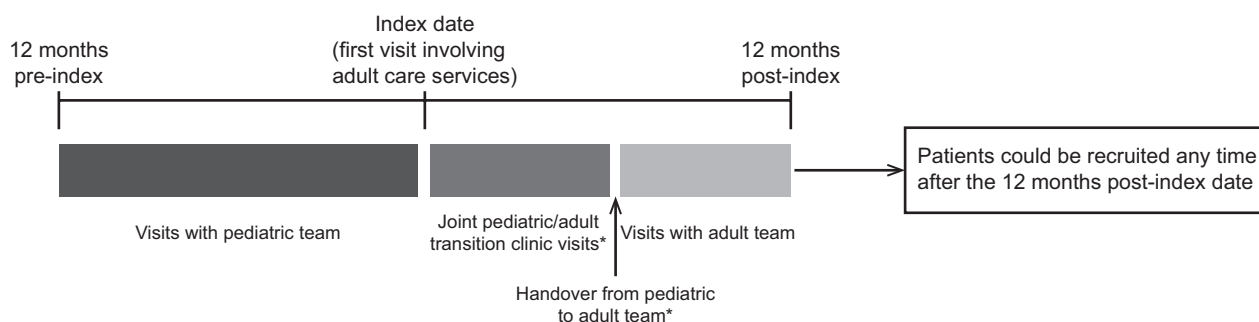
AbbVie funded this study and participated in the study design, research, analysis, data collection, interpretation of data, review, and approval of the publication. All authors had access to relevant data and participated in the drafting, review, and approval of this publication. No honoraria or payments were made for authorship. pH Associates was commissioned by AbbVie to manage data collection, data analysis, and provide medical writing support. Additional medical writing assistance was provided by Louise Wright, PhD, Russell Craddock, PhD, and Laura Chalmers, PhD of 2 the Nth, which was funded by AbbVie.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal's Web site ([www.jpgn.org](http://www.jpgn.org)).

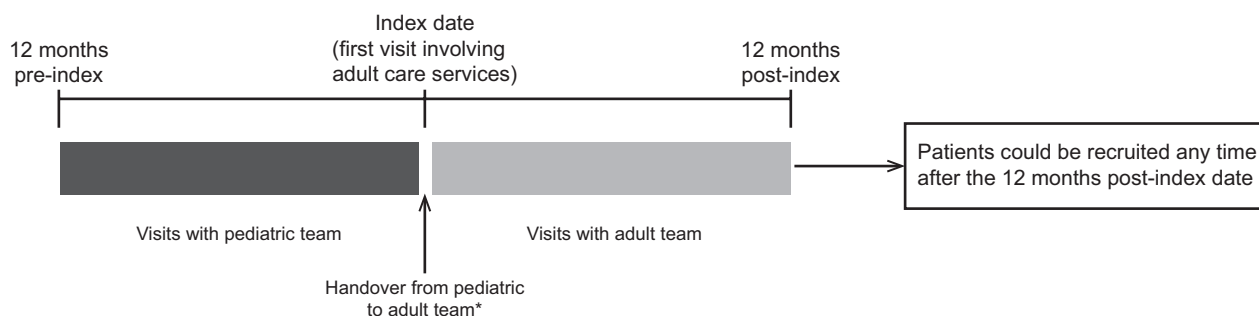
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DOI: 10.1097/MPG.0000000000003244

## Transition group



## Non-transition group



**FIGURE 1.** Study design. \*Number of joint pediatric/adult visits and point of handover to adult team is patient-dependent but  $\geq 2$ .

pediatric to adult care, often depending on the needs and structure of the local healthcare service (2). Transferring patients from pediatric to adult services, and the associated disruption in continuity of care, presents challenges to both patients and clinicians. For example, non-adherence to medication can be a problem in adolescents with IBD transferring from pediatric to adult services and is associated with adverse effects (3–6), including disease relapses, which adversely impact quality of life (QoL) and incur unwanted healthcare costs (5,7).

