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CEDAR

Centre for Healthcare Evaluation, Device Assessment and Research

Inflammatory Bowel Disease (IBD) service development by reinvesting cost saving; impact on patient outcomes

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Welsh Value in Health Centre

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

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Abbreviations

Abbreviation	Definition
A&E	Accident and Emergency
ACF	Agenda for change
APC	Admitted Patient Care
CAV UHB	Cardiff and Vale University Health Board
DHCW	Digital Health and Care Wales.
FTE	Full time equivalent
GP	General practitioner
HRG	Healthcare resource group
IBD	Inflammatory bowel disease
IV	Intravenous
ICD	International Classification of Diseases
IQR	Interquartile range
MDT	Multi-disciplinary team
NHS	National Health Service
NICE	National Institute of Health and Care excellence
OPCS	Codes that are used to classify different types of health care procedure
PAS	Patient access schemes
PSSRU	Personal Social Services Research Unit
SC	Subcutaneous
UHL	University Hospital Llandough
WViHC	Welsh Value in Health Centre

About Cedar

CEDAR is an NHS-academic research and evaluation centre which is part of Cardiff and Vale University Local Health Board and Cardiff University. As a healthcare technology research centre, Cedar focuses on research and evaluation involving medical devices and diagnostics. We work with the NHS, academic institutions, commercial sector, publicly funded organisations, and charities. Our areas of expertise include systematic reviewing, health economics, clinical trial facilitation, qualitative research, analysis of routinely-collected and linked health data, and medical device regulations.

Acknowledgements

We are grateful to the IBD clinical team at University Hospital Llandough who allowed access to their datasets, provided clinical and service insights and supported the recruitment of service users to complete a semi-structured survey. The service users who completed the semi-structured survey and in-depth interviews were extremely valuable, and we would like to thank them for taking the time to help us with the data collection. We would also like to acknowledge the Information Services Division at Digital Health and Care Wales, who collated and supplied the PEDW data.

Funding sources & conflicts of interest

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Executive summary

Approximately 25,000 people in Wales have Crohn's disease or ulcerative colitis, which are forms of inflammatory bowel disease (IBD). IBD can have significant health and socio-economic impacts, in addition to high health service costs for those with severe disease. One of the high costs comes from the use of biologics as a treatment.

The IBD service in Cardiff and Vale University Health Board (CAV UHB) have invested in changes which aim to streamline the service and improve patient experience and outcomes. These service changes have been gradually implemented since 2017 and include: use of Patient Reported Outcome Measures (PROMs); patient-initiated follow-up; hot clinics; dedicated infusion rooms. The aim of these measures is to reduce the occurrence and severity of IBD flares, to improve management of the condition in the community and prevent the need for hospital admissions and invasive surgeries.

The aim of this report is to evaluate the impact of these service changes on patient reported outcomes by looking at (i) service user perception of the IBD service, (ii) impact on the number of surgeries and emergency hospital admissions, and (iii) the cost effectiveness of the service changes.

There were 115 responses to a semi-structured survey which sought service user feedback. These highlighted positive perceptions of treatments and service experience. The service was rated 9.5 (IQR: 8-10) out of 10 and 91.3% of responders would recommend the service to friends and family. Similar positive responses were also found within the in-depth interviews (n=13), which highlighted three key themes (staff behaviours, facilities, and the service in general) of service user perception of the IBD service. Participants stated that improvements should be made by increasing service-user empowerment, having more two-way communications that allow a discussion, having an out of hours service and increasing the option for privacy in the infusion room.

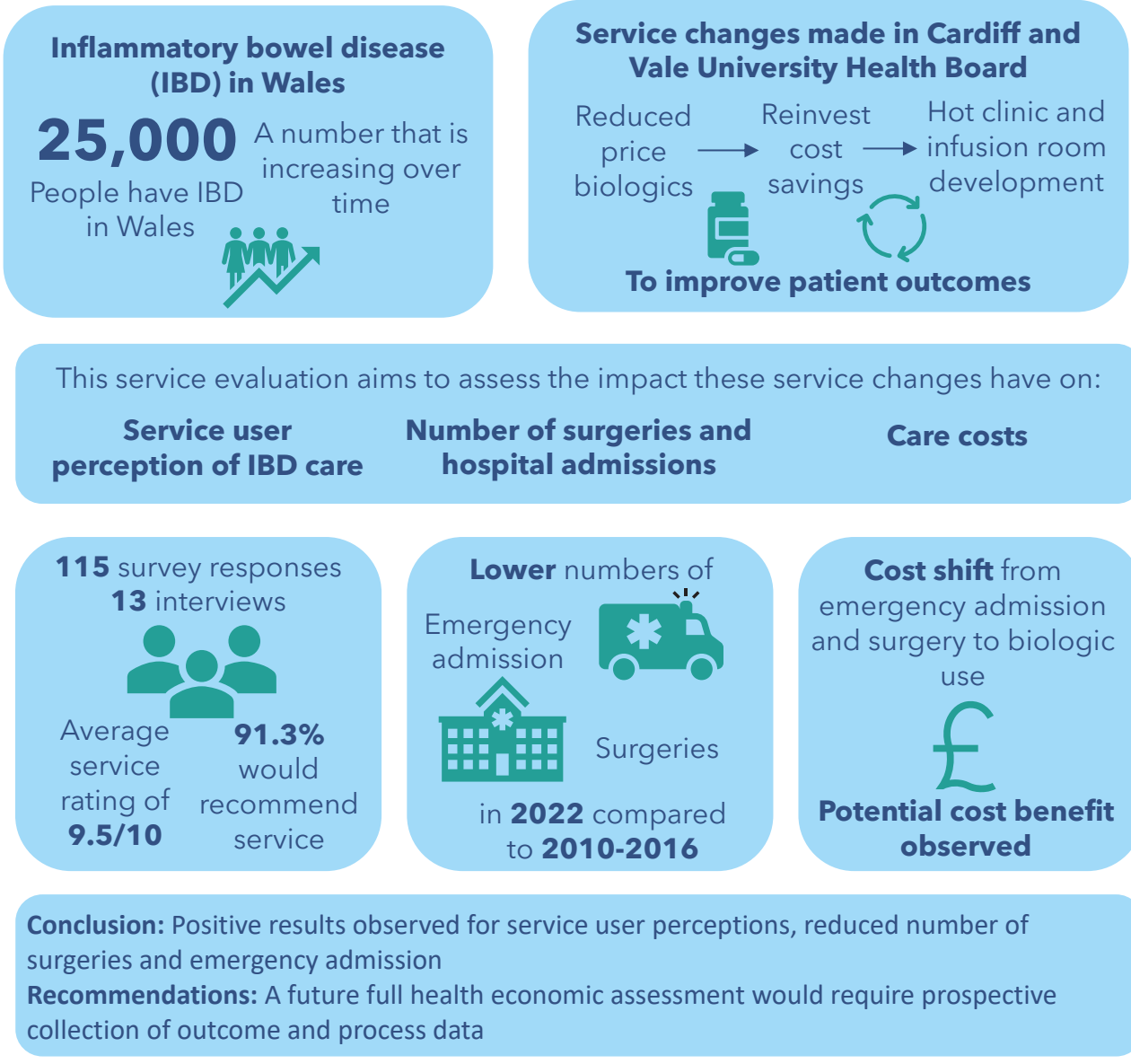
Quantitative analysis of routine hospital episode data found that there had been a reduction in the number of emergency admissions IBD in 2022, 2021 and 2017 and a reduction in the number of related surgeries in 2022 compared to 2010-2016 distributions.

A narrative health economic assessment showed lower costs from reduced emergency admission and surgeries. Other costs such as biologic use had increased but with evidence of strategies in place to reduce the cost per patient

where possible. Use of the IBD telephone line increased from 2016 to 2022, which carried an increased cost, however had potential to reduce the number of patients seeking help via GP or A&E attendance.

This evaluation indicated that the IBD service changes in CAV UHB have had positive results on patient satisfaction, reduced emergency admissions and surgeries, however, full causality could not be ascertained. Furthermore, due to a limitation in the data, a full cost-benefit could not be concluded. Future evaluation should focus on prospectively obtaining meaningful outcomes data for the hot clinic and telephone helpline and track process and outcome information for service users on biologics.

Visual summary



Inflammatory Bowel disease (IBD) service development; impact on patient outcomes

1 Introduction

1.1 Inflammatory Bowel Disease (IBD)

Inflammatory bowel disease (IBD) is an umbrella term for a chronic inflammation of the tissues of the digestive tract. Crohn's disease and ulcerative colitis fall under the IBD umbrella and affect approximately 25,000 individuals in Wales (Crohn's & Colitis UK, 2021). Symptoms include diarrhoea, blood in stools, unintended weight loss, stomach cramps, fever, fatigue, flatulence, and anaemia (National Health Service (NHS), 2023), which can have a significant impact on an individual's quality of life. Flares and uncontrolled IBD can result in emergency hospital admissions, along with being detrimental to a person's mental health and wellbeing (Eugenicos and Ferreira, 2021), ability to engage with social activities (Paulides *et al.*, 2022), work (van Gennep *et al.*, 2021) and travel (Philip *et al.*, 2018). Also, those diagnosed with IBD are at a greater risk of developing bowel cancer (Axelrad *et al.*, 2016).

Treatments of IBD include: lifestyle management (e.g., dietary changes, nutritional treatments and supplements, smoking cessation); aminosalicylates (i.e., 5-ASAs), immune suppressants (e.g., steroids, azathioprine); biologics (e.g., adalimumab, infliximab); and surgery (e.g., colectomy, ileostomy, ileoanal pouch, bowel resection). The use of biologics in IBD care is a new and emerging field, and comes at a high cost; but they have been found to be cost effective in the majority of cases (Juillerat *et al.*, 2022). Biologics are effective at reducing the need for invasive and life altering surgeries, which in themselves require large amounts of ongoing resources, as well as reducing the need for hospital admissions (Juillerat *et al.*, 2022). The National Institute of Health and Care Excellence (NICE) have guidelines for the management of both Crohn's (NICE, 2019a) and ulcerative colitis (NICE, 2019b), along with evaluating and approving the use of individual biologics for severe active disease. These management guidelines are also supplemented by IBD standards produced by IBD UK (and the British Society of Gastroenterology consensus guidelines (Lamb *et al.*, 2019).

The increasing prevalence of Crohn's disease and ulcerative colitis within the UK (King *et al.*, 2020) will impact on service demand and planning (Ashton and Beattie, 2023) and therefore a cost effective and equitable IBD service is required. The chronic nature and need for life long IBD treatments, compounded by the increasing cost of delivering treatments, means that evaluations should include improvements in disease management and the reduction in indirect costs such as lost productivity; with one approach being through a value-based healthcare lens (Burisch *et al.*, 2023).

1.2 Service provision in Cardiff and Vale University Health Board (CAV UHB)

The IBD service at CAV UHB has taken forward this challenge of improving patient outcomes among their service users through a series of service developments and changes.

In 2017 the IBD team in CAV UHB were able to secure reduced-priced biologics from Takeda,[1] which allowed them to invest the savings on the anticipated cost in improving the IBD service for users. The changes to the IBD service have been gradually introduced since 2017 and include the collection of Patient Reported Outcome Measure (PROM) data, patient-initiated follow-up, hot clinics, dedicated infusion rooms and optimising the provision of biologics both for cost and patient outcome (Table 1). The aim of these service changes is to reduce the occurrence and severity of flares; to improve management of the condition in the community; and prevent the need for hospital admission and invasive surgeries (Figure 1).

[1] For question relating to this commercial contract, please contact Takeda.

Table 1 Description of services available to IBD service users

Service	Description
IBD helpline	Service users who are concerned about their symptoms or treatment can phone and leave a message, and a nurse will return the call between the hours of 09:00-17:00. Although the telephone helpline has been running for a long time (unknown start date), the number of calls has increased significantly over the years.
Self-management	Service users who are not on medication or only on 5ASAs (oral or topical) can be on the self-management pathway. Each year they are sent a letter to undertake a blood test and stool sample. If test results are normal, a follow-up letter is sent. Any abnormal results are followed up by a telephone call from the IBD specialist nurse. Self-management also includes development of care plans and patient education.
Hot clinic	When service users are experiencing a flare, they are able to access the hot clinic, where bloods and abdominal X-rays are undertaken (organised by the IBD specialist nurses) and a consultation with a specialist registrar. This whole process takes approximately 1-1.5 hours. For challenging cases a discussion with the IBD consultant may also be required.
Biologics	Optimising biologics use, including undertaking regular reviews and multi-disciplinary team meetings (MDT) to determine the use/type of biologic for each service user.
Infusion room	A dedicated clinical space for biologic infusion to occur for IBD service users only.

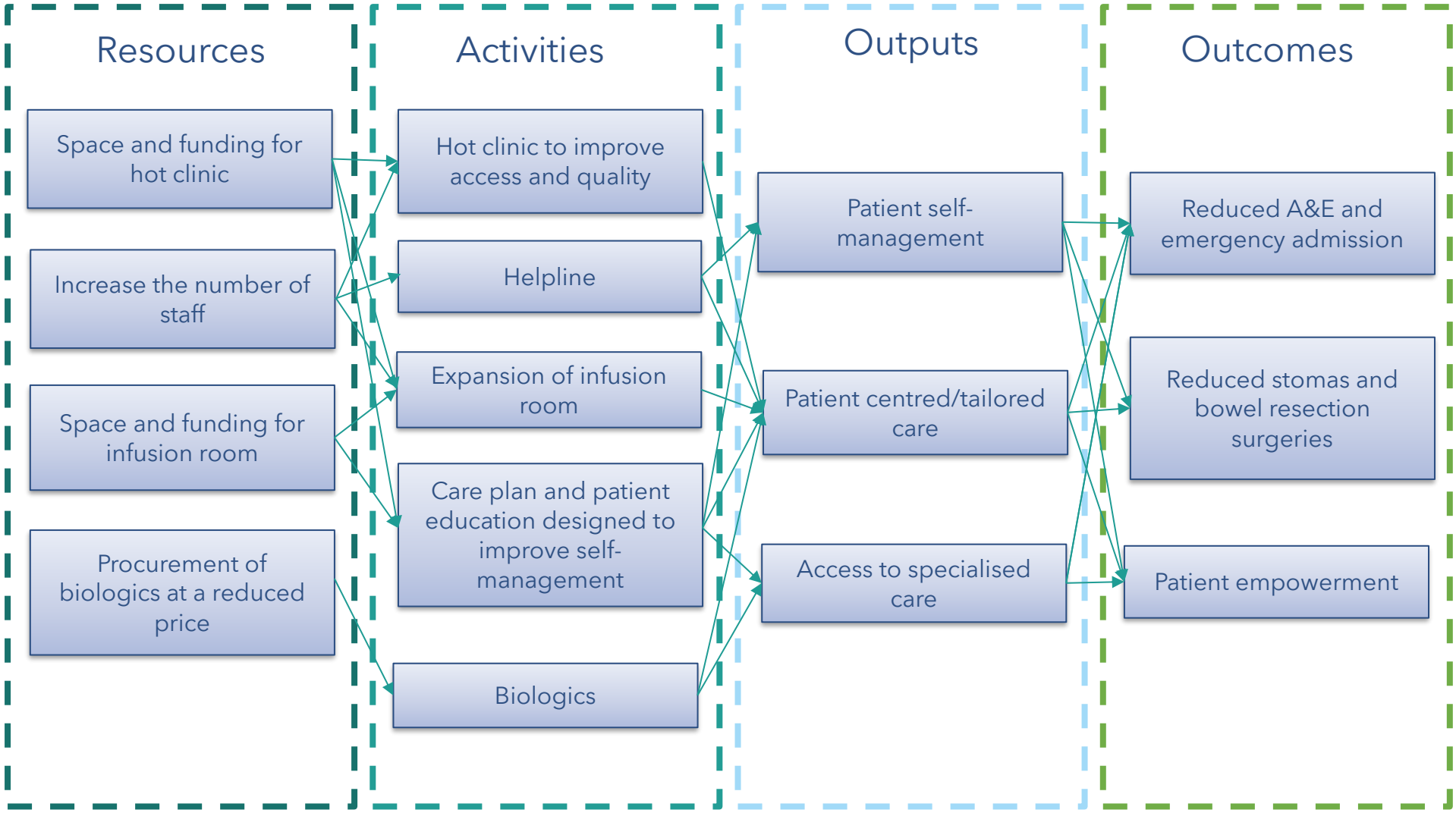


Figure 1 Logic model of the resources, activities, output and outcomes of the IBD service changes

1.3 Aims and objectives

In response to the changes to the IBD service, an evaluation was commissioned to investigate the impact of these changes on patient outcomes.

This report aimed to answer the following questions:

1. What are IBD service users' perception of IBD care?
2. What is the cost effectiveness of the change in IBD service provision?
3. What is the impact of the change in IBD service provision on the occurrence of bowel surgery?
4. What is the impact of the change in IBD service provision on the number of emergency admissions?

