Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

Supplementary Document 1

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

Delphi survey invitation for Round 1

Establishing Key Performance Indicators for Diagnosis and Management of Inflammatory Bowel Disease in UK – KPI development Summary

Introduction

The delivery of inflammatory bowel disease (IBD) care is being reviewed in order to improve and reduce the variability of the standards of health care and quality of service that patients with IBD receive (1-3). The ability to monitor and benchmark services can help stream pathways towards patient-centred health care, as well as guide and focus clinical service commissioning towards greater efficiency. This process would ultimately drive change that leads to improvements in clinical outcomes and experiences of patients with IBD. Key performance indicator (KPIs) are quality metrics that aim to measure performance to identify quality of service, allow benchmarking (to provide comparability) and facilitate recognition of areas for improvement of the service being delivered (4). These KPIs should be able to assess performance and process, allow robust representation of the quality of care, support accountability and quality improvement. Monitoring and benchmarking KPIs to individual IBD services can help drive trusts towards targeted quality improvements at a local level.

Several quality and performance indicators have been developed and implemented to cover a range of areas of IBD practice in the UK over the last 15 years (5). The IBD Audit, established in 2004, undertook 5 rounds of national audit between 2005 to 2016 on a nearly biannual basis (6). This captured data on inpatient care, experiences, primary care services, organisational care and biological therapies and led to improvements that included a reduction in adult inpatient IBD mortality and time from diagnosis to commencement of treatment with biological therapies. This then transitioned to the IBD Registry which facilitated longitudinal collection and reporting of metrics around screening prior to biologics initiation and monitoring of biological therapies (7). With a growing population of IBD patients within the UK, access to newer therapies, evolution of treatment targets and a shift towards patient empowerment, there is now a need to revisit quality indicators (2, 8). The recent national IBD benchmarking that combined feedback from patients and services through IBD UK highlighted key themes that urgently need addressing (9). These included impact of delayed diagnosis, rapid access to specialist care during flares and need for personalised care plans. Furthermore, the UK has seen the rapid introduction of major, and possibly long-lasting changes in provision of IBD services during the COVID-19 pandemic (10). With these changes likely to have a significant impact on clinical pathways and patient outcomes / experiences there is now a

clear need to reassess which quality metrics can now provide dynamic benchmarking of important contemporary challenges that will help facilitate a positive change for patients and services.

The identification of KPIs for IBD services will provide consensus-derived standards, thereby delivering a tool for monitoring quality throughout providers of such services in the UK. Through panel meetings with Stakeholders including the BSG IBD Section, IBD Registry, CCUK and IBD UK (and RCP) four potential KPIs have been identified for further exploration.

1. **Time from primary care referral to diagnosis of IBD in secondary care**
2. **Time to initiation of IBD specific treatment following a diagnosis of IBD**
3. **Excess steroid use**
4. **Biologic and immunomodulator pre-screening and assessment**

The primary aim of this Delphi process is to obtain expert consensus on KPIs and the associated quality improvement / benchmarking process with respect to its relevance, feasibility for IBD services and patients across the UK.

Methodology

A two stage Delphi consensus-building approach will be carried out. Panellists will be selected from key stakeholder groups including BSG IBD Section, IBD Registry, IBD UK, CCUK and regional IBD service representatives (including nurses, trainees and across different District General Hospitals and Teaching Hospitals). The Delphi survey will be conducted using REDCap. In Round 1, a proposed description of the data collection process, metrics and outcome will be outlined along with statements across several domains supporting each candidate KPIs (as shown in the following sections). Panellists will be asked to independently rank the statements for each KPI, using a 5-point Likert scale ('strongly agree', 'agree', 'neither agree nor disagree', 'disagree', 'strongly disagree'). For each statement, panellists will be given the option to select 'unable to comment' as an alternative response. Panellists will also be given the option to provide free-text comments to support and elaborate on their decision.