Some pediatric patients transfer directly to adult care, with or without a plan agreed between pediatric and adult services to ensure continuity of care, but with no subsequent support from pediatric services (“non-transition care”). Other patients undergo “structured transition” (“joint transition care”), involving a dedicated period of ongoing collaborative care delivered by pediatric and adult clinicians. Structured transition programs vary across services and are influenced by factors including the patient’s age and maturity, disease status, adherence to medication, and availability of adult IBD specialists.

Recent evidence suggests that a co-ordinated and age-appropriate transition program may improve disease outcomes in IBD (8) and is recommended in the UK and European IBD treatment guidelines (1,2,9); however, a better understanding of the impact of IBD-specific transition services on patient-related outcomes and healthcare resource use is required to develop robust, evidence-based recommendations for transition care in IBD.

This study compared the impact of structured transition care and non-transition care on IBD-related resource and medication use and patient-reported outcomes in patients with IBD (Crohn’s disease [CD] and ulcerative colitis [UC]), in the UK.

## MATERIALS AND METHODS

The TRANSIT observational study was conducted at 11 secondary/tertiary care gastroenterology services in the UK. Participants had a confirmed CD or UC diagnosis before the age of 16, and were ages  $\geq 16$  years and had been under the care of adult gastroenterology services for  $\geq 12$  months at recruitment. Eligible patients were identified through screening of clinic lists.

## Participants

Transition patients were defined as those who had made  $\geq 2$  visits to gastroenterology clinics with both pediatric and adult clinicians jointly present. Patients with only one joint visit were excluded. As this was a mixed methodology observational study, different models of transitional care were used across participating centers, with no evidence favoring a particular type (1) (Table, Supplemental Digital Content 1, <http://links.lww.com/MPG/C432>). Non-transition patients were defined as those who registered with adult gastroenterology services and transferred without visits jointly attended by pediatric and adult clinicians (Fig. 1).

## Data Collection

Retrospective data were collected from medical records dated between February 2014 and January 2016. The index visit was defined as the first visit to adult gastroenterology services (jointly attended by a pediatric clinician for transition patients). Data were collected for the 12-month periods pre- and post-index visits. For transition patients, the earliest and latest dates of the observation period were September 2006 and January 2016,

respectively (median index date: January 8, 2013), and February 2005 and January 2016, respectively, for non-transition patients (median index date: February 12, 2013). Patient demographics, medication history, Montreal disease classification (CD only) (10), details of transfer from pediatric to adult services (ie, dates and number of joint visits), disease flares (defined as those resulting in hospitalization and/or an increase in IBD medication), Harvey Bradshaw Index and/or partial Mayo scores, and CD/UC-related NHS hospital resource use data were collected. A single course of medication was defined as the duration a patient received an IBD medication at a stated dose, including daily continuous tapering of dosage. Any change in type of IBD medication or a gap of  $\geq 1$  week between stopping and starting a medication was counted as a separate course. Hospital resource use included planned outpatient visits (including visits regarding initiating advanced therapy), day case attendances, elective admissions (planned overnight stays), and non-elective admissions (unplanned overnight stays).

Patient questionnaires were completed anonymously following recruitment and included the: Short Inflammatory Bowel Disease Questionnaire (SIBDQ), a disease-specific health-related QoL questionnaire (11); Inflammatory Bowel Disease Control Questionnaire (IBDC-Q) for overall disease control and the IBDC-Q visual analog scale for perceived disease control over the preceding 2 weeks (12); Hospital Anxiety and Depression Scale anxiety and depression subscale scores (13); Net Promoter Score ("Friends and Family" score; a single question on the likelihood of the patient recommending the service); Medication Adherence Rating Scale (14); Work Productivity and Activity Index (GH V2.0) (15); and a study-specific questionnaire focusing on education completed to date, the impact of disease on education, levels of family support during transition, and level of engagement with the clinic.

## Estimation of Resource Costs

Estimated costs of hospital attendances in the 12 months post-index visit were calculated using UK-specific reference costs from 2014 to 2015 (16–18), which are shown in Table, Supplemental Digital Content 2, <http://links.lww.com/MPG/C432>. The date of discharge was unknown for two non-elective admissions (one each from the transition and non-transition groups); in these cases, the median length of stay (LOS) for all other admissions was applied. The most current NHS reference costs were obtained in May 2020 to estimate the cost to the NHS of providing the equivalent secondary care services in 2020 (19).