2 Methods

2.1 Study parameters

2.1.1 Population

Users of CAV UHB's IBD services with a confirmed diagnosis of IBD, including Crohn's disease, ulcerative colitis and unspecified IBD. International Classification of Diseases 10th Revision (ICD-10) codes used to identify service users with IBD are listed in Appendix 1.

2.1.2 Service change group

Cohort of service users receiving standard care post-2017, which included the use of biologics for service users who met the criteria for use.

2.1.3 Comparator group

Cohort of service users receiving standard IBD care pre-2017.

2.1.4 Outcome

Two health outcomes were considered within the analysis, (i) bowel surgery and (ii) emergency hospital admissions, within CAV UHB. Identification of bowel surgeries was undertaken using OPCS procedural codes, listed in Appendix 2.

2.2 Primary data collection

2.2.1 Semi-structured survey

A semi-structured survey (Appendix 3) was administered to service users identified through the CAV UHB IBD clinic lists, via the secure online survey tool, Microsoft Forms. The survey captured data on:

1. Service user demographics

2. Service experience questions
3. Service rating questions

2.2.2 Qualitative interviews

Service users were asked at the end of the semi-structured questionnaire if they would be willing to be contacted to take part in an in-depth interview. Those who opted in were contacted via email to arrange a date and time for the interview, which were undertaken via Microsoft Teams or telephone. A clinical evaluation scientist (KEW) undertook the interviews with the service users following a topic guide (Appendix 4) covering treatments received to date, knowledge of services available, thoughts and perceptions of services, facilitators and barriers to access, recommendations for improvements and views on the service changes. All interviews were recorded using Microsoft Teams or an encrypted voice recorder and transcribed verbatim.

2.3 Secondary data

2.3.1 IBD service data

The IBD service at CAV UHB has been collating a live dataset from patient records of service users under their care, which aims to characterise their current patient base. The dataset includes basic demographic information (name, date of birth, gender, consultant, hospital number), current and past medications (start date, dose and frequency, end date, reasons for stopping), self-management, last multi-disciplinary team (MDT) review, surgeries received, date of last endoscopy. Further records are kept for service users attending the hot clinic which includes information on age, presenting issue, tests requested and results, outcomes, in-patient admission and change of type or dose of biologic.

2.3.2 Admitted Patient Care (APC) dataset

Admitted Patient Care is a dataset that contains all inpatient and day case activity undertaken in NHS Wales; including basic demographic, clinical and administrative details (e.g., diagnostic and operative procedures (ICD10 and OPCS4), healthcare resource group (HRG) code, age and sex of patient).

Data on bowel surgery and emergency hospital admissions, for service users residing in CAV UHB between January 2010 - June 2023 was requested from DHCW. Due to the potential for delayed reporting of an estimated 6 months, only data up until the end of December 2022 was used within the analysis. The University Hospital of Wales is a tertiary centre, so there are some service users who are transferred for treatment (predominantly surgery) from other health boards. The IBD service under evaluation is only available to residents within CAV

UHB therefore the residency of the service users was used as inclusion criterion rather than the location of the procedure.

2.4 Data analysis

2.4.1 Quantitative analysis

The same analysis methods were deployed for both the change in number of surgeries, and the change in number of emergency admissions. The number and percentage of events, and basic characteristics (e.g., diagnosis, age, admission methods) were described. The pre- and post-service change comparison was undertaken looking at the distribution of the number of events between 2010-2016 and comparing the number of events in 2016 to 2022. These two one-year-long pre- and post-intervention time points were chosen as (i) a year would capture any seasonal variations, (ii) it contains the latest possible full data set to account for time lag (i.e., 2022), (iii) it reduces the potential confounding impact that COVID-19 may have had on health service delivery and care. The results are presented using bar graphs and box plots, which were created using R statistical software (version 4.0.0) and RStudio integrated development environment (version 2020-04-24).

2.4.2 Qualitative analysis

Transcripts were analysed in Microsoft Excel to gain basic participant characteristics such as diagnosis, length of time receiving care for CAV UHB, treatments and services used and their perceptions of the service. Service user perceptions were determined using thematic analysis by one author to identify overarching themes, which are narratively described within the report. Verbatim quotes were included to illustrate the themes.

2.4.3 Health economic assessment

Cost effectiveness was originally planned if PROM data containing EQ-5D was available, however although this has been collected over a number of years, it is not available in an accessible format for data analysis. Therefore, a cost consequence approach was undertaken for the health economic assessment, comparing 2016 data to 2022 data (see section 2.4.1 for the rational on dates used for the comparison). Table 2 illustrates the items included, and where the data was obtained; along with further details of services that add particular value. The staffing costs have been calculated for staffing, assuming that 100% of their time is used for the IBD service, unless otherwise clearly stated. The costs are reported as the full costing (Personal Social Services Research Unit (PSSRU), 2022) including the costs of estates and all associated resources involved in the service, as is conventional for health economic assessments. Other costs, such as

appointment or procedure costs, taken from NHS Cost Collection (Department of Health and Social Care, 2020; NHS England, 2022), include the same assumptions.

It should be noted that the service has provided biologics at some level since approximately 2004, however this has grown in time as additional technologies became available and the evidence base for them increased, including their cost effectiveness in the NICE clinical guidelines. Therefore, this report does not attempt to consider the cost-effectiveness of the biologics themselves, but rather the impact of negotiated discounts in facilitating spend on improved clinic facilities and the provision of biologics to a wider range of patients.

During the data collection and analysis, it became apparent that some critical data fields were unavailable, meaning that a full cost consequence may be misleading, as it would not capture the full impact of the changes made to the service. Therefore, each service area and change has been described in detail, including the costs in 2016 and 2022 where possible, if this has been a cost saving or increase to the IBD clinic, if it may have resulted in cost savings elsewhere in the health service, and if it is likely to have had a positive or negative impact on patient experience.

Table 2 Data items considered within the health economic assessment

	Item	How data was derived
Event	Overall number of emergency IBD admissions	APC. See section 2.3.2 for details.
	Total number of IBD related surgeries (including stoma surgeries)	APC. See section 2.3.2 for details.
	Biologics administered	The IBD service keeps a routine record for each service user on the type of current treatment they are on.
	Number of hot clinic visits	All service user attendances at the hot clinic are recorded, including the tests requested and outcomes, specifically if the type or dose of biologics were changed, and any admission to hospital.
	Telephone triage outcome	There are no complete electronic records for the telephone triage system, however there are paper notes. Where appropriate any details of actions or outcomes for each call should be recorded in the patient notes. Outcomes of call are therefore not used within this report due to the time required to extract the data from individual patients notes.
	Helpline telephone call duration	Length of telephone call is not routinely recorded therefore a snap shot of the nurse time spent dealing within each of the call was obtained from a one-week in August 2023, which documented 709 minutes of nurse time for 81 calls, therefore an average call was 8.8 minutes.
	Number of helpline telephone calls	IBD clinic records that document the number of calls received per month.
	Number of service users on the self-management pathway	The IBD service keeps a routine record for the number of patients self-managing.
Cost	Cost of delivery hot clinic	Visits to the hot clinic were costed at an estimated 1 hour of clinician time using the full PSSRU costing (as this includes use of facilities). Additional costs were added for blood test and abdominal X-rays for all patients and flexi sigmoidoscopy for 8% of patients, based on clinical estimates of the

		most common procedures. It should be noted that these staff costs are included in the overall IBD cost calculation, however this looks at a more granular detail for a particular aspect of the service.
	Cost of self-management pathway	The self-management pathway involves a reminder letter sent by clinic coordinator (band 3) and review of blood results by IBD specialist nurse (band 8a). If blood results are normal a letter is sent to service users, if anything abnormal is detected a follow-up phone call is undertaken by the IBD specialist nurse (band 8a).
	Cost of telephone helpline	The cost of the telephone helpline (service provision and advice) is based on the average duration of the calls (see above) and the band of nurse (AFC Band 6 and 8a). It is assumed that the duration of call and banding of staff remained unchanged between 2016 and 2022. Qualitative information from clinic staff supports this as a reasonable assumption, however no historic data is available for the duration of the calls, outcomes or staffing.
	Cost of biologics	The number of patients treated, and the biologics used were compared for 2017 (when data was available) and Analysis of this data is not a strict comparison of the two spends, as the standard care expected within the NHS has evolved over this time period and the available biologics and their cost has changed.
	Cost of GP visit	Consultations with a GP were costed using PSSRU at £36 per visit
	Cost of A&E attendances	A&E attendances were costed at £352.57 per visit (NHS England Cost Collection 2021-22), with an assumption that all are visits to a full emergency service provider, and that a minimum investigation of a blood test would take place (level 2 investigation). A weighted average of all visits at this level of investigation or greater, and any treatment resulted in a cost of £352.57 per visit.
	Cost of emergency admission	Cost of surgery was taken from published data in NHS England Cost Collection (2021-22). HRG codes were taken from the APC data, where

		HRG codes collected in 2016 were not available in 2022 data, the 2022 HRG code for the equivalent description was used. A weighted average of long stay and short stay non-elective costs was used.
	Cost of surgery	Cost of surgery was taken from published data in NHS England Cost Collection (2021-22). HRG codes were taken from the APC data, and costs were for the total HRG codes. Where HRG codes collected in 2016 were not available in 2022 data, the 2022 HRG code for the equivalent description was used. The surgeries that were admitted through A&E were costed as non-elective surgery, and a weighted average of long stay and short stay non-elective costs was used. The remainder were costed as elective.
	Cost of stomas	Stomas have been assumed to cost £1,065.90 per year, per person. This is taken from the NICE Technology appraisal guidance TA547 Tofacitinib for moderately to severely active ulcerative colitis (2018), where the Evidence Review Group (ERG) estimated an annual cost of £1,065.90 per person with a stoma, including nurse time and stoma products. This equated to £426.36 per person in the post-surgery health states for this population, assuming 40% have a stoma. An alternative cost was available from NHS Scotland National Stoma Quality Improvement Report (2019) who stated that stoma care products and their supply costs between £780 - £2300 per patient per year (NHS Scotland, 2019).

Notes:
Abbreviations: HRG = Healthcare resource groups, AFC = agenda for change, GP = general practitioner

3 Results

3.1 What are IBD service users' perception of IBD care?

3.1.1 Semi-structured survey

3.1.1.1 Participant characteristics and service use

In total 115 responses were received to a specially designed survey, predominantly from service users attending the infusion room at Llandough hospital, of which 76 (66.1%) have Crohn's, 38 (33%) have ulcerative Colitis and one (0.9%) has unspecified IBD. The mean age of the responders was 43.1 years old (SD: 14.6), with the majority of responders being male (n=59; 51.3%), of white ethnic origin (n=1020; 88.7%) and in fulltime employment (n=66) (Appendix 5). Time since diagnosis was reported as between one to 41 years (Mean: 11.9 years; SD: 9.7). Only three (2.6%) responders with Crohn's reported that they were currently self-managing.

The most used reported treatments were biologics (n=104; 90.4%), thiopurines (n=67; 58.3%) and aminosalicylates (n=32; 27.8%) (Figure 2). Only 24 (20.9%) responders had received any form of surgery for their IBD. All responders had used the infusion room (n=115; 100%) and 73 (63.5%) responders had received support from the IBD specialist nurses. Only three (2.6%) responders had used the hot clinic (Figure 3).

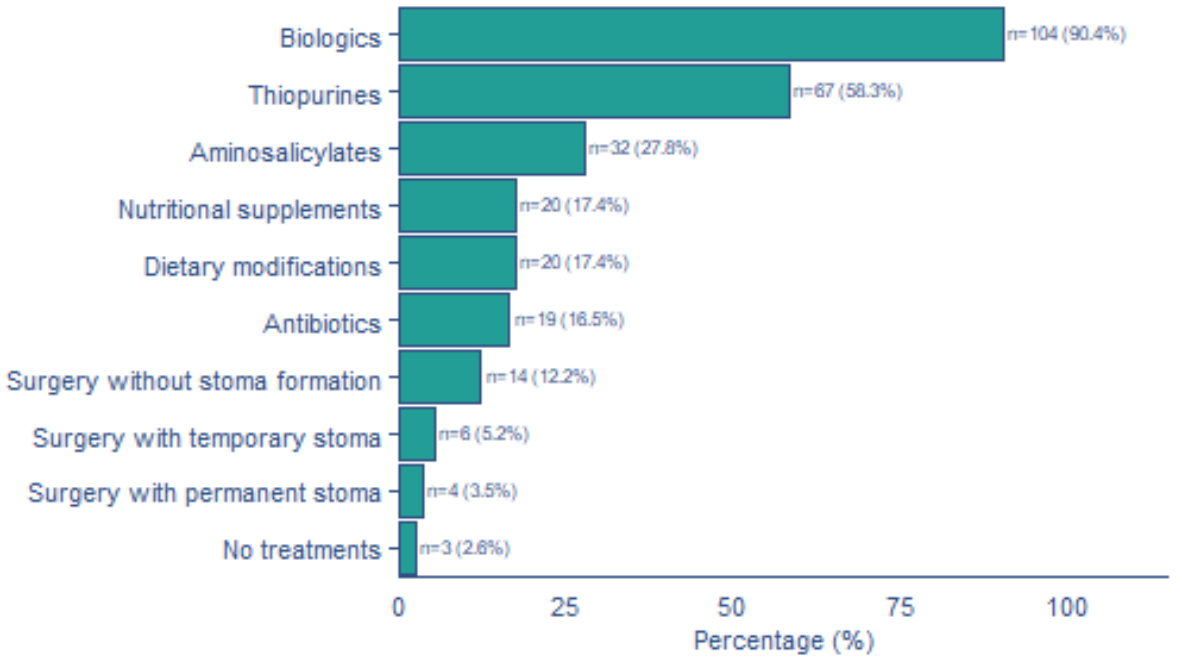


Figure 2 Self-reported treatments received since IBD diagnosis

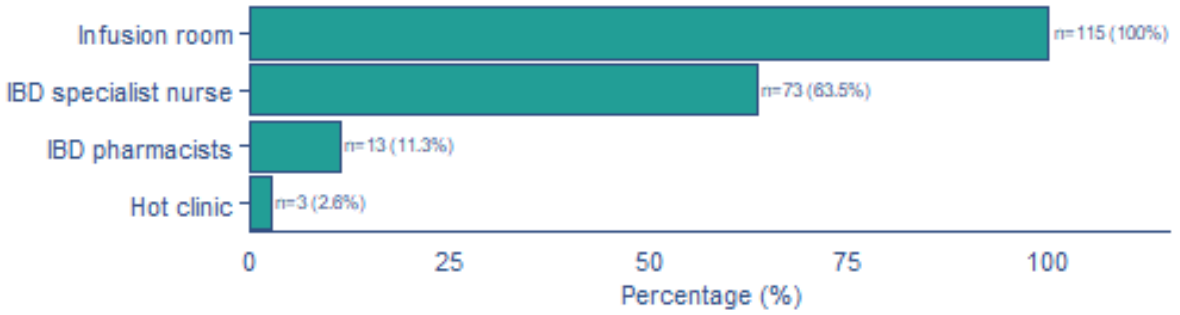


Figure 3 Self-reported service use

3.1.1.2 Perception of IBD treatments

Favourable responses were received for all questions on perception of treatment, with over half of participants strongly agreeing that the treatments improved their quality of life (54.8%) and symptoms (54.8%) (Figure 4). However, 12.2% did strongly agree that they waited too long for their diagnosis.

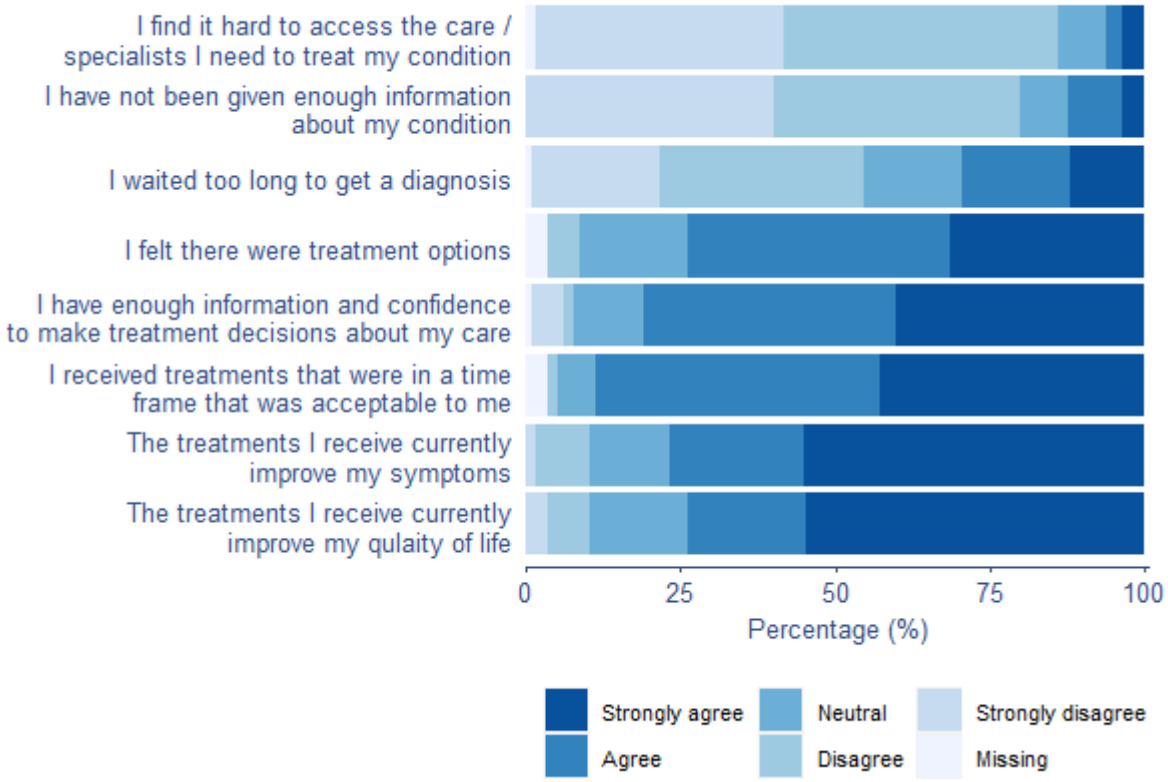


Figure 4 Participant perception of IBD treatment(s)

3.1.1.3 Experience of the IBD service

Favourable responses were received across all service experience questions, apart from being able to speak Welsh to staff (Figure 5). Out of the 13 participants who responded to this question, six responders (46.2%) felt they were never able to speak Welsh to staff when they needed to. The waiting time to use the service was reported positively: 26% of responders reported the waiting time was shorter than expected, and 59% reported the wait was about right. Overall, the median service rating was high at 9.5 (IQR: 8-10) out of 10 and 91.3% (105/115) would recommend the service to friends and family (Figure 6).