Responses to the Round 1 survey will be analysed by the representative members of BSG IBD Subcommittee, IBD Registry and CCUK. For a statement to be accepted, at least 80% consensus (agree or strongly agree) will be needed. The relevance/importance of the candidate KPI will initially be assessed based on consensus at which point it may be rejected or accepted as a KPI. For KPIs that are accepted, revisions will then be made to the proposed data collection process, clinical and patient reported metrics being collected and reporting of the benchmarking process based on the responses. The revised survey will then be subject to Round 2 of the Delphi process with a potential for Round 3 depending on the degree of consensus obtained.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

KPI 1 and KPI 2: Time to diagnosis and time to treatment

Brief Summary

Delay in diagnosis and treatment of IBD have significant short and long-term implications to the patient suffering from the disease and the health service. These can have a major impact on the quality of life of patients, impede career aspirations and are associated with worse clinical outcomes (11-13). Furthermore, with rapidly rising incidence of IBD globally and point prevalence of IBD expected to hit 1% by 2028 in parts of UK, timely diagnosis is now a relevant public health priority (14). A recent study from the UK highlighted that patients waited over 5 years for a diagnosis from the onset of symptoms (15). Amongst patients later diagnosed with IBD, less than half received specialist review within 18 months from presenting with chronic GI symptoms. A key finding demonstrated in the IBD UK National Report (to be published) was that over a quarter of patients waited over a year for a diagnosis with 41% visiting A&E at least once prior to their diagnosis (9). Reaching a diagnosis of IBD consists of several discrete stages. With the broad variety of types and intensity of presenting symptoms this initial step involves referral from primary to secondary care. With the increasing uptake of non-invasive tests including faecal calprotectin in primary care this has helped with overcoming this to an extent. A further potentially modifiable cause of diagnostic delay is lack of access to rapid secondary care diagnostic pathways. The National Institute for Health and Care Excellence (NICE) quality standards for IBD states that patients with suspected inflammatory bowel disease should have a specialist assessment within 4 weeks of referral (16). However, as demonstrated through the IBD UK National Report, only 29% of patients surveyed had been seen by a specialist within 4 weeks. Furthermore, 24% of patients surveyed reported waiting two weeks or longer to start treatment after diagnosis. Understanding the pathways involved at different stage could inform effective interventions to reduce overall diagnostic and treatment delays.

Aim

Establish potential for time to diagnosis of IBD following referral to secondary care and time to commence IBD specific treatment following diagnosis as KPIs for assessing of quality of IBD care in UK

KPI 1: Time from primary care referral to diagnosis in secondary care

Definition: Time to diagnosis is defined as weeks between referral from primary care to a documented diagnosis of IBD in secondary care.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

- Referral to secondary care is made through multiple referral pathways and may include referrals via choose and book, two week wait or straight to test.

- Documented diagnosis is defined as a formal documentation of a confirmed diagnosis of IBD in the patients records.

- Whilst an investigation may suggest or confirm a diagnosis of IBD, when and how this diagnosis is confirmed and document would be based on the discretion of the clinician rather than an investigation.

Proposed process for quality improvement analysis

- IBD services will be invited to collect defined metrics as part of the KPI.

- Data may be collected prospectively at the point of diagnosis or retrospectively at a later review.

- To facilitate comparability and benchmarking only patients with a new documented diagnosis of IBD made from a specified future date should be registered (date to be confirmed).

- A minimum of 25 newly diagnosed patients will be required to be registered per site for representative benchmarking. In order to avoid bias patients should not be pre-selected.

- A defined period of data collection is not needed as this will be a rolling QI metric with near-real time KPI reporting (once minimum dataset collected) .

- Diagnosis of IBD made during hospitalisation may need to be excluded from this KPI (Delphi). Whilst this is an important cohort of patients, it would be challenging to identify those out who have had an admission due to an acute onset of severe disease as opposed to those who may have had a significant diagnostic delay following referral from primary care. Measuring delays in elective care diagnostic activity may help provide a representation of organisational factors that lead to diagnosis delays resulting in hospitalisation.

Expected standard: Benchmark diagnostic times for each IBD service in relation to national performance of IBD services.

At present there is no defined nationally expected standard for time from referral to diagnosis in secondary care. Although the NICE IBD Quality standard [QS81] states patients must be seen in secondary care within 4 weeks of referral from primary care, this does not specify that diagnosis should have been made at this initial point of contact in secondary care. There is also no published national data on what the current interval referral to diagnosis interval is as well as what interval would be defined as a diagnostic delay.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance
placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

In view of this we propose that the first round of national quality improvement analysis should benchmark diagnostic times for each IBD service against national performance of IBD services. This initial exercise may also help define expected targets that would need to be achieved as part of future rounds of audits.

Proposed metrics to measure KPI:

- Date of referral to secondary care (DD/MM/YYY)
- Date of a diagnosis (DD/MM/YYY)

Reported benchmarking outcome measures:

- Median weeks between referral from primary care to a documented diagnosis of IBD made by the IBD service being audited
- Percentile score