## Statistical Analyses

Sample size calculations were based on the number of patients required to demonstrate a statistically significant reduction in disease flares between groups. A sample size of 100 patients per group was calculated to be sufficient to demonstrate a significant mean reduction in disease flares (primary outcome) of 0.4/year, based on previously reported mean (standard deviation [SD]) flare rates of 3.3 (2.8) flares/year for CD and 3.0 (2.9) flares/year for UC (20–22); however, in practice, a lower sample size of 95 transition patients and 34 non-transition patients was accepted, owing to recruitment difficulties in some study centers. Therefore, a larger difference in the number of disease flares per patient in a 1-year period would be required to report a statistically significant effect.

For continuous data, descriptive statistics included number of patients, mean, SD, median, minimum, maximum, and confidence intervals (CIs) of the mean (where appropriate). Categorical data were presented as frequencies and percentages. Where appropriate, data were stratified and presented by IBD diagnosis (CD/UC).

Hypothesis tests were evaluated at the 5% significance level. For the primary outcome, between-group differences in the number of flares per patient were estimated using the independent samples *t*-test, while within-group comparisons were estimated using the paired *t*-test. Categorical data were compared by the chi-squared or Fisher exact tests.

When comparing overall estimated costs in the 12 months post-index visit in transition versus non-transition groups, mean costs were presented in line with recommendations from published research and 95% CIs of the mean calculated using bootstrap simulation (23). Overall costs were compared between groups using a Mann-Whitney *U* test. Analyses were conducted using only the available results with no imputation of missing values (with the exception of missing LOS data for hospitalizations when calculating financial costs, whereby the median LOS of all other admissions was applied). The denominator is reported for all other cases where required data were missing from the original medical record or not completed in the patient questionnaire. Data were analyzed using Microsoft Excel and Stata v14.1.

## Ethics

Ethical review was provided by the UK National Research Ethics Service (reference: 14/NW/1193), and local Research and Development management approvals were obtained from each participating Trust. All patients included in the study provided consent to complete the study questionnaires and for their medical records to be accessed by a researcher and used for research purposes. The STROBE checklist for observational cohort studies was used.

## RESULTS

### Patient Characteristics

A total of 129 patients (range: 2–22 per center) were included in the analysis: 95 transition patients and 34 non-transition patients.

Patients in the transition and non-transition groups were similar in terms of sex, IBD diagnosis, and age at index visit and recruitment (Table 1). The median time from index date to recruitment was 2.1 years and 2.3 years for transition and non-transition patients, respectively. A median of 2.0 transition visits was observed for transition patients. A higher proportion of transition patients were receiving immunomodulators at the 12 months post-index visit compared with non-transition patients (67% and 41%, respectively). Distribution of all other IBD-related therapies at the index visit was similar in transition and non-transition patients ( $P > 0.05$ ), with 9% of transition patients ( $n = 9$ ) and 21% of non-transition patients ( $n = 7$ ) taking corticosteroids (Table 1).

According to the location component of the Montreal disease classification score (CD only) at diagnosis, around half of patients with CD in both the transition and non-transition groups had the ileocolonic disease (category L3) at the point of diagnosis (48% [32/67] and 50% [11/22], respectively) (Table, Supplemental Digital Content 3, <http://links.lww.com/MPG/C432>). In addition, numerically fewer patients had the penetrating disease at diagnosis in the transition group compared with the non-transition group (8% [5/59] vs 26% [5/19], respectively;  $P > 0.05$ ).

### Disease Flares

In the 12 months pre-index visit, there was no significant difference in the mean number of flares per patient in the transition versus non-transition group (0.4 vs 0.6, respectively;  $P > 0.05$ ).