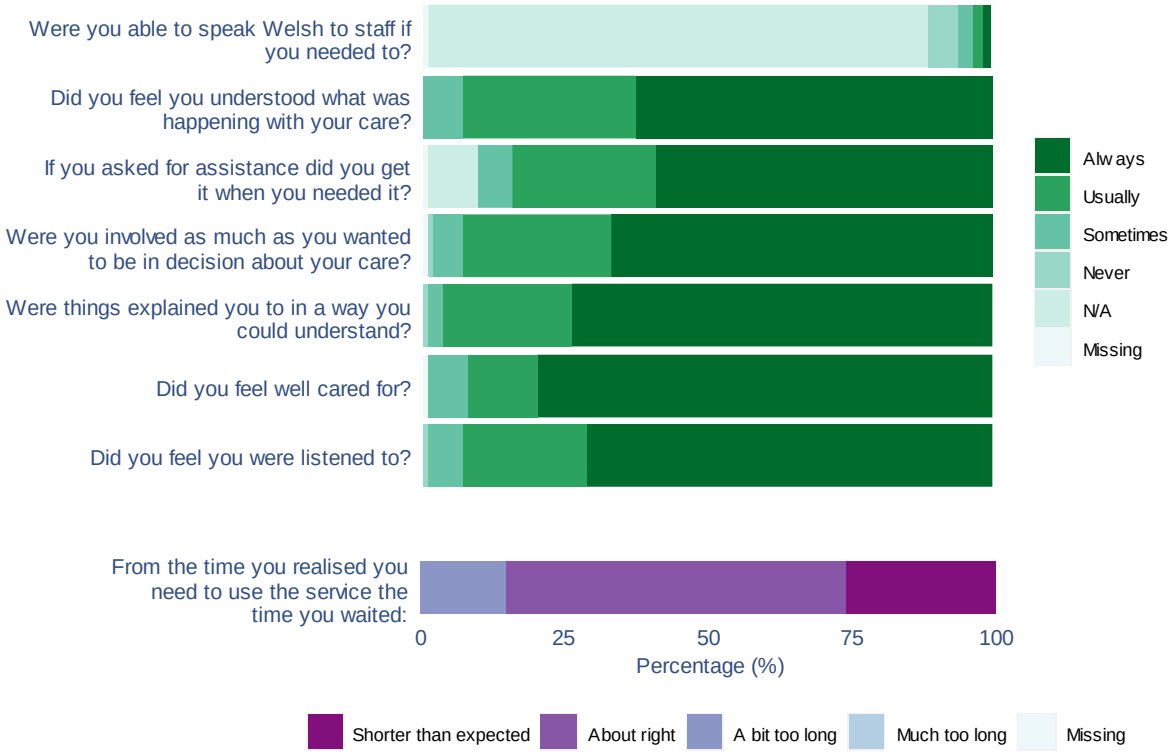


Figure 5 Participant reported service experience

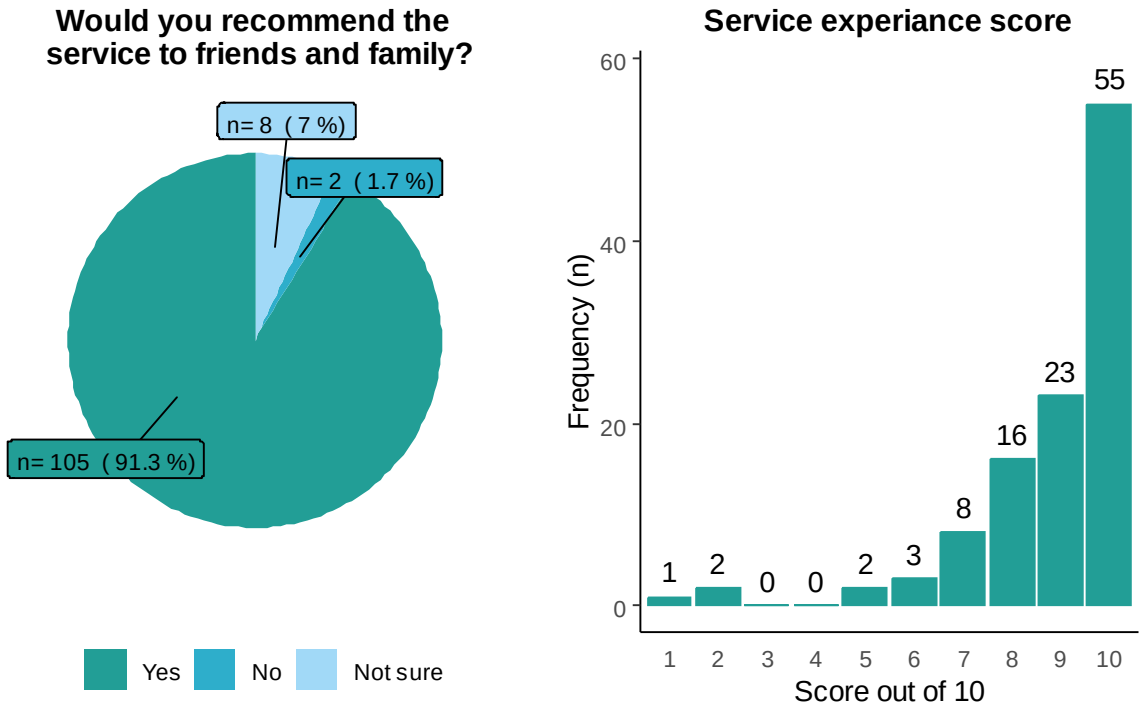


Figure 6 Participant service experience measures

3.1.1.4 Free-text responses

The participants reported a wealth of positive experiences, with the most common being the kindness, patience, knowledge, reassurance and professionalism of the staff, the IBD nurse, reasonable time frame and that the service reduces feelings of isolation (n = 8 each). However, a range of improvements were suggested by participants, with the provision of face-to-face consultations (n=3) and shortening of waiting lists (n=2) being most notable.

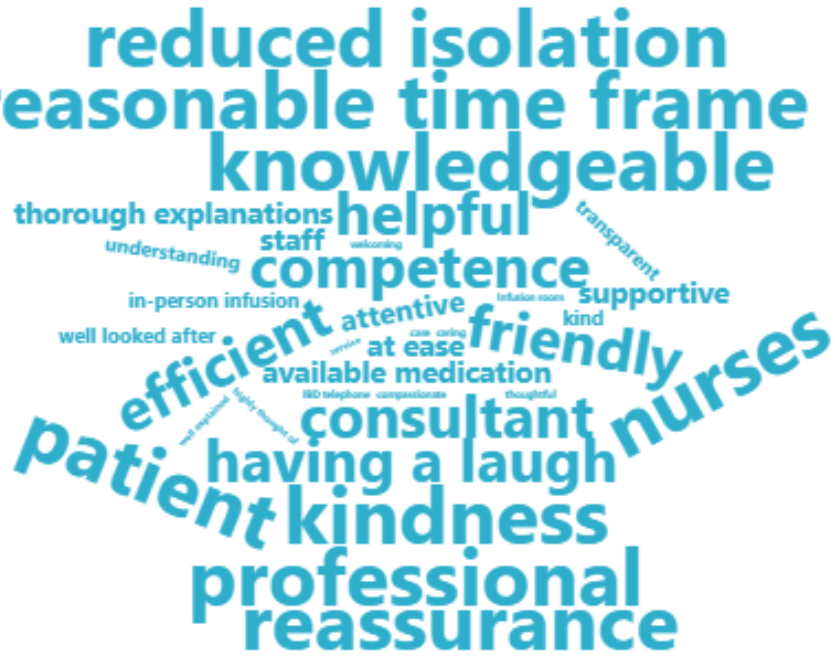


Figure 7 Word cloud of participants good experience on the IBD service

"Love the IBD Nurses at the infusion room they make your infusions so much nicer" (Female, Crohn's disease)

"Very grateful for the service, it's changed my life" (Female, Ulcerative colitis)

Figure 8 World cloud of area where participants felt the service could improve
Numbers = face-to-face consultations (n=3), shortening of waiting lists (n=2), all other response (n=1)

Negative feedback received was mainly pertaining to other services (e.g., primary care, length of time to diagnosis, surgery waiting lists etc.) rather than the IBD service.

"Diagnosis process took almost 8 years. I feel if it was diagnosed earlier the problem would not be so bad and treated much sooner." (Male, Ulcerative colitis)

3.1.2 In-depth interviews

All 31 service users that opted in for an interview during the survey were sent an emailed invitation for the interview, with a follow-up email sent 10 days after if no response was received. There were 13 completed interviews (42%), four withdrawals (13%) and 14 non-responses (45%).

Out of the 13 service-users interviewed, eight (61.5%) have Crohn's disease and four (30.8%) have ulcerative colitis. One service user (7.7%) did not indicate what form of IBD they were diagnosed with. Year of diagnosis ranged from 2001 to 2022, with seven (53.8%) diagnosed before 2017; although two of these service users transferred to the care of the CAV UHB IBD service after 2017. Three (23%) indicated they were diagnosed privately.

Interviewees were asked if they knew of the IBD services that were available to them within CAV UHB. Awareness of the IBD nurses telephone line was high among all interviewees, with all reporting using it and were either given the number at diagnosis, by the IBD nurses or at their first appointment. All interviewees were on biologics and therefore knew of and used the infusion room. However, there were no reports of knowledge or use of the hot clinic. Only one participant was aware of the IBD pharmacists and dieticians.

P17: "Well I can't say I have ever had to speak to the pharmacist but I know they are there in the background. And the dietician when I was newly diagnosed I was seen quite a few times and they were really knowledgeable and helpful. But because I have been really well for so long I have not needed to see the dietician for a really long time." (Female, Crohn's disease)

All the service users interviewed were very positive about the IBD service, with three themes being identified around staff behaviours, facilities and the service in general. Few participants, who had been receiving infusions pre-2017 (n=5), knew of, or had heard of service changes (n=1/5, 20%), but changes to the infusion room were observed by a few participants, even though they did not link this to a service change. Where service users had not been receiving infusions pre-2017, they were asked what they currently thought of the infusion room, the data for which is included under the facilities theme rather than the observed changes to the service.

3.1.2.1 Perception – staff behaviours

Participants were extremely positive towards the nursing and support staff, with no negative comments or suggestion for improvements being given. Staff were described as "going above and beyond", approachable, caring, patient, knowledgeable, responsive, empathetic and specialised. Service users particularly valued the fact that the staff were friendly and helpful, and that they took the time to explain everything, and they did not feel that staff were rushed. In addition, they valued the staff building relationships and taking an interest in the service user, which provides a personal element to the care they receive.

P10: "I think the staff are phenomenal, I have never had a bad experience with the staff to be fair. The nurse at Llandough and the same with the nurses at the Heath, are always willing to go above and beyond to get you out." (Male, Crohn's disease)

P26: "They are really friendly, they are really helpful. They just understand. They chat you through everything if you are stuck or you are confused. They will sit you down and go through it.

They know if I am feeling well and having a laugh with them. Or if I am just sitting there, just saying I don't feel great and they ask what is wrong and how can we help. It is nice when you are feeling really rough but also nice where you are having a laugh." (Female, Crohn's disease)

P17: "Yeah. I cannot speak highly enough they are really organised and very caring and they do a great job." (Female, Crohn's disease)

3.1.2.2 Perception – facilities

The infusion room facilities were positively described by service users as spacious, clean and comfortable. The room was also described as busy and the members of staff on duty were consistent resulting in continuity in care and were always available. Some participants discussed the value of staff consistency allowing them to ask questions, as they felt it was a "safe space". In addition, some service users value the face-to-face contact in the infusion room to discuss how they are feeling, which they otherwise would not have talked about. In addition, service users felt reassured that the infusion room was located next to the in-patient ward, where there were doctors who could be contacted in the event of an issue arising. Furthermore, some participants enjoyed talking to and meeting other service users within the infusion room.

P18: "I've been fortunate that the two occasions I've been there they've had at least two of the same staff on duty, so there's elements of continuity there as well. You know, see, I don't mind being in a room with other people receiving their infusions at the same time. I could imagine, maybe it may not be to everybody's kind of liking, really. But yeah, it's it. It's been fine. There's kind of been maybe five of us maximum in there. So space wise you feel as if you've got enough space. It's got a toilet just off it. So yeah, it's been fine. I can only comment positively, really about it. I've never kept waiting. You know, if my appointment is at a certain time, I'm seen promptly." (Male, Ulcerative colitis)

P10: "I have been going 6, 7 years now, I feel that they are part of my family now, so I see them every 6 weeks, so they no every part of my life, partners and relationship woes and everything. So it feel like a safe space, where you feel you can go with problems." (Male, Crohn's disease)

Negatives included the lack of parking at Llandough, preference towards a hospital ward setting and that the room was a little small. Although no one said that they felt uncomfortable with the lack of privacy within the room, four participants stated that they could see it would be an issue for other people.

P23: "Its fine. I imagine there would be some people to have a curtain or something separating them form the other patients, to have a bit more privacy. As

at the moment it is just one open room where we all sit there together and have our drips done. Personally, I am not particularly bothered but the demographic that go in there are so varied. And I imagine some would prefer that privacy." (Male, Ulcerative colitis)

P18: "[I have problems] parking and physically accessing the service, it's a nightmare trying to park at Llandough hospital certain times of the day. I'm aware they've got a shuttle service or a park and ride service, but I tell what you've got this type of condition. And you've got a flare up. It can be quite anxiety provoking, kind of what you're thinking. Well, "God, you know I can't be driving around (and) around the car park". You know there are times where you really do have to plot where you're nearest toilet is to kind of put things bluntly." (Male, Ulcerative colitis)

3.1.2.3 Perception – the service in general

There were a wealth of positive comments on the IBD service in general, with it being described as well organised, efficient, consistent and friendly. Service users particularly valued the "one stop shop" nature of the service and the fact that their appointment never gets rearranged or cancelled. Some participants did say it took them a while to fully understand how the system worked or that they originally were not fully engaged with the service and wished they had been before problems started to arise.

P14: "It [infusion room appointments] never gets, cancelled or rearranged. Like it's only if, I've had to move it. Otherwise it's always consistent, there's never any issues, so that's really good." (Female, Crohn's disease)

3.1.2.4 Service access problems – internal and the wider system

Participants did not report problems with access to the IBD services, with the IBD telephone lines being described as responsive and helpful. However, there were reports of problems accessing consultant appointments and with telephone consultations and locum consultants often being mentioned as areas that did not meet the service users' expectations. Those service users receiving face-to-face contact found this extremely valuable, with one participant stating that she only rings the IBD nurses in an emergency but relies on the face-to-face interaction for non-emergency issues and questions. Furthermore, one participant did find early morning appointments difficult to attend.

Coordination of care between other departments (e.g., dieticians, primary care, surgery etc.) were talked about as areas where access and receiving care had been difficult, and often resulted in delays to treatment. Furthermore, one participant said they would value the input of a dietician earlier on to firstly understand the relationship between their diet and IBD and providing

skills/knowledge during a flare, rather than having to wait for a referral at that point.

P10: "Phone call consultation with the Doctor at the Heath are supposedly, every 6 months, but I have not had one for a year and a half because they cancelled, moved, cancelled, move. I missed the face to face aspect. Because over the phone the doctor cannot see if you are doing well. So it is very easy, so if you look at bit pale, the doctor can say are you ok? But over the phone it is very easy to go yeah everything is fine. Over the phone there is no face-to-face interaction.

My last phone call consultants was "how are you?", "how are your Crohn's?" and that was the end of the conversation. When you are up there it tends to be a bit more in-depth. I had a face-to-face before COVID they wanted to know everything, how I was, was I feeling fatigued, have I got any issues, how was I finding the treatment, what medications I was on. And all stuff like that, but now it is "how are you", "how's you Crohn's" , that's it tara." (Male, Crohn's disease)

P26: "I really don't want the injection, as I don't fancy jabbing myself and no one else will want to jab me. And I am thinking, if I don't go up there [to the infusion room at Llandough]. What happens if I am sicker, like I am now. How are they going to know, if I am on the outside, doing my own injection and I just go up for blood. Who then do I talk to? If have got the IBD nurses, I can ring them but I don't want to nag them all the time. Do you know what I mean? And if I am not at the IV room then who do I speak to as the GP is rubbish. So I have to, well I prefer to go up there as say, I am not feeling well today, or things are getting worse." (Female, Crohn's disease)

Service users were asked if they had any suggestions to improve the service. These suggestions included:

- Having an email address for small enquires (e.g., blood test results etc.).
- Removing the answer phone system.
- Using an App for two-way sharing of information.
- Having an out of hours and emergency telephone line that is separate from the existing telephone line.
- Increasing privacy in the infusion room.
- Guides on how best to deal with flares out of area (e.g., while on holiday).

- Give the service users an opportunity to have a face-to-face in a nurse lead clinic in cases where consultant appointments are via telephone.
- Focus on prevention (e.g., education on diet and lifestyle management) rather than being reactive to flares.

P14: "I think the only the only thing for me that I've felt like I've needed that I haven't been able to have is like dietary or nutrition advice…….. I wanna try and prevent anything further happening. I get that, obviously, the hospital is less inclined to prevent, and they're just more there to like fix things when things go wrong, if that makes sense." (Female, Crohn's disease)

3.1.2.5 Observed changes to the IBD service

The changes made to the infusion room were reported as a vast improvement compared to the previous provision. Positive and negative comments on the infusion room can be found in section 3.1.2.2. In addition, one service user reported that Llandough was not as convenient for their infusions compared to The University Hospital of Wales. Some participants did indicate that they were asked a series of questions before every infusion but could not identify this as a PROM or what it was used for.

P26: "Yeah, they have moved to Llandough. So yeah, they went to small room, that was just horrible as it was pokey. Now it is a bigger room, that they have TV that they stick goldfish on or they stick like a picture of the sea. That's nice – chilling. They have got music on this little TV that plays music so you have a bit of music in the background. You just listen to that or you go on your phone or the nurses are there and have a little chat with you and see how you have been. So it is really lovely as well. It is really spacious as well, so you can sit where you want, you don't have to be on top of each other." (Female, Crohn's disease)

P14: "I live in North Cardiff, so getting down to Llandough is [more difficult than the Heath]." (Female, Crohn's disease)

3.2 What is the impact of the change in IBD service provision on the occurrence of bowel surgery?

There were 648 surgeries among service users with Crohn's disease (n=397; 61.3%) and with ulcerative colitis (n=251; 38.7%) between 2010-2022. The majority of the events occurring in adults aged over 50 years of age (67.1%) and were elective surgeries (63%) (Appendix 6).

The number of surgeries per year varied over time among service users diagnosed with IBD (Figure 9). Although there was no correlation over time, 2022 had a significantly lower number of surgeries comparative to the distribution between 2010-2016 (the distribution is represented by the box and whisker plot in Figure 9). Conversely, 2019 had a significantly higher number of surgeries comparative to the distribution between 2010-2016 (Figure 9). There was no significant difference when only looking at the surgeries associated with stoma formation between 2016 and 2022; but the number of events per year are low limiting any substantive conclusion (Figure 10).

3.3 What is the impact of the change in IBD service provision on the number of emergency admissions?

Between 2010-2022 there were 2,219 emergency admissions among IBD service users with Crohn's disease (n=1092; 49.2%) or with ulcerative colitis (n=1127; 50.8%). The majority of those admitted were via A&E (55.3%) and aged under 50 years old (69.4%) (Appendix 9).

The number of emergency admissions among IBD service users varied over time (Figure 11). The years 2022, 2021 and 2017 had a significantly lower number of emergency admissions compared to the distribution between 2010-2016 (the distribution is represented by the box and whisker plot in Figure 11). However, when looking at emergency admissions via A&E only, 2020 and 2015 had a significantly higher number of emergency admission compared to the distribution between 2010-2016. This suggest that although the overall number of emergency admissions are going down, for those that are admitted proportionally more are going through A&E, rather than direct admission to a ward.

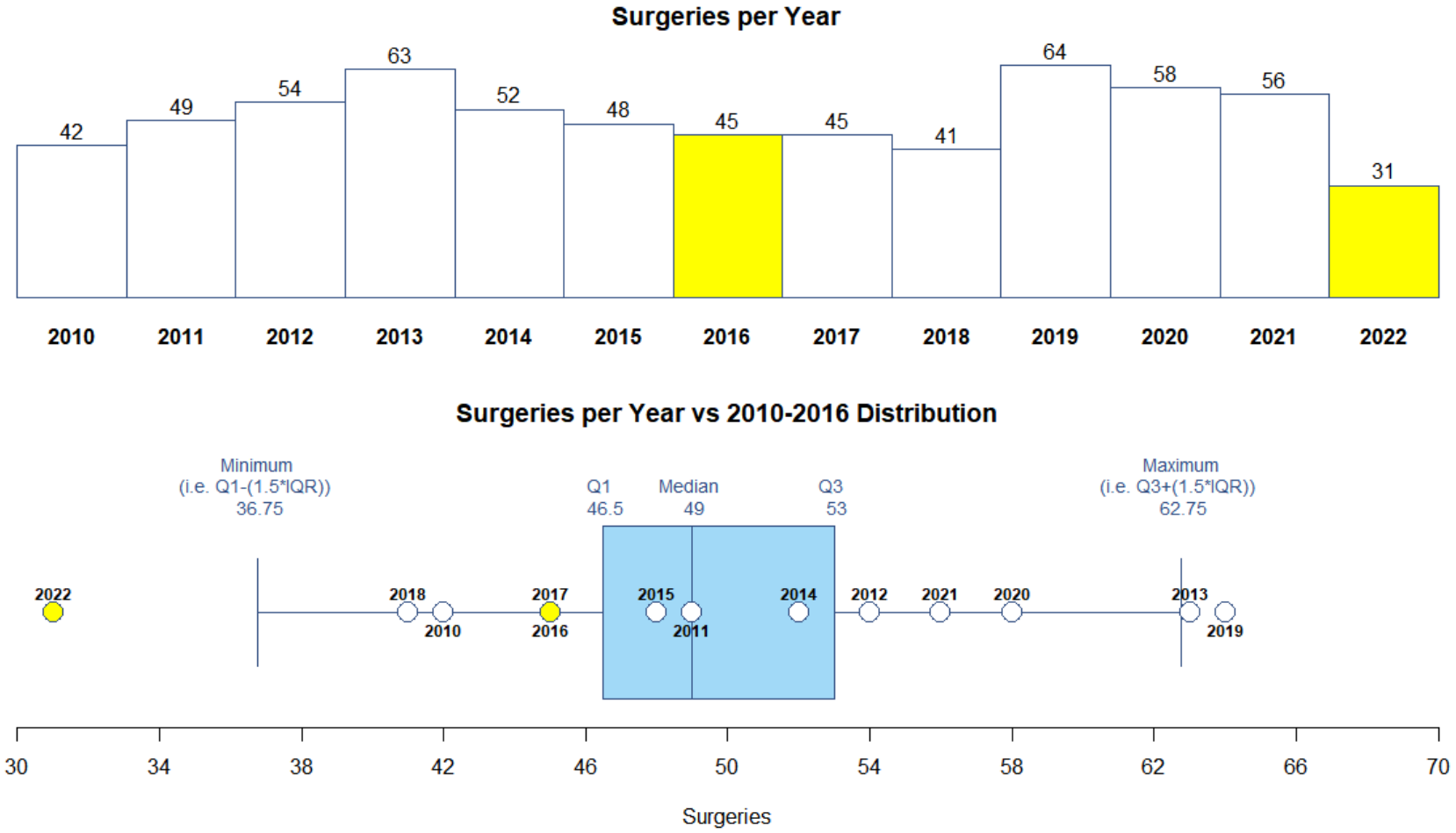


Figure 9 Number of surgeries per year over time.
Abbreviations: IQR = interquartile range (represented by the blue box), Q1 = quartile 1 or 25th percentile, Q3 = Quartile 3 or 75th percentile.
Each point represents the number of stoma surgeries performed in a given year.

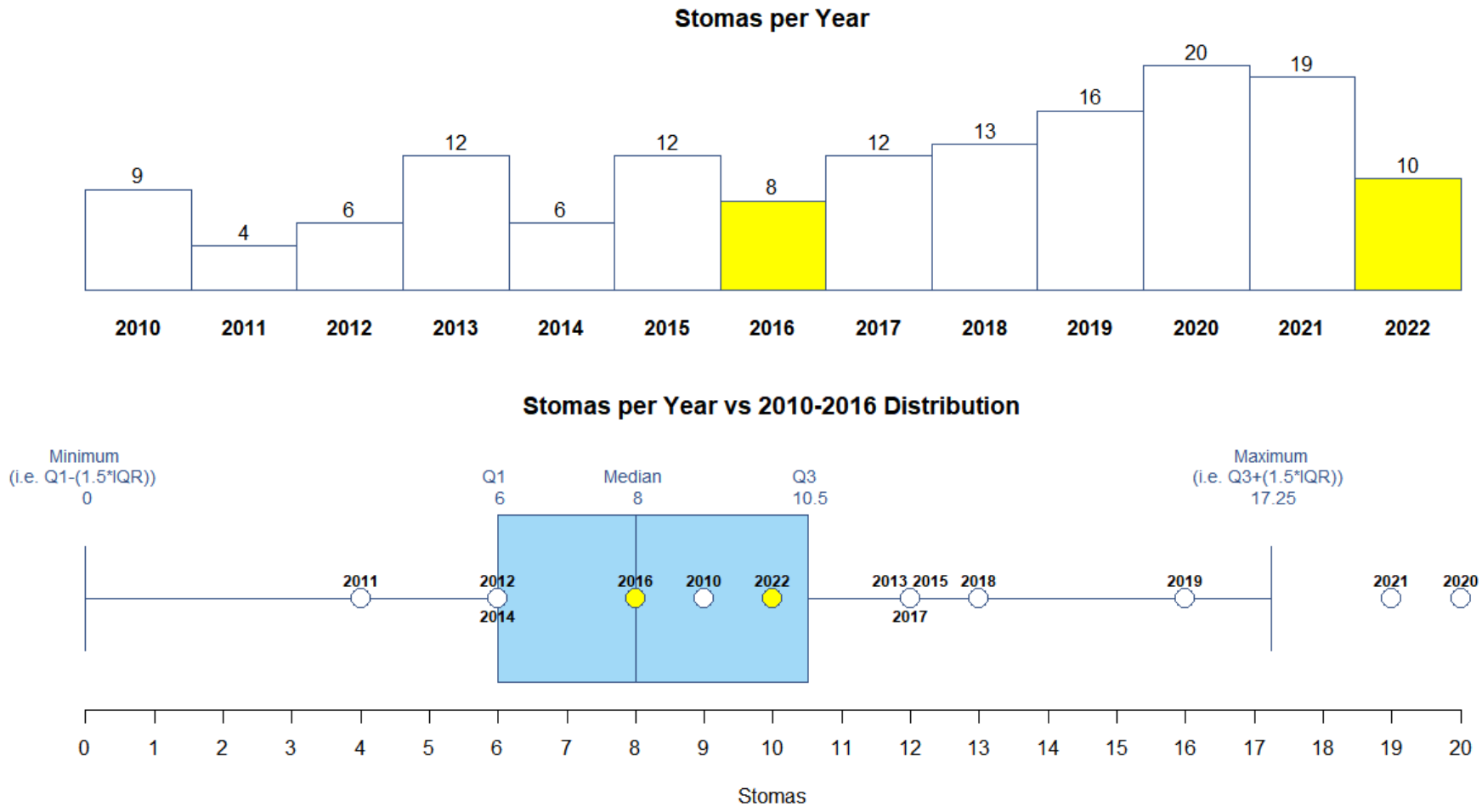


Figure 10 Number of stoma surgeries per year over time
Abbreviations: IQR = interquartile range (represented by the blue box), Q1 = quartile 1 or 25th percentile, Q3 = Quartile 3 or 75th percentile.
Each point represents the number of stoma surgeries performed in a given year.

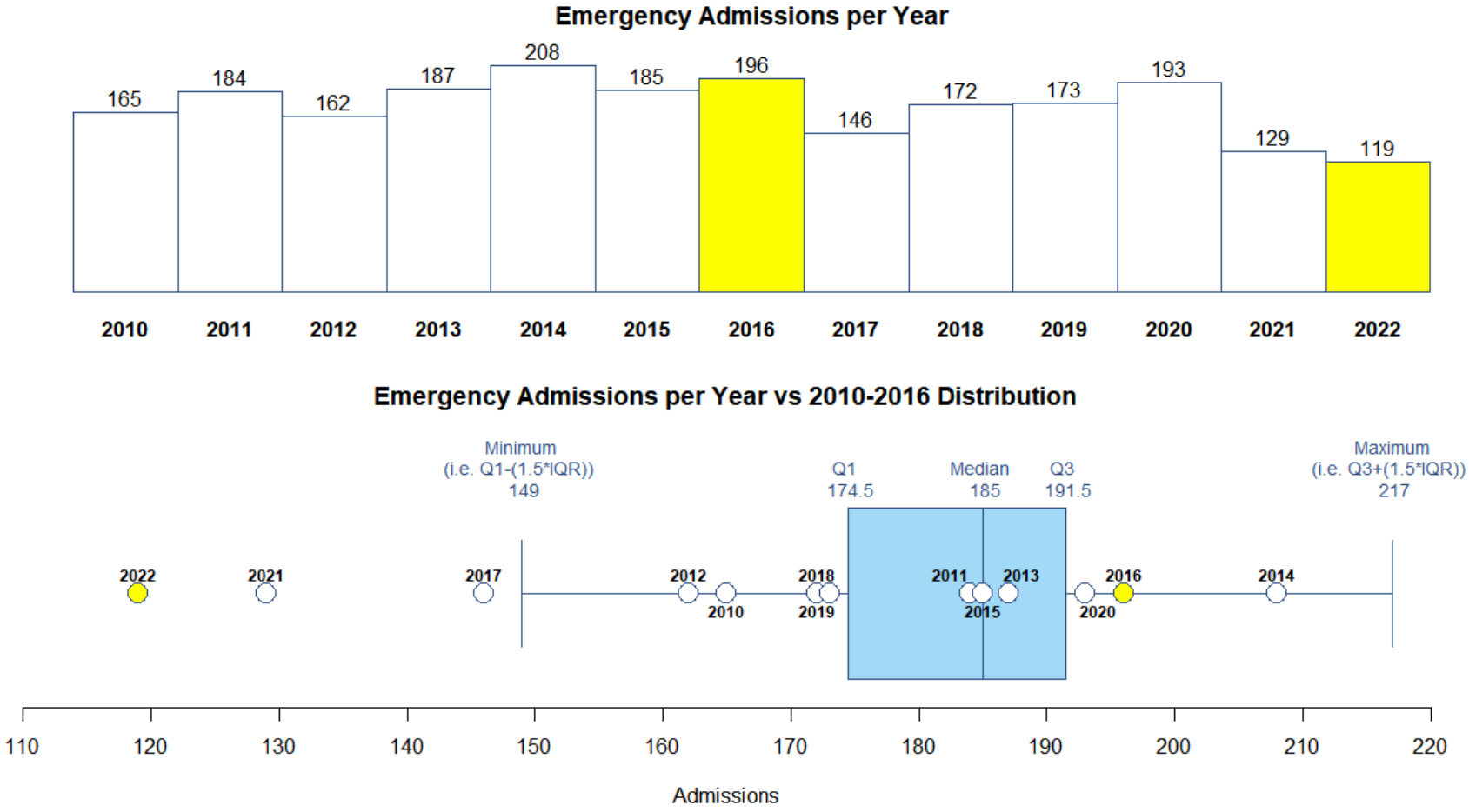


Figure 11 Number of emergency admissions per year over time.
Abbreviations: IQR = interquartile range (represented by the blue box), Q1 = quartile 1 or 25th percentile, Q3 = Quartile 3 or 75th percentile.
Each point represents the number of stoma surgeries performed in a given year.