TABLE 1. Participant demographics and clinical characteristics

	Transition patients (n = 95)	Non-transition patients (n = 34)	P value
Female*	45 (47)	14 (41)	>0.05
Age at recruitment (y) <sup>†</sup>	19.6 (18.7–21.0)	19.3 (18.2–21.3)	>0.05
Age at index <sup>‡</sup> visit (y) <sup>†</sup>	17.4 (16.6–17.8)	16.6 (16.2–17.4)	>0.05
Time from index <sup>‡</sup> to recruitment (y) <sup>†</sup>	2.1 (1.4–3.2)	2.3 (1.5–4.5)	>0.05
Socioeconomic status (IMD ranking) <sup>†§§</sup>	2.9 (3.0–8.0)	2.6 (5.0–8.0)	–
Diagnosis*			
CD	74 (78)	25 (74)	–
UC	21 (22)	9 (26)	–
Transition visits <sup>†</sup>	2 (2–3)	Not applicable	–
IBD-related treatments 12 months post-index <sup>†</sup> visit*			
Aminosalicylates	46 (48)	19 (56)	–
Corticosteroids	28 (29)	20 (59)	–
Immunomodulators	76 (80)	24 (71)	–
Biologics	48 (51)	18 (53)	–
IBD-related treatments 12 months post-index <sup>†</sup> visit*			
Corticosteroid-free	67 (71)	14 (41)	<0.05

CD = Crohn's disease; IBD = inflammatory bowel disease; IMD = index of multiple deprivation; IQR = interquartile range; UC = ulcerative colitis. Data presented as \*n (%) or <sup>†</sup>median (IQR). <sup>‡</sup>Index date was defined as the first patient visit to an adult gastroenterology care service (alongside a pediatric healthcare professional for transition patients or first adult care visit for non-transition patients); median index dates: January 8, 2013 (transition patients) and February 12, 2013 (non-transition patients). <sup>§</sup>IMD is the official measure of relative deprivation for small areas (neighborhoods) in England, and the IMD decile (1 [most deprived] to 10 [least deprived]) reported here is for English centers only. <sup>§§</sup>n = 85 (transition group); n = 33 (non-transition group).

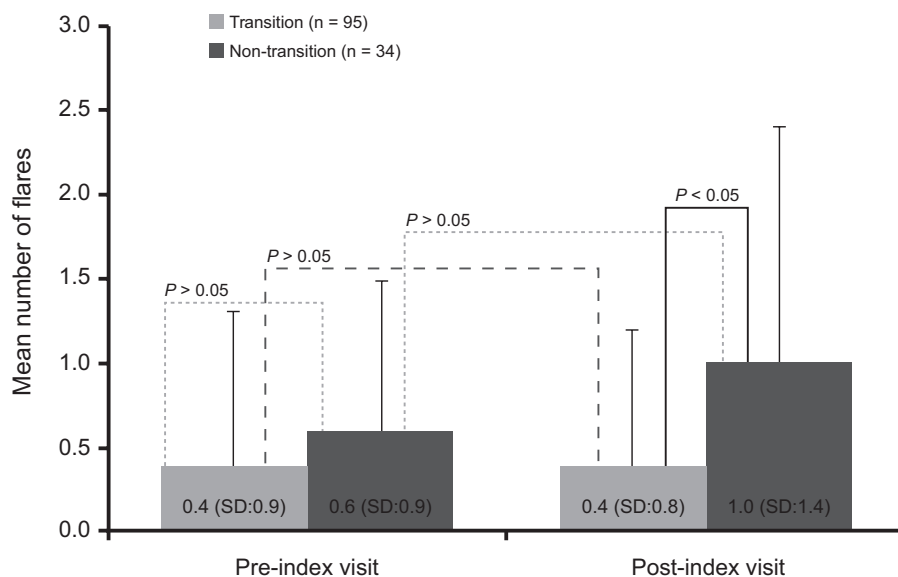
[Fig. 2]), with a median of 0 in both groups. In contrast, in the 12 months post-index visit, the mean number of flares per patient was significantly lower in the transition versus non-transition group (0.4 vs 1.0, respectively;  $P < 0.05$ ), with a median of 0 in both groups. No significant differences in the number of flares pre-versus post-index visit were observed within groups.