3.4 What is the cost effectiveness of the change in IBD service provision?

The IBD service has evolved over several years, utilising the cost savings from negotiated reductions in biologics costs as well as charitable donations to expand the staffing as well as services offered and the available facilities. Staffing has grown to include specialist registrars, a prescribing pharmacist, additional band 6 nurse time, additional administration time and a band 6 IBD manager, indicating the expansion of the service, but may also reflect an increasing prevalence of IBD. Some of the data was only available for University Hospital Llandough (UHL), (IBD helpline, self-management and hot clinics), although provided at both UHL and University Hospital of Wales (UHW). Other services are only provided at UHL (infusion room) and so these reflect the whole CAV UHB population. Data for total procedures or admissions is also for the entire CAV UHB population. The two sites are anecdotally noted to have similar population characteristics. The costs of providing the IBD service are comprised of the staffing, provision of facilities for hot clinics and infusion rooms, appropriate testing and provision of medication including biologics. The key elements of the IBD service are discussed below, including their cost, the changes that have occurred between 2016 and 2022 and their impact (either from data, or a discussion of potential impact).

3.4.1 IBD Helpline at UHL

The number of calls to the IBD helpline at UHL have increased from 1,238 in 2016 to 3,703 calls in 2022. This increase in calls results in an annual cost increase to the IBD clinic of £20,880 (2016 = £10,486, 2022 = £31,364) based on the average 8 minutes of nurse time used to respond to the calls. However, this service is likely to prevent expenditure in other areas of the health service. Some of the calls are for routine issues such as blood test results, however others allow service users to access specialist advice and triaging. These service users may otherwise have visited the GP, or A&E services, however we do not have any quantitative data available on the current outcomes of the helpline, or on what would have happened without it.

Although we cannot directly compare healthcare costs associated with the increased use of the helpline between 2016 and 2022, we can consider the plausible outcomes, and their costs relative to the provision of the helpline service. The cost of the helpline in 2022 is equivalent to the cost of 871 standard GP appointments or 89 A&E visits. This means that if either 24% of patients who called would otherwise have called a GP, or 2% of patients who called would otherwise have visited A&E, then the helpline would be cost neutral. If more patients would have accessed either of these services then the IBD helpline is saving health care

resources in other areas of the health board. Figure 13 and Figure 12 demonstrate the potential outcomes for someone who has a flare up both with and without the IBD helpline in place. This could be used to build a simple decision tree economic model if there were data on the proportion of patients experiencing the different outcomes.

To quantify this with more certainty a short audit of the outcomes of phone calls could be completed, to see how many still require this type of intervention, or are calling about test results or routine follow up and would not have required additional healthcare without the helpline.

An audit following the introduction of a telemedicine service in a hospital in Scotland (Squires, 2015) found that for 93% of the calls patients stated they would otherwise have sought alternative health care. They reported that over a 5-month period, with 441 calls, 32% stated they would have visited the GP, 59% a consultant visit, 1% A&E and 2 % would have been admitted. Based on these findings the authors calculated, using NHS reference costs for 2010/11, a mean saving of £8,096 per month. There are a number of limitations in this study, primarily that patients may not have been explicitly given the option of selecting "no alternative healthcare would have been sought". In addition, patients may not have followed through with appointments, or been able to access them directly, in all cases. Therefore the "avoided outcomes" may be overstated. The study does illustrate an analysis with relatively simple data collection, that improves the understanding of the service.

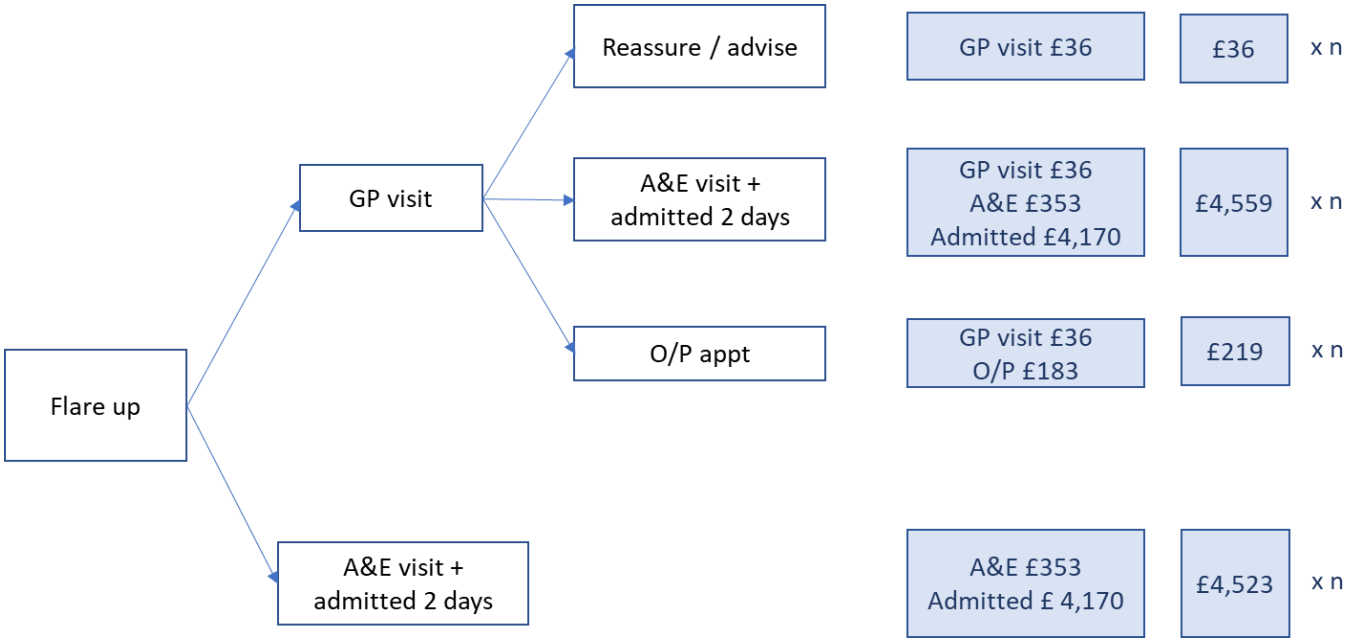


Figure 13 Decision tree for service without IBD helpline

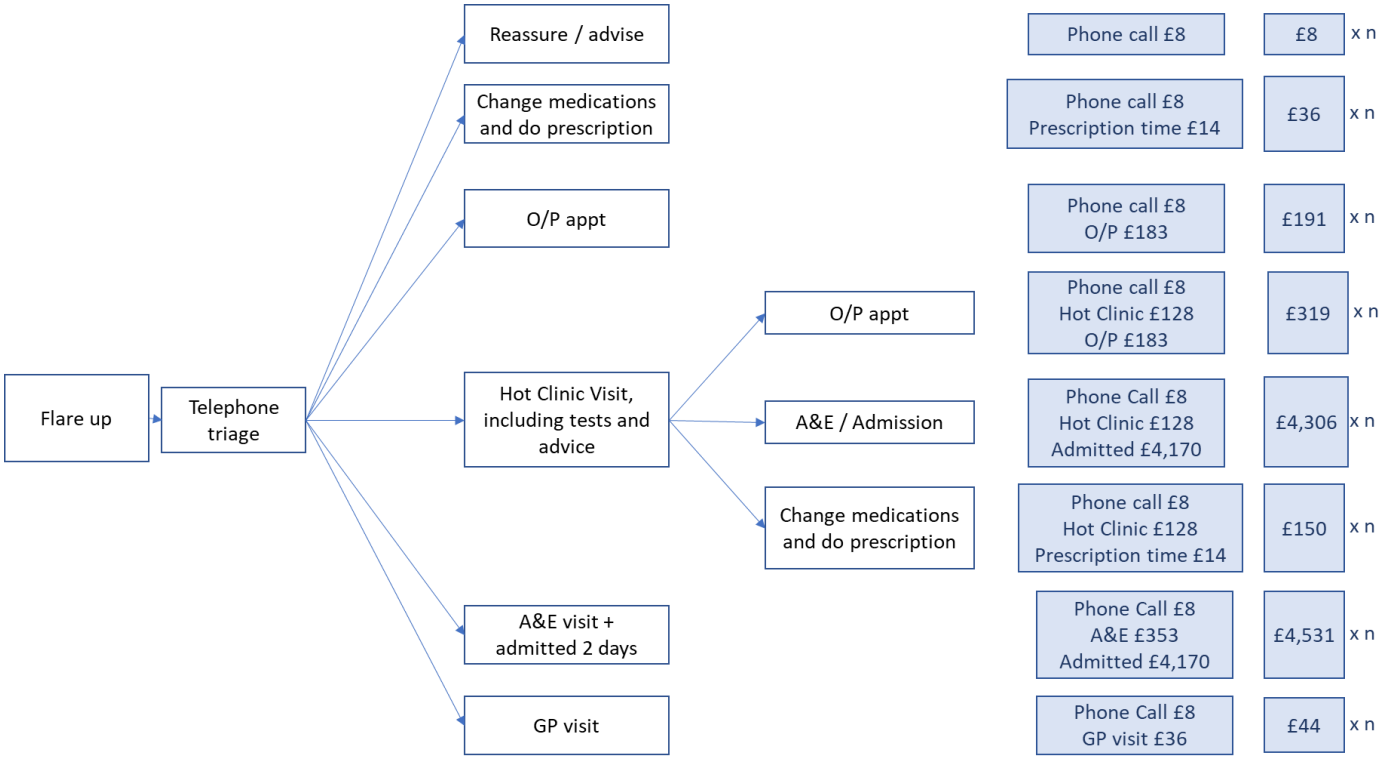


Figure 12 Decision tree for service with IBD helpline and hot clinic

3.4.2 Self-management at UHL

The development of a nurse led self-management service, has resulted in 331 service users at UHL self-managing and thus avoiding routine outpatient appointments with a consultant. Normally patients would have one appointment a year, at a cost of £183 per appointment. Where patients are able to self-manage, they would send in a blood test and stool sample once a year and then normally access the helpline if advice was needed. If that was not sufficient they may visit the hot clinic or have an outpatient appointment. For example, a patient that required no additional support would use healthcare resources of £46 per year, including blood and stool tests and 15 minutes of nurse time to send a follow up letter. If the patient called the helpline three times in a year, this would be a total cost of £60 per year.

With the addition of a visit to the hot clinic this would then be £202 during the year, compared to the £183 for an outpatient appointment. However, a flare up requiring a visit to the hot clinic may not have been avoided by the routine outpatient appointment. Data collected on the number of healthcare contacts for patients using self-management would enable this to be calculated in the future.

3.4.3 Hot clinic – all of CAV UHL

In 2022, the hot clinic saw 49 service users, all of whom received appropriate investigations on the same day, including blood tests and abdominal X-ray, with four service users going onto have flexible sigmoidoscopy examination on the same day or within 48 hours. The majority of outcomes were giving reassurance, laxatives or steroids. However, 14 (28.6%) had biologics started or changed, and two (4.1%) service users were admitted.

Prior to the establishment of the hot clinic, staff report that patients would likely have been admitted to a ward for investigation, with a one or two day stay. Data on emergency admissions related to IBD shows a decrease in admissions between 2016 and 2022 (section 3.3). We cannot be sure if this is related only to the hot clinic, or is also related to increased use of biologics or other changes in service provision. Therefore, we have investigated costs of the current hot clinic provision and routes that may have been taken previously, while the overall reduction in costs for emergency admissions is presented in section 3.4.5

Each hot clinic attendance is costed at £128, which includes staff time and overheads, plus basic office facilities, blood tests, and an X-ray for each patient, with 8% receiving sigmoidoscopies and 4% being admitted to hospital. It does not include the costs of changes to biologics as this is an ongoing cost, and it is assumed that this would have been changed via an admission or outpatient

appointment in the comparator arm if the hot clinic were not available. The cost of the biologics would not have been included in the NHS Cost Collection for admissions or outpatient HRG groups. The PSSRU staffing costs include a cost for estates, but may not cover all the facilities and consumables used within a hot clinic visit. Therefore, the cost may be a slight underestimate.

If there is an assumption that all those who attend the hot clinic would have instead attended A&E (£353), the hot clinic represents a cost saving of £211 per person. If the patient were admitted from A&E, as may often be the case for people with IBD, then a much higher cost saving would be expected. The cost of an emergency admission, based on data from the APC data for 2022, and applying unit costs for NHS Cost collection 2021/22 was estimated as £4,170 per person admitted. However, this uses a weighted average of long and short stay costs (weighting according to data across NHS England), and is likely to include costs for surgery that would not be avoidable. Applying short stay costs only would result in £1,448 per person admitted.

Description	Unit Cost	Source
Hot Clinic attendance	£128	Staffing (PSSRU 2022) plus blood tests, and an X-ray for each patient, with 8% receiving sigmoidoscopies
A&E attendance	£353	NHS Cost collection 2021/22
Emergency admissions, mean cost per patient,	£1,448	NHS Cost collection 2021/22, short stay costs only, for those codes where available
Emergency admissions, mean cost per patient	£4,170	NHS Cost collection 2021/22, weighted average of long and short stays

3.4.4 Biologics – all of CAV UHB

The number of biologics available and their cost have changed over the time period of interest, due to NICE approving more biologics and also drug patents expiring so biosimilars can be produced at a competitive market rate. Therefore, it is very difficult to accurately compare the costs of biologic provision between 2016 to 2022. CEDAR have not had access to the total spend on biologics, or total number of patients receiving biologics for both these time periods, and so have limited discussion to the negotiated discounts for Vedolizumab.

CAV UHB have negotiated an additional discount for one particular biologic (Vedolizumab), over and above the Patient Access Scheme price. This means that the initial 3 infusions are reimbursed, which reduced the price in the first year by approximately £5,000 per patient. The subsequent years are at the standard PAS price available to the NHS, although the availability of self-administered

subcutaneous injections is a cost saving when compared to intravenous delivery of the same biologic. Intravenous (IV) delivery requires time at the infusion clinic, with facilities and nurse time as well as consumables. NICE resource impact sheets for TA342 (Vedolizumab for treating moderately to severely active ulcerative colitis) use an NHS Tariff (2022/23) of £391 for this administration, although the HRG group is not specific to infusion of biologics. The same resource impact sheet suggests a default £50 per month for administration and delivery of subcutaneous (SC) medication, although consideration of local costs is recommended. More recent company submissions to NICE use a different approach, with IV administration being the cost of a face to face outpatient appointment, and no cost applied to the delivery of SC injections. In either case, there is a cost reduction for delivery by SC, even considering the increased frequency of delivery for SC compared to IV.

For Vedolizumab there are three initial IV infusions, followed by either IV every 8 weeks, or SC every 2 weeks (in some cases this may be escalated to every week based on the clinician's judgement, however this is outside of the marketing authorisation licence for Vedolizuamb). Table 3 presents approximate costs for year 1 (including the negotiated reimbursement) and subsequent years.

Table 3 Per patient costs for Vedolizumab, excluding administration, prescribing or delivery costs

	Year 1 (no discount	Year 1 (with discount)	Year 2
IV	£13,336	£8,335	£11,669
SC (2 weeks)	£13,626	£8,625	£9,750
SC (1 week)	£22,251	£17,250	£19,500

Overall it is expected that the IBD service annual costs of biologics will have increased, as the standard of care has changed nationally. There are a number of different biologics available and decision making is a complex combination of clinical, social and economic factors, as many biologics now have alternatives of IV, SC or even tablet forms available.

The SBAR developed by the IBD team documenting the reinvestment of cost savings from Vedoluzimab contracts within Gastroenterology planned for. The SBAR projections planned for 179 patients in Cardiff and Vale in 2020/21, with 90% of these using SC delivery. In the data shared with CEDAR there are currently 214 patients in the maintenance phase, with 76% using SC. There are an additional 26 in the induction phase of Vedoluzimab with planned use of SC for maintenance. This means that the savings expected for first year Vedoluzimab are being realised, if these patients are assumed to have been using Vedoluzimab

with no discount otherwise. As VAT is payable on hospital administered medicines, but not on prescription medicines administered by patients at home, there are additional savings that can be realised in the move to SC administration. It should be noted that after the first year there is no subsequent discount over and above the Patient Access Schemes (PAS) price, and that there are a range of other biologic options available, some of which are at a lower price.

When considering cost savings from initial infusions, the annual cost of the ongoing treatment will also need to be considered, alongside the cost of any alternative biologic. This can be facilitated by a resource such as the impact template provided in TA342.

Data provided by the IBD service demonstrates a rise in the total number of IV infusions from 2017 to 2021, followed by a decrease of 180 infusions (Figure 14). This is primarily a decrease in the IV provision of Vedolizumab, which has occurred alongside a move to currently providing 168 patients with SC pens that they can administer at home.