## Medication Use

During the 12 months post-index period, the transition group received a median (interquartile range [IQR]) of 2.0 (2.0–3.0)

courses of IBD medications per patient (including steroids, biologic agents, aminosaliclates, and immunomodulators), which was significantly lower compared with the non-transition group (3.5 [2.0–5.0] courses per patient;  $P < 0.05$ ).

A significantly higher proportion of patients in the transition group were steroid-free in the 12 months post-index visit compared with the non-transition group (71% vs 41%, respectively;  $P < 0.05$  [Table 1]). The median (IQR) number of steroid courses prescribed was lower in transition patients compared with non-transition patients (0.0 [0.0–1.0] vs 1.0 [0.0–1.0] courses per patient).



**FIGURE 2.** Mean (SD) number of flares per patient in the 12-month periods pre- and post-index visits. Statistical analysis of the between-group differences in number of flares per patient was estimated using the independent samples *t*-test, while within-group comparisons were estimated using the paired *t*-test. SD = standard deviation.

TABLE 2. Hospital visits and admissions

Type of hospital visit	12 months pre-index visit		12 months post-index visit	
	Transition (n = 95)	Non-transition (n = 34)	Transition (n = 95)	Non-transition (n = 34)
Outpatients	89 (94)	32 (94)	89 (94)*	25 (74) <sup>†</sup>
A&E visits	8 (8)	3 (9)	8 (8)	6 (18)
A&E visits leading to admission	5 (5)	3 (9)	5 (5)	6 (18) <sup>†</sup>
Inpatient admission	12 (13)	8 (24)	12 (13)	7 (21)
IBD flare-related admissions	5 (5)	8 (24) <sup>†</sup>	8 (8)	6 (18)
Day case	43 (45)	16 (47)	26 (27)	9 (26)

Data presented as n (%) of patients with each type of hospital visit/admission. A&E = accident and emergency; IBD = inflammatory bowel disease.

\*Not 100% despite inclusion criterion for transition patients requiring a minimum of two joint visits, because in two centers transition patients attended a dedicated adolescent service and these visits were omitted from the resource use data collection.

<sup>†</sup> $P < 0.05$ , transition versus non-transition in the 12-month pre- or post-index period.

## Hospital Visits and Admissions

The proportions of patients attending  $\geq 1$  of each type of hospital visit or admission in the 12 months pre- and post-index visit are presented in Table 2. No patient in either the transition or non-transition group failed to attend a planned hospital admission (ie, an admission lasting  $\geq 1$  night) in the 12 months pre- and post-index visit. In the post-index period, the proportion of patients with an accident and emergency visit leading to inpatient admission was significantly higher in the non-transition group compared with the transition group (18% vs 5%, respectively;  $P < 0.05$ ). The proportion of patients with  $\geq 1$  outpatient visit was significantly lower in the non-transition group compared with the transition group (74% vs 94%, respectively;  $P < 0.05$ ). Of the patients with  $\geq 1$  outpatient appointment in the 12 months pre-index visit, fewer patients in the transition group missed  $\geq 1$  appointment compared with the non-transition group (16% vs 25%, respectively). In the 12 months post-index period, more patients in the transition group missed a planned outpatient appointment compared with the non-transition group (12% vs 4%, respectively).

The numbers of each type of hospital visit or admission per patient in the 12 months pre- and post-index visits are shown in Table, Supplemental Digital Content 4, <http://links.lww.com/MPG/C432>. There was a significant reduction in the overall number of outpatient visits per patient in the non-transition group for the 12 months post-index visit versus the 12 months pre-index visit ( $P < 0.05$ ).

## Estimated Costs of Hospital Visits and Admissions

Table 3 shows the estimated costs associated with planned and unplanned hospital visits and admissions in the 12-month period post-index visit. Total mean estimated costs were £1644.22 for transition patients and £1827.32 for non-transition patients (cost difference,  $P = 0.21$ ). Costs based on May 2020 estimates suggest that there was no difference between transition and non-transition patients (mean estimated costs £1735.45 and £1964.03, respectively; cost difference,  $P = 0.10$ ; Table, Supplemental Digital Content 5, <http://links.lww.com/MPG/C432>), in line with the 2014–2015 estimates.

## Patient-completed Questionnaires

In all questionnaires completed, no significant differences were observed between the transition and non-transition groups ( $P > 0.05$ ).

## DISCUSSION

This observational study is the first multicenter, real-world study to evaluate the impact of structured transition from pediatric to adult care on objective patient outcomes in IBD and associated hospital resource use. A significant reduction in flares, greater prevalence of steroid-free patients, fewer prescribed courses of

TABLE 3. Costs associated with hospital attendances and medications

	Mean estimated cost in 12 months post-index visit	
	Transition (n = 95)	Non-transition (n = 34)
Mean (95% CI) total known cost of hospital visits and admissions		
Planned*	£1357.26 (£1049.42, £1665.10)	£860.68 (£538.14, £1183.21)
Unplanned*	£286.96 (£2.33, £571.59)	£966.65 (£193.91, £1739.38)
Mean (95% CI) total known cost of hospital visits and admissions per patient	£1644.22 <sup>†</sup> (£1206.27, £2082.17)	£1827.32 (£827.72, £2826.93)

Note: mean estimated costs were calculated based on 100% of patients in each group. As acknowledged above, Fiona Glenn analyzed the data. IBD = inflammatory bowel disease; CI = confidence interval.

\*Planned costs include outpatient physician and non-physician visits (including visits regarding initiation of advanced therapy), day case attendances (including admissions for IBD-related interventions), and elective inpatient admissions; unplanned costs include accident and emergency attendances and non-elective inpatient admissions.

<sup>†</sup> $P = 0.21$ , transition versus non-transition patients, Mann-Whitney  $U$  test.

IBD medication, and fewer emergency visits leading to hospital admission in the 12 months following the first adult care visit were observed among pediatric patients undergoing structured transition compared with non-structured transition. Our results are similar to a recent single-center UK retrospective study in adolescents with pediatric-onset IBD, which demonstrated several benefits of structured transition (8).

While UK and European reviews of transitional care in IBD have led to the recent publication of consensus guidelines for clinical practice (1,24), there remain little published UK-specific data on clinical outcomes of structured transition services for patients with IBD (25–27).

During the first 12 months following transfer to adult care services, the overall estimated cost of hospital resource use per patient was similar between transition and non-transition patients (£1644 vs £1827, respectively; Table 3). These costs are consistent with previous observations, which found that the average cost for patients receiving secondary care was approximately £1256 for UC and £1652 for CD (28). Unplanned procedures comprised ~20% of the total costs for transition patients, compared with ~50% for non-transition patients; a lack of structured transition may result in high-cost variation due to the high proportion of unplanned events, whereas transition service-associated costs could be easily planned and budgeted for.

Furthermore, similarities in hospital resource use costs between transition and non-transition patients show that transition care is not necessarily as expensive as often perceived, due to the need for joint care visits. The first 12 months of patient care are likely to be the most expensive for transition patients, and lower costs can be expected in subsequent years, when the transfer into adult care is complete.

It should be noted, however, that the present study was not designed to fully evaluate all costs associated with transition and non-transition care, such as the cost of stable maintenance therapy or other longer-term costs; therefore, the financial implications of a structured transition program may benefit from further research.

## Limitations

While this multicenter study was UK-wide, patients undergoing structured transition are more likely to be clustered in larger centers with established transition services and to self-select (ie, are more motivated to attend) transition clinics, compared with non-transition patients, who are more likely to be distributed in both large and small centers. The target sample size of 100 patients per group for evaluating differences in disease flares in the 12 months post-index visit was not achieved; in particular, the number of non-transition patients was lower than expected; however, despite the reduced sample size, a significant difference in flares was demonstrated ( $P < 0.05$ ).

This study recruited patients from high-volume gastroenterology centers “interested” in IBD, so even non-transition patients were managed by “IBD-focused” clinicians, which might not be the case for non-transition patients in smaller centers; however, all IBD clinics in this study should have had access to dedicated IBD nurses for adult care, who provided a consistent point of contact post-index visit, ensuring that all patients had access to timely and appropriate interventions.