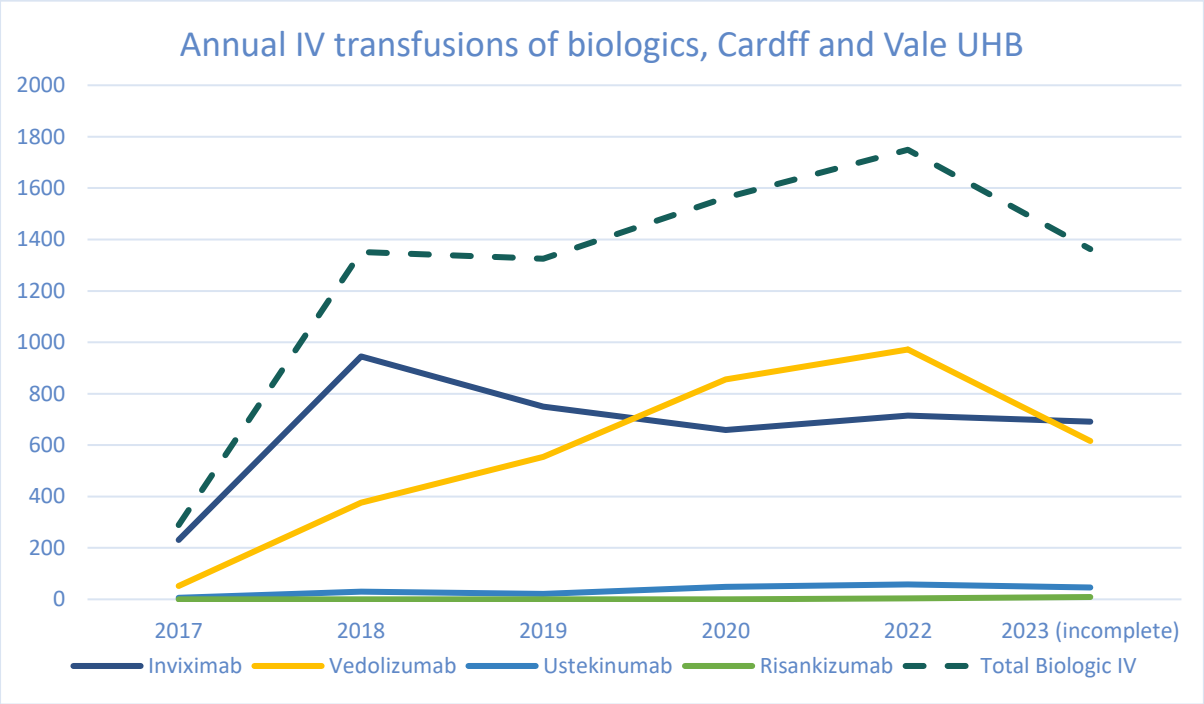


Figure 14 Annual IV transfusions of biologics, Cardiff and Vale UHB

A direct comparison of IV and SC delivery is not possible as both IV and SC delivered in clinic are recorded by the number of transfusions or injections delivered. SC at home is recorded by the number of patients participating. In order to get a very rough approximation, we have assumed that all IV doses are for patients receiving maintenance transfusions every 8 weeks (Figure 15). This ignores the initial starting regimen, or anyone receiving more than 1 transfusion

every 8 weeks. For SC delivered in the infusion room we have assumed that this is every 2 weeks. For SC at home, there are currently (December 2023) 168 patients who are using this method. The SC home delivery commenced in 2021 and we have assumed a linear growth to estimate numbers for 2021 and 2022. It can be seen that the overall number of patients receiving Vedolizumab has increased, but with a decline in the proportion using IV infusion.

SC delivery is generally less costly than IV delivery, and the cost of the biologics is comparable for the standard regimen of every 8 weeks vs every 2 weeks. This may need further consideration for patients requiring SC weekly, or alternative IV regimens.

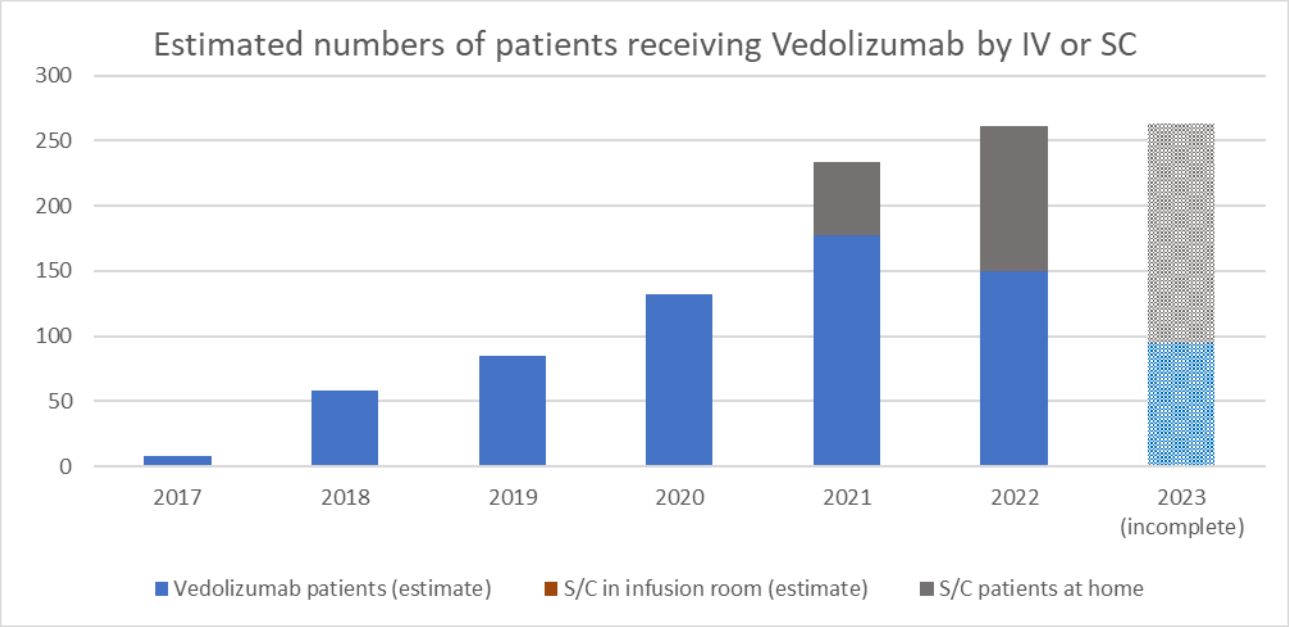


Figure 15 Estimated numbers of patients receiving Vedolizumab by IV or SC

3.4.5 Emergency admissions – all of CAV UHB

The number of emergency admissions decreased between 2016 to 2022, from 196 to 119, representing an annual cost saving of £145,548. This costing was based on the HRG code found alongside the emergency admission, some of which were surgical procedures and therefore could be double counted within the surgeries cost as well. It is estimated that approximately 13 service users may have been included in both the surgical and emergency admission cost calculations.

3.4.6 Surgeries – all of CAV UHB

A decrease in the number of surgeries was observed between 2016 to 2022, from 45 to 31, representing an annual cost saving of £147,299.

3.4.7 Stoma care costs– all of CAV UHB

While this may be the optimum treatment approach for some patients, for many it represents a negative impact on their quality of life as well as an annual cost of consumables and the risk of adverse events. There were 8 stomas surgeries undertaken in 2016, compared to 10 in 2022, representing an annual cost increase of £2,131.80 per year in ongoing stomas care costs. However, it is unclear how many of these are permanent or temporary stomas and whether these numbers have been undercounted based on the primary procedure code used, so these longer-term on-going costs cannot be determined; as these cost estimates are likely only applicable to these years analysed.

3.4.1 Summary for costs and consequences

As previously stated, a full assessment could not be made due to data availability. The known costs and consequences as described in the previous sections are summarised in Table 4, but should always be read in the context of the caveats and assumptions already discussed. Much of the data relies on estimations and there are parts of the patient pathway that are missing.

Table 4 Description of partial costs and consequences

	2016	2022
Costs		
IBD phone line	£10,486	£31,364
Hot clinic	£0	£6,254
Self-managing	£0	£15,341
Surgeries	£522,667	£375,368
Emergency admissions	£641,716	£496,167
Biologics	Unknown	Unknown
Other costs?	Unknown	Unknown
Consequences, in terms of services delivered. Quality of life outcomes not available		
Phone calls to IBD line	1238	3703
Hot clinic visits	0	49
Number self-managing	0	331
IV infusions of biologics	293 (2017)	1761
Patients using SC at home	0	168 (2023, incomplete)
Consequences, in terms of outcomes. Quality of life outcomes not available		
Non-elective surgery numbers	31	18
Elective surgery numbers	14	13
Number of stomas	8	10
Number of emergency admissions	196	119
GP Visits	Unknown	Unknown
Visits to A&E	Unknown	Unknown
Longer term consequences	Unknown	Unknown

4 Discussion

This report aims to assess the impact of the IBD service changes in CAV UHB through service user perception, the change in the emergency admission, the number of IBD related surgeries and cost effectiveness. The prevalence of IBD has been increasing steadily in the UK, therefore it is imperative to understand and deliver a cost-effective value-based IBD service.

The complex nature of the service changes in both the gradual roll out and external factors such as: an increase in the number of biologics available, healthcare pressure, and a global pandemic, have made it challenging to assess and quantify the patient benefits due to the IBD service changes. The exact causality of the observed decreases in emergency hospital admission and number of IBD related bowel surgeries cannot be determined from this evaluation, but previous studies have shown a relationship with biologics and IBD telephone helplines (Hayee *et al.*, 2015). In order to mitigate against some of the confounding factors, the most recent data was used which indicate encouraging results for reductions in hospital admissions and surgeries. However, there is the potential that the records are not fully complete despite allowing for a 6-month delay in reporting. It is possible that the reduction could be a "natural" dip/fluctuation or as a result of another confounding factor, such as fewer general anaesthetic list available since the pandemic in 2020. Therefore, further prospective longitudinal data should be collected, ideally with a control, to fully assess the impact of the service on patient outcomes and healthcare resource use.

Gethins (2020) noted that 16% of IBD patients were admitted unnecessarily, with up to a quarter of patients waiting two days for specialist intervention on a gastroenterology ward. The hot clinic provided by CAV UHB, allows service users to be reviewed within a few hours and have appropriate management strategies put in place to deal with flares in the community. This could be one of the reasons for the observed reduction in hospital admissions. However, pathways that patients took when being admitted to hospital as an emergency were not explored. Anecdotal reports from clinicians indicate that many patients still end up in A&E while they wait for a bed, due to the requirement for high intensity monitoring. In addition, emergency admissions data indicated a higher proportion of those admitted were via A&E, rather than direct admission to the ward in recent years, comparative to pre-2016 (Appendix 9). It should also be noted that the APC data could not determine if an admission was due to IBD or if a service user with IBD had an emergency admission for another reason. In addition, surgeries were coded as elective or emergency, however, there is anecdotal reports that more "semi-elective surgeries are occurring as alternative options (e.g., therapeutics) are

explored as first line options after an emergency admission, resulting in surgery occurring a few days after admission.

One stand-out result was the overwhelming positive service user perception of the service, with high praise for the IBD staff, specifically the IBD specialist nurses. It has previously been noted within the literature that specialist nurses that were caring, empathetic and provided support, advice and disease management were valued to service users within their care (Belling *et al.*, 2008). Unfortunately, it was not possible to obtain perceptions for service users within the nurse-lead self-management pathway, therefore this report cannot comment on the patient reported benefit of this pathway. Further assessment should be undertaken given the potential value the self-management pathway could hold and should also consider reduced travel time and associated environmental impact of travel to in-patient clinics. This is particularly noteworthy given that there were mixed views on virtual contact/consultations identified, which was another aspect that was not fully explored within this evaluation. Within the literature there was evidence of high levels of reported satisfaction of virtual IBD clinics, but the results of which were influenced by personality type (Storan *et al.*, 2023).

There were some potentially useful suggestions for improvements made by service users, which included removing the answering phone system, having an email address, using an app to help prevent flares and to improve communication between departments. Some of these suggestions have previously been explored within the literature (Cross *et al.*, 2023; El-Naggar *et al.*, 2021; Kelso and Feagins, 2018). Furthermore, systemic communication problems between departments negatively impacting care has previously been reported by other groups (Cross *et al.*, 2023). Poor communication between departments goes beyond that of the IBD service but should be taken into consideration when helping and directing users to other support or care, especially if contact is limited (e.g., on the self-management pathway). However, it should be noted that many of the suggestions for service improvements within this report came from individuals who already appeared quite empowered in managing their condition and accessing the service. Therefore, some of the suggestions to increase the level of empowerment may not be suitable to all service users due to digital inequities or current lack of service engagement/empowerment.

Although a full cost consequence approach to the health economic assessment was not possible due to some critical data fields being unavailable, a narrative analysis identified a cost shift from surgery and emergency admission towards biologic therapy. A service change where biologics make up most of the incurred costs has been documented in the Netherlands (van der Valk *et al.*, 2014) and

other high-income countries (Burisch *et al.*, 2023). The increased use, and therefore cost of the IBD helpline should be put into context of the potential cost saving presented elsewhere. A study at an NHS hospital in Glasgow Scotland, found that there were cost savings from an IBD advice line run by clinical nurse specialists, compared to the cost of GP or consultant appointments (Squires *et al.*, 2016). This study also documented the reason for the call to the advice line, but did not report outcomes (e.g., medication change, arranging outpatient appointment). Both of these factors should be taken into consideration if a more robust assessment of the economic benefit of CAV UHB IBD service changes was required. Furthermore, future investigations could include a societal perspective, including indirect costs such as loss of productivity and absenteeism (Burisch *et al.*, 2023) as well as changes to quality of life. This could be aided by the scale up and encouragement of use of electronic PROMs among staff and service users. Continual assessment of the biologic costs should be undertaken due to the dynamic and changing situation in new biologic availability, increase in biosimilars and change in mode of delivery (e.g., infusion vs. sub-cutaneous injection or tablets).

This evaluation of the IBD service within CAV UHB has shown a high satisfaction among service users, and a reduction in surgery and emergency hospital admissions. The cost benefits of the change could not be fully concluded due to data limitations and changes in biologics cost and availability. Further investigation should look at perceptions and outcome of service users on the self-management pathways, prospectively review and track outcomes of service users on biologics and collect meaningful data on outcomes from the hot clinic and telephone helpline.

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Appendix 1

Appendix 1 ICD-10 codes used to identify IBD patients

K50 Crohn disease [regional enteritis]	
	K50.0 Crohn disease of small intestine
	K50.1 Crohn disease of large intestine
	K50.8 Other Crohn disease
	K50.9 Crohn disease, unspecified
K51 Ulcerative colitis	
	K51.0 Ulcerative (chronic) pancolitis
	K51.2 Ulcerative (chronic) proctitis
	K51.3 Ulcerative (chronic) rectosigmoiditis
	K51.5 Left sided colitis
	K51.8 Other ulcerative colitis
	K51.9 Ulcerative colitis, unspecified

*Appendix 2 OPCS procedural code used to identify surgeries. An * marks those code used to identify stoma surgeries*

Jejunum (G58-G67)
G58 Excision of jejunum
G59 Extirpation of lesion of jejunum
G60 Artificial opening into jejunum
G63 Other open operations on jejunum
G67 Other operations on jejunum
Ileum (G69-G82)
G69 Excision of ileum
G70 Open extirpation of lesion of ileum
G71 Bypass of ileum
G72 Other connection of ileum
G73 Attention to connection of ileum
G74 Creation of artificial opening into ileum*
G75 Attention to artificial opening into ileum*
G78 Other open operations on ileum
G82 Other operations on ileum
Colon
H04 Total excision of colon and rectum
H05 Total excision of colon
H06 Extended excision of right hemicolon
H07 Other excision of right hemicolon
H08 Excision of transverse colon
H09 Excision of left hemicolon
H10 Excision of sigmoid colon
H11 Other excision of colon
H12 Extirpation of lesion of colon
H13 Bypass of colon
H14 Exteriorisation of caecum*
H15 Other exteriorisation of colon*
H16 Incision of colon
H19 Other open operations on colon
H30 Other operations on colon
Appendix (H01-H03)
H01 Emergency excision of appendix
H02 Other excision of appendix
H03 Other operations on appendix
Rectum (H33-H46)
H33 Excision of rectum
H34 Open extirpation of lesion of rectum
H40 Operations on rectum through anal sphincter
H41 Other operations on rectum through anus
H46 Other operations on rectum

Anus and perianal region
H47 Excision of anus
H48 Excision of lesion of anus
H49 Destruction of lesion of anus
H54 Dilation of anal sphincter
H55 Other operations on perianal region
H56 Other operations on anus

Appendix 3 Semi-structured survey

Inflammatory bowel disease (IBD) service evaluation

We would like to understand your use and experience of the inflammatory bowel disease (IBD) service within Cardiff and Vale University Health Board. This information will help us understand what works well for patients so we can improve the service for the future. We would be grateful if you could complete this short survey so we can understand the needs of people using the IBD service.

The survey should take around 10-15 minutes to complete. Please answer the questions as honestly as possible. You will be asked to choose the option that best describes how you are feeling. All responses are anonymous and will not be identifiable to your care team. There are also some background questions to help us understand more about you as an individual.

All the information you provide will be stored securely. The anonymised information will be used in a report to learn about the IBD service and the difference it makes to people with IBD.

If you would like to undertake this survey in Welsh please use the drop down menu in the top right hand corner of the form.

Cardiff and Vale UHB is the data controller for any personal data that is collected. The lawful basis for processing data under the UK GDPR is Article 6(1)(e) and Article 9(2)(h)

Data will be retained in line with the Records Management Code of Practice for Health and Care 2022

For any complaints in relation to how your data has been handled, please contact Uhb.Dpo@wales.nhs.uk

To see more information in relation to see how your information is processed, please see our privacy notice at https://cavuhb.nhs.wales/use-of-site/privacy-policy/

The following pre-survey questions are designed to check your eligibility to participate in the survey. The main survey question will follow on the next page.

a. Have you received a diagnosis of IBD?

Yes – Crohn's	
Yes – Ulcerative colitis	
Yes – Unspecified	
No	

b. Do you usually receive your IBD care through Cardiff and Vale UHB?

Yes – currently receiving care	
Previously received care but have now moved out of the area and receiving care else where	
No	

Start of main questionnaire:

1. Demographics
    a. What is your age?

_____ [format as a numeric between 18-100]

b. What is your sex at birth? [format to be only able to select 1 option]

Male	
Female	
Prefer not to say/other	

c. What is your ethnicity? [based on ONS options] [format to be only able to select 1 option]

Asian or Asian British	
Indian	
Pakistani	
Bangladeshi	
Chinese	
Any other Asian background	
Black, Black British, Caribbean or African	
Caribbean	
African	
Any other Black, Black British, or Caribbean background	
Mixed or multiple ethnic groups	
White and Black Caribbean	
White and Black African	
White and Asian	
Any other Mixed or multiple ethnic background	
White	
English, Welsh, Scottish, Northern Irish or British	
Irish	
Gypsy or Irish Traveller	
Roma	
Any other White background	
Other ethnic group	
Arab	
Any other ethnic group	
Prefer not to say	

d. What is your occupation (select all that apply)?

Full-time employed or self-employed	
Part-time employed or self-employed	
Unemployed/ seeking work	
Looking after home/family	
Student	
Retired	
Long-term sick	
Disabled	
Other (Please state)	
Prefer not to say	

2. IBD (type of IBD [asked at beginning])
   a. Approximately when were you diagnosed with IBD (year)?

_____ [Numeric year]

   b. Do you self-manage your IBD (i.e., without medications or treatments from the IBD service)?

Yes – I self-manage	
No – I take medications/treatments from the IBD service	

   c. What treatments and services have you received/used so far for your IBD (select all that apply)?

Treatments	
No treatments	
Aminosalicylates or mesalazines (e.g., Octasa / Salofalk)	
Thiopurines (e.g., Azathioprine, 6 mercaptopurine, Methotrexate)	
Biologics (e.g., Infliximab, Adalimumab, Vedolizumab, Ustekinumab)	
Antibiotics	
Dietary modifications	
Nutritional supplements	
Surgery without stoma formation	
Surgery with temporary stoma	

Surgery with permanent stoma	
Other _____ (please state)	
Services	
Infusion room	
Hot clinic	
IBD specialist nurse	
IBD pharmacists	
Other _____ (please state)	

3. Please answer the following questions thinking about the treatments you have received from the C&V IBD service

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The treatments I am currently receiving have improved my symptoms					
The treatments I am currently receiving have improved my quality of life					
I have not been given enough information about my condition					
I have enough information and confidence to make treatment decisions about my care					
I felt there were treatment options					
I received treatments in a timeframe that was acceptable to me					
I waited too long to get a diagnosis					
I find it hard to access the care / specialists I need to treat my condition					

4. Please answer the following questions thinking about your care you have received from the C&V IBD service [formatted to be only able to select 1 option]

Question	Answers
Did you feel that you were listened to?	Always, Usually, Sometimes, Never
Did you feel well cared for?	Always, Usually, Sometimes, Never
From the time you realised you needed to use this service, was the time you waited:	Shorter than expected, About right, A bit too long, Much too long
If you asked for assistance, did you get it when you needed it?	Always, Usually, Sometimes, Never, Not applicable
Did you feel you understood what was happening in your care?	Always, Usually, Sometimes, Never
Were things explained to you in a way that you could understand?	Always, Usually, Sometimes, Never
Were you involved as much as you wanted to be in decisions about your care?	Always, Usually, Sometimes, Never
Where you able to speak in Welsh to staff if you needed to?	Always, Usually, Sometimes, Never, Not applicable

5. Service rating
    a. Using a scale of 0-10 where 0 is very bad and 10 is excellent, how would you rate your overall experience?

0 (very bad)	1	2	3	4	5	6	7	8	9	10 (excellent)

    b. Would you recommend the service to friends and family? [formatted to be only able to select 1 option]

Yes	
No	
Not sure	

c. Was there anything particularly good about your experience that you would like to tell us about? [open]

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d. Is there anything that we could change to improve our service? [open]

---

e. Is there anything else you would like to tell us? [open]

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6. Would you be willing to undertake an interview of approximately 30-60 mins? If, yes please provide your name and telephone number / email address.

Appendix 4 Topic guide for in-depth interviews

Interview

Thank you for taking the time to speak to me today. My name is Katherine, and I am a research scientist who works for the NHS, based at Cardiff & Vale University Health board.

I would like to speak to you today about your experience of the inflammatory bowel disease (IBD) service in Cardiff and Vale Health board. We're really interested to hear what you have to say, and want to know the good and the bad so that we can make the service as good as possible in the future, so please be as honest as possible.

This information will be used as part of an assessment of the service and will provide information for future decisions. Nothing we talk about today will affect the care you receive in any way and the clinical team will not know what you tell me today.

Anything we discuss will be anonymous, but we may use anonymised quotes (meaning your name will be removed) in reports and feedback that we provide.

Are you happy to go ahead with the interview?

Yes / No

I will be taking notes during our conversation, but to make sure that I don't miss anything important it would be helpful for me to record our conversation. Would you be happy for me to record our conversation?

Yes / No

1. Tell me about your IBD diagnoses and treatment to date.
    a. When were you diagnosed?
    b. What were you diagnosed with?
    c. How long did it take you to receive a diagnosis of IBD?
    d. What treatments have you had (e.g., lifestyle management, immune suppressants, biologics, surgery etc.)
2. How long have you been under the care of C&V? [Probe to see if this is before 2017]
3. What services are you aware of that are available to you to help your IBD?
4. How did you learn about the C&V IBD services (e.g., clinician, specialist nurse, leaflets, receptionist, GP)?
5. What have you used/ what do you think about the services (ask even if they have not used them (e.g., not severe enough to need biologics)?

6. Is there anything in particular you like about the IBD service?
7. Have you had any problems in accessing the service?
8. What do you think would of happened if you were not able to access the services?
9. What improvements do you think can be made?

[Ask if the patient has been in the system pre-2017]

Since 2017 Cardiff and Vale IBD service have introduce patient report outcome measure (PROM) tools, patient-initiated follow-up, hot clinics, dedicated infusion rooms and securing reduced price biologics, with the aim to improve patients care and prevent emergency hospital admission and surgery.

10. Have you heard/know of the service changes? What do you think of these changes? [describe changes if they are not aware of them ore require further clarification]
11. Do you think you have benefited or been disadvantaged by these changes?
12. Do you think these changes will have an impact of IBD care?

Is there anything else you would like to tell me?

Appendix 5 Semi-structured survey responders characteristics

	Crohn's (N=76)	Ulcerative colitis (N=38)	Unspecified IBD (N=1)	Total (N=115)	p value
Age (years)					0.004
Mean (SD)	39.3 (13.1)	49.5 (15.1)	52.0 (NA)	43.2 (14.6)	
Range	18- 76	21- 80	52- 52	18- 80	
Missing	20	5	0	25	
Sex					0.567
Female	36 (47.4%)	19 (50.0%)	1 (100.0%)	56 (48.7%)	
Male	40 (52.6%)	19 (50.0%)	0 (0.0%)	59 (51.3%)	
Ethnicity					0.025
Asian or Asian British	3 (3.9%)	4 (10.5%)	1 (100.0%)	8 (7.0%)	
Mixed or multiple ethnic groups	2 (2.6%)	0 (0.0%)	0 (0.0%)	2 (1.7%)	
Other ethnic group	1 (1.3%)	0 (0.0%)	0 (0.0%)	1 (0.9%)	
Prefer not to say	2 (2.6%)	0 (0.0%)	0 (0.0%)	2 (1.7%)	
White	68 (89.5%)	34 (89.5%)	0 (0.0%)	102 (88.7%)	
Employment status*					
Full time	43 (56.6%)	22 (57.9%)	1 (100.0%)	66 (57.4%)	0.682
Part time	14 (18.4%)	4 (10.5%)	0 (0.0%)	18 (15.7%)	0.501
Unemployed	2 (2.6%)	0 (0.0%)	0 (0.0%)	2 (1.7%)	0.593
Student	8 (10.5%)	1 (2.6%)	0 (0.0%)	9 (7.8%)	0.321
Retired	4 (5.3%)	9 (23.7%)	0 (0.0%)	13 (11.3%)	0.013
Long term sick	7 (9.2%)	0 (0.0%)	0 (0.0%)	7 (6.1%)	0.148
Disabled	0 (0.0%)	1 (2.6%)	0 (0.0%)	1 (0.9%)	0.360
Number of years since diagnosis					0.288
Mean (SD)	13.0 (10.1)	9.7 (8.7)	12.0 (NA)	11.9 (9.7)	
Range	0-41	0-29	12-12	0-41	
Missing	12	6	0	18	
Do you self-manage your IBD?					0.454
Self-manage	3 (3.9%)	0 (0.0%)	0 (0.0%)	3 (2.6%)	
Take medication or receive treatments	73 (96.1%)	38 (100.0%)	1 (100.0%)	112 (97.4%)	

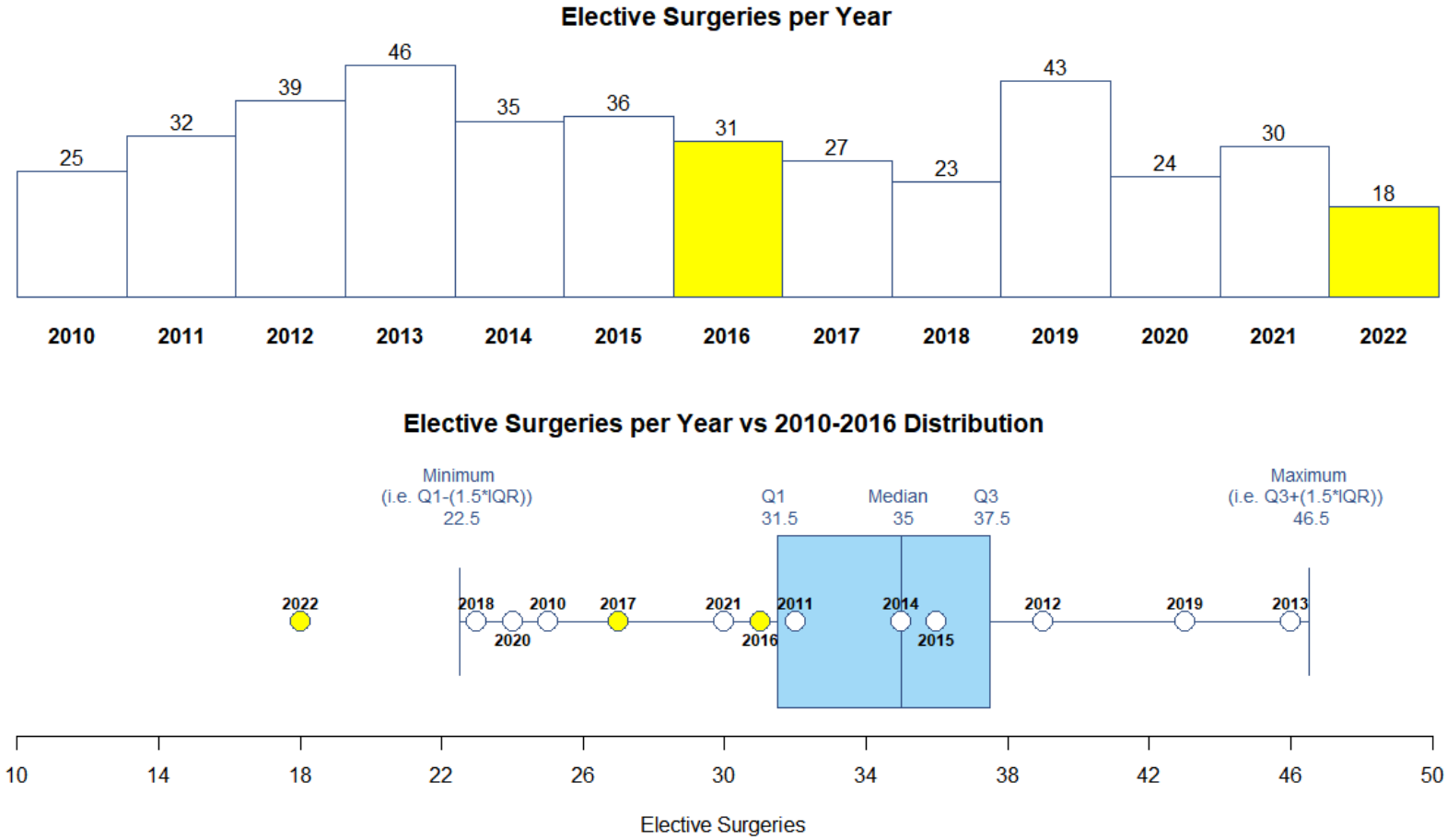
Footnotes:
Abbreviations: N=number of observations, SD = Standard deviation
Continuous variables are reported as mean, standard deviation and range
Categorical variables are reported a number of observations (n) and percentages (%)
* Employment status could have multiple responses, so each category was assessed separately and therefore each column has a greater value than the number of observations.

Appendix 6 Characteristics of bowel surgeries among IBD service users between 2010-2022 by year

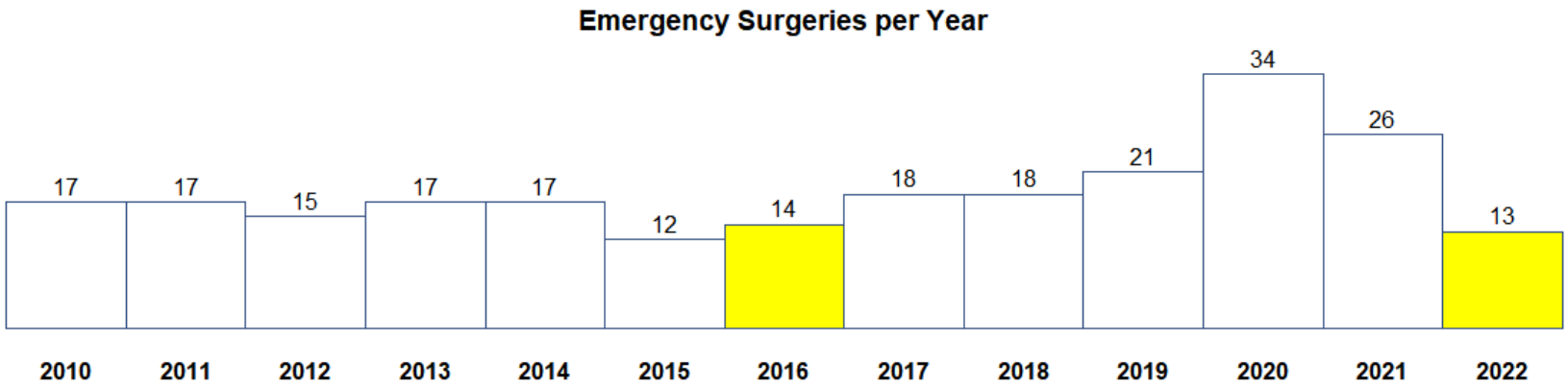
	Total	Admission methods for surgery			Type of IBD		Age group	
		Elective	Emergency	Transfer	Crohn's disease	Ulcerative colitis	<50 year	<50 years
2010	42	25 (59.5%)	13 (31%)	4 (9.5%)	17 (40.5%)	25 (59.5%)	17 (40.5%)	25 (59.5%)
2011	49	32 (65.3%)	15 (30.6%)	2 (4.1%)	34 (69.4%)	15 (30.6%)	15 (30.6%)	34 (69.4%)
2012	54	39 (72.2%)	15 (27.8%)	0 (0%)	39 (72.2%)	15 (27.8%)	17 (31.5%)	37 (68.5%)
2013	63	46 (73%)	16 (25.4%)	1 (1.6%)	36 (57.1%)	27 (42.9%)	21 (33.3%)	42 (66.7%)
2014	52	35 (67.3%)	17 (32.7%)	0 (0%)	28 (53.8%)	24 (46.2%)	22 (42.3%)	30 (57.7%)
2015	48	36 (75%)	12 (25%)	0 (0%)	23 (47.9%)	25 (52.1%)	10 (20.8%)	38 (79.2%)
2016	45	31 (68.9%)	14 (31.1%)	0 (0%)	30 (66.7%)	15 (33.3%)	18 (40%)	27 (60%)
2017	45	27 (60%)	16 (35.6%)	2 (4.4%)	31 (68.9%)	14 (31.1%)	11 (24.4%)	34 (75.6%)
2018	41	23 (56.1%)	18 (43.9%)	0 (0%)	27 (65.9%)	14 (34.1%)	16 (39%)	25 (61%)
2019	64	43 (67.2%)	19 (29.7%)	2 (3.1%)	39 (60.9%)	25 (39.1%)	20 (31.2%)	44 (68.8%)
2020	58	24 (41.4%)	32 (55.2%)	2 (3.4%)	34 (58.6%)	24 (41.4%)	20 (34.5%)	38 (65.5%)
2021	56	29 (51.8%)	26 (46.4%)	1 (1.8%)	37 (66.1%)	19 (33.9%)	15 (26.8%)	41 (73.2%)
2022	31	18 (58.1%)	13 (41.9%)	0 (0%)	22 (71%)	9 (29%)	11 (35.5%)	20 (64.5%)

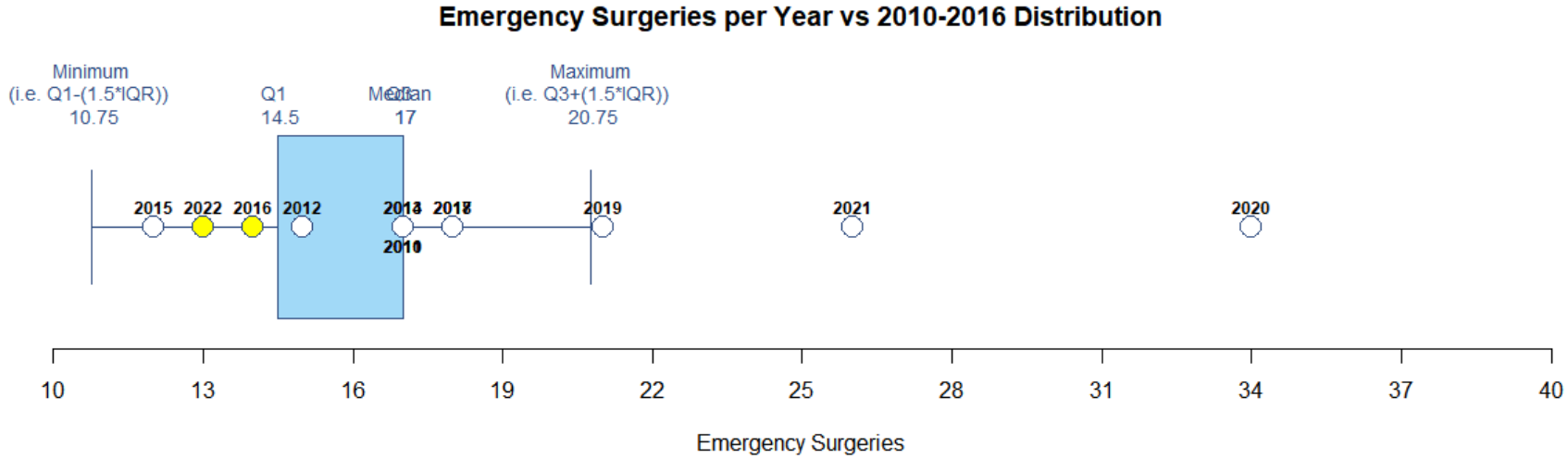
	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
G58 - Excision of jejunum	0 (0%)	0 (0%)	0 (0%)	1 (1.6%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.6%)	1 (1.7%)	0 (0%)	0 (0%)
G59 - Extirpation of lesion of jejunum	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
G63 - Other open operations on jejunum	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (3.2%)
G69 - Excision of ileum	4 (9.5%)	4 (8.2%)	5 (9.3%)	2 (3.2%)	2 (3.8%)	4 (8.3%)	2 (4.4%)	4 (8.9%)	2 (4.9%)	4 (6.2%)	6 (10.3%)	5 (8.9%)	0 (0%)
G74 - Creation of artificial opening into ileum	8 (19%)	2 (4.1%)	4 (7.4%)	5 (7.9%)	3 (5.8%)	9 (18.8%)	5 (11.1%)	8 (17.8%)	9 (22%)	9 (14.1%)	17 (29.3%)	12 (21.4%)	8 (25.8%)
G70 - Open extirpation of lesion of ileum	1 (2.4%)	0 (0%)	0 (0%)	2 (3.2%)	0 (0%)	0 (0%)	0 (0%)	1 (2.2%)	1 (2.4%)	1 (1.6%)	0 (0%)	0 (0%)	0 (0%)
G78 Other open operations on ileum	1 (2.4%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (4.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

G75 - Attention to artificial opening into ileum	1 (2.4%)	1 (2%)	0 (0%)	4 (6.3%)	1 (1.9%)	1 (2.1%)	0 (0%)	2 (4.4%)	1 (2.4%)	5 (7.8%)	2 (3.4%)	3 (5.4%)	1 (3.2%)
G72 - Other connection of ileum	3 (7.1%)	1 (2%)	2 (3.7%)	4 (6.3%)	4 (7.7%)	4 (8.3%)	1 (2.2%)	1 (2.2%)	1 (2.4%)	2 (3.1%)	0 (0%)	1 (1.8%)	0 (0%)
G73 - Attention to connection of ileum	1 (2.4%)	4 (8.2%)	6 (11.1%)	1 (1.6%)	2 (3.8%)	1 (2.1%)	2 (4.4%)	1 (2.2%)	1 (2.4%)	7 (10.9%)	2 (3.4%)	4 (7.1%)	0 (0%)
H07 - Other excision of right hemicolon	7 (16.7%)	14 (28.6%)	18 (33.3%)	10 (15.9%)	14 (26.9%)	6 (12.5%)	13 (28.9%)	14 (31.1%)	12 (29.3%)	10 (15.6%)	11 (19%)	15 (26.8%)	13 (41.9%)
H11 Other excision of colon	2 (4.8%)	12 (24.5%)	7 (13%)	8 (12.7%)	7 (13.5%)	6 (12.5%)	5 (11.1%)	1 (2.2%)	4 (9.8%)	3 (4.7%)	4 (6.9%)	5 (8.9%)	0 (0%)
H05 - Total excision of colon	1 (2.4%)	0 (0%)	0 (0%)	1 (1.6%)	1 (1.9%)	2 (4.2%)	3 (6.7%)	0 (0%)	1 (2.4%)	4 (6.2%)	0 (0%)	1 (1.8%)	1 (3.2%)
H04 - Total excision of colon and rectum	2 (4.8%)	1 (2%)	2 (3.7%)	3 (4.8%)	3 (5.8%)	2 (4.2%)	1 (2.2%)	0 (0%)	1 (2.4%)	3 (4.7%)	1 (1.7%)	0 (0%)	1 (3.2%)
H09 - Excision of left hemicolon	0 (0%)	1 (2%)	1 (1.9%)	1 (1.6%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.6%)	2 (3.4%)	0 (0%)	0 (0%)
H06 - Extended excision of right hemicolon	0 (0%)	1 (2%)	0 (0%)	0 (0%)	2 (3.8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
H15 Other exteriorisation of colon	0 (0%)	1 (2%)	2 (3.7%)	3 (4.8%)	2 (3.8%)	2 (4.2%)	3 (6.7%)	2 (4.4%)	3 (7.3%)	2 (3.1%)	1 (1.7%)	4 (7.1%)	1 (3.2%)
H10 - Excision of sigmoid colon	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (4.2%)	0 (0%)	1 (2.2%)	1 (2.4%)	0 (0%)	1 (1.7%)	0 (0%)	0 (0%)
H19 Other open operations on colon	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2.2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
H08 - Excision of transverse colon	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
H02 Other excision of appendix	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.7%)	0 (0%)	1 (3.2%)
H33 - Excision of rectum	8 (19%)	4 (8.2%)	6 (11.1%)	11 (17.5%)	8 (15.4%)	9 (18.8%)	6 (13.3%)	6 (13.3%)	2 (4.9%)	10 (15.6%)	6 (10.3%)	2 (3.6%)	2 (6.5%)
H41 Other operations on rectum through anus	1 (2.4%)	0 (0%)	1 (1.9%)	1 (1.6%)	0 (0%)	0 (0%)	0 (0%)	1 (2.2%)	0 (0%)	1 (1.6%)	1 (1.7%)	0 (0%)	0 (0%)
H46 Other operations on rectum	0 (0%)	0 (0%)	0 (0%)	2 (3.2%)	0 (0%)	0 (0%)	1 (2.2%)	0 (0%)	0 (0%)	0 (0%)	1 (1.7%)	1 (1.8%)	0 (0%)
H55 - Other operations on perianal region	1 (2.4%)	2 (4.1%)	0 (0%)	1 (1.6%)	1 (1.9%)	0 (0%)	2 (4.4%)	1 (2.2%)	0 (0%)	0 (0%)	1 (1.7%)	1 (1.8%)	2 (6.5%)
H54 - Dilation of anal sphincter	1 (2.4%)	0 (0%)	0 (0%)	1 (1.6%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.6%)	0 (0%)	0 (0%)	0 (0%)
H48 - Excision of lesion of anus	0 (0%)	0 (0%)	0 (0%)	2 (3.2%)	2 (3.8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
H56 - Other operations on anus	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (3.6%)	0 (0%)



Appendix 7 Number of elective surgeries per year over time.
Abbreviations: IQR = interquartile range (represented by the blue box), Q1 = quartile 1 or 25th percentile, Q3 = Quartile 3 or 75th percentile.
Each point represents the number of stoma surgeries performed in a given year.
Note: the values for 2020 and 2021 may not be representative due to the impact COVID-19 measures had on healthcare provision.





Appendix 8 Number of emergency surgeries per year over time.
Abbreviations: IQR = interquartile range (represented by the blue box), Q1 = quartile 1 or 25th percentile, Q3 = Quartile 3 or 75th percentile.
Each point represents the number of stoma surgeries performed in a given year.
Note: the values for 2020 and 2021 may not be representative due to the impact COVID-19 measures had on healthcare provision.

Appendix 9 Characteristics of emergency admission among IBD service users between 2010-2022 by year

	Total	Admission method						Type of IBD		Age group	
		A&E or Dental Casualty	GP	Consultant Clinic	Other Emergency	Emergency Transfer	NHS Direct	Crohn's disease	Ulcerative colitis	<50 year	<50 years
2010	165	53 (32.1%)	93 (56.4%)	2 (1.2%)	9 (5.5%)	8 (4.8%)	0 (0%)	74 (44.8%)	91 (55.2%)	125 (75.8%)	40 (24.2%)
2011	184	56 (30.4%)	108 (58.7%)	8 (4.3%)	6 (3.3%)	5 (2.7%)	1 (0.5%)	107 (58.2%)	77 (41.8%)	148 (80.4%)	36 (19.6%)
2012	162	66 (40.7%)	74 (45.7%)	6 (3.7%)	15 (9.3%)	1 (0.6%)	0 (0%)	71 (43.8%)	91 (56.2%)	118 (72.8%)	44 (27.2%)
2013	187	80 (42.8%)	66 (35.3%)	4 (2.1%)	30 (16%)	7 (3.7%)	0 (0%)	81 (43.3%)	106 (56.7%)	124 (66.3%)	63 (33.7%)
2014	208	90 (43.3%)	81 (38.9%)	7 (3.4%)	28 (13.5%)	2 (1%)	0 (0%)	83 (39.9%)	125 (60.1%)	142 (68.3%)	66 (31.7%)
2015	185	133 (71.9%)	34 (18.4%)	2 (1.1%)	14 (7.6%)	2 (1.1%)	0 (0%)	81 (43.8%)	104 (56.2%)	131 (70.8%)	54 (29.2%)
2016	196	87 (44.4%)	45 (23%)	16 (8.2%)	47 (24%)	1 (0.5%)	0 (0%)	110 (56.1%)	86 (43.9%)	139 (70.9%)	57 (29.1%)
2017	146	106 (72.6%)	19 (13%)	1 (0.7%)	12 (8.2%)	8 (5.5%)	0 (0%)	76 (52.1%)	70 (47.9%)	94 (64.4%)	52 (35.6%)
2018	172	111 (64.5%)	34 (19.8%)	6 (3.5%)	19 (11%)	2 (1.2%)	0 (0%)	112 (65.1%)	60 (34.9%)	110 (64%)	62 (36%)
2019	173	122 (70.5%)	25 (14.5%)	6 (3.5%)	16 (9.2%)	4 (2.3%)	0 (0%)	96 (55.5%)	77 (44.5%)	110 (63.6%)	63 (36.4%)
2020	193	137 (71%)	32 (16.6%)	7 (3.6%)	12 (6.2%)	5 (2.6%)	0 (0%)	85 (44%)	108 (56%)	135 (69.9%)	58 (30.1%)
2021	129	102 (79.1%)	15 (11.6%)	1 (0.8%)	11 (8.5%)	0 (0%)	0 (0%)	63 (48.8%)	66 (51.2%)	85 (65.9%)	44 (34.1%)
2022	119	86 (72.3%)	19 (16%)	0 (0%)	11 (9.2%)	3 (2.5%)	0 (0%)	53 (44.5%)	66 (55.5%)	80 (67.2%)	39 (32.8%)

Appendix 10 Economic evaluation: unit costs

Category	Description	Unit	Cost	Source
Staff	Band 6 nurse	per hour	£53.00	PSSRU 2022
	Band 7 nurse	per hour	£64.00	PSSRU 2022
	Band 8a nurse	per hour	£72.00	PSSRU 2022
	Consultant (medical)	per hour	£143.00	PSSRU 2022
	Registrar (medical)	per hour	£73.00	PSSRU 2023
Diagnostics	Blood test	procedure	£6.29	C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR)
	Abdominal X-ray	procedure	£38.28	
	Stool test	procedure	£25.62	Holmes (2020)
	colonoscopy as o/p	procedure	£509.97	NHS Cost Collection 2021/22: FE32Z, Diagnostic Colonoscopy, 19 years and over
	flexible sigmoidoscopy as o/p	procedure	£371.26	NHS Cost Collection 2021/22: FE35Z Diagnostic Flexible Sigmoidoscopy, 19 years and over
Medication	Biologics	see separate pricing, confidential.		
	Steroids and laxatives			These have not been priced, as there is no indication that use has changed due to service changes. Costs are expected to be low per patient compared to other items
Secondary care	Consultant outpatient appointment	per appt	£182.93	NHS Cost Collection 2021-22: WF01A Consultant led, Non-Admitted Face-to-Face Attendance, Follow-up
	A&E attendance	per attendance	£352.57	NHS Cost Collection 2021-22. See calculation for weight cost

	Emergency admission (2016)	per admission	£3,274.06	NHS Cost Collection 2021-22, mean cost derived from HRG codes from the APC data extract for 2016
	Emergency admission (2022)	per admission	£4,169.47	NHS Cost Collection 2021-22, mean cost derived from HRG codes from the APC data extract for 2033
	Bowel resection surgery, non-elective	procedure	£12,009.80	NHS Cost Collection 2021-22, mean cost derived from weighted average of long and short stay costs, using HRG codes from the APC data
	Bowel resection surgery, elective	procedure	11709.614	NHS Cost Collection 2021-22, mean cost derived from elective costs, using HRG codes from the APC data
Primary care	GP appointment	per appt (9.22 min)	£36.00	PSSRU 2022 including direct care staff costs, excluding qualifications
Other care	Stoma costs	per year	£1,065.90	NHS Scotland

Appendix 11 Health economic assessment: Resource and clinical outcome numbers

Category	Description	2016	Source	2022	Source
IBD phone line	Number of phone calls	1238	IBD data	3708	IBD data
	Duration per phone call (minutes)	8.8	Assumption: same as 2022	8.8	Review of 1-week log
Hot clinic	Number attending hot clinic	0		49	IBD hot clinic data
	Abdominal x rays (n)	0		49	
	Blood tests (n)	0		49	
	Flexi sigmoidoscopy (n)	0		4	
	Nurse (per visit)	0		0.5	15 minutes per visit
	Specialist registrar (per visit)	0		0.5	30 minutes per visit
	Consultant/SPR meeting (per visit)	0		0.025	15 minutes each, for 10% of visits
	A&E attendance	49	Assumption: all patients visiting Hot clinic in 2022 would have attended A&E previously	0	Assumption: no patients visiting Hot clinic in 2022 would also attend A&E for the same event
Self-managing	Number self-managing	0		331	IBD data
	O/P appointments	331	Assumption: Currently self-managing patients would have had at least one o/p appt per year previously	0	Assumption
	Blood test		Assume included in O/P appointment	331	IBD clinic procedure: Once per year
	Stool tests		Assume included in O/P appointment	331	IBD clinic procedure: Once per year

	Nurse time for letter to patient			0.25	Assumption of 15 minutes for nurse time
A&E admittance	A&E admittance				
Surgeries	Elective bowel surgery	31	APC 2016	18	APC 2022
	Non-elective bowel surgery	14	APC 2016	13	APC 2022
	Total surgery (elective)	45	APC 2016	31	APC 2022
	Elective stoma surgery	8		10	
	Non-elective stoma surgery				
Other	Time to write prescriptions			0.25	Assumption of 15 minutes nurse time