This was a mixed methodology study and a number of different models of transition care were used. The centers participating in the study may have differed in terms of structure, personnel, size, and patient population. Additionally, the study did not take into consideration variation in processes of transition between centers and between patients. This was challenging because the transition process can take many years, making it

difficult to define a consistent date of formal transition to adult care. Therefore, the date of first contact with adult care was chosen as the index date in this study to enable a consistent approach between centers and between transition and non-transition patients; however, it should be noted that the index date marks different points in the patient journey for the transition and non-transition groups, which may affect the validity of the comparisons between the two groups.

Flares could not be verified precisely as data were collected retrospectively and patients may not have always reported specific symptoms of flares to their clinician. Therefore, our analysis was limited to the use of a proxy (corticosteroid requirement, therapy escalation, or hospitalization) to indicate flares.

An inherent limitation of all retrospective observational research is the quality and completeness of the information routinely recorded in patients’ medical records. This may be a possible explanation for the low flare rates observed in this study compared with previous reports.

Patient questionnaires were collected at recruitment owing to the retrospective study design and therefore may not uniformly depict outcomes from patients at one specific timepoint of the IBD transition care pathway. Only start/stop dates of various IBD medications along with dosage were available from medical records, and the analysis did not distinguish between induction and maintenance treatments.

## CONCLUSION

The results from this first multicenter study evaluating structured IBD transition care in the UK (based on joint attendance of pediatric and adult services at clinics) suggest a positive and cost-neutral impact on measurable outcomes in patients with pediatric-onset IBD following transfer to adult healthcare services. Due to the lack of standardized resources across pediatric IBD in the UK, TRANSIT focused on visits jointly attended by clinicians from pediatric and adult services as a simple baseline measure that applied to all participating clinics. Focusing on this single measure enabled the collation of clinically meaningful transition care data. Future large prospective studies with longer follow-up periods that consider different transition care models are needed to confirm these findings.

**Acknowledgments:** The authors wish to thank the Principal Investigators (PIs) and clinical staff who supported this study, and the patients who contributed their data, at the following centers: James O. Lindsay (PI), Barts Health NHS Trust; Sara McCartney (PI), University College London Hospitals NHS Foundation Trust; Shaji Sebastian (PI), Hull University Teaching Hospitals NHS Trust; Jeff Butterworth (PI), Shrewsbury and Telford Hospital NHS Trust; Ian Shaw (PI), Gloucestershire Hospitals NHS Foundation Trust; Matthew Brookes (PI), The Royal Wolverhampton NHS Trust; Adam Farmer (PI), University Hospitals of North Midlands NHS Trust; Daniel R Gaya (PI), NHS Greater Glasgow and Clyde; Marta Carpani (PI), Royal Free London NHS Foundation Trust; Alan Lobo (PI), Sheffield Teaching Hospitals NHS Foundation Trust; and Jimmy Limdi (PI), Pennine Acute Hospitals NHS Trust.

The authors also wish to thank OPEN VIE (formerly pH Associates), a company specializing in real-world evaluation, who supported AbbVie and the authors in the conduct of the study, analysis of the results (Fiona Glen, PhD), and medical writing (Kavitha Baruah and Fiona Glen, PhD).

**Data Sharing Statement:** AbbVie is committed to responsible data sharing regarding the clinical trials we sponsor. This includes access to anonymized, individual, and trial-level data (analysis data sets),

as well as other information (eg, protocols and Clinical Study Reports), as long as the trials are not part of an ongoing or planned regulatory submission. This includes requests for clinical trial data for unlicensed products and indications.

These clinical trial data can be requested by any qualified researchers who engage in rigorous, independent scientific research, and will be provided following review and approval of a research proposal and Statistical Analysis Plan and execution of a Data Sharing Agreement. Data requests can be submitted at any time and the data will be accessible for 12 months, with possible extensions considered. For more information on the process, or to submit a request, visit the following link: <https://www.abbvie.com/our-science/clinical-trials/clinical-trials-data-and-information-sharing/data-and-information-sharing-with-qualified-researchers.html>.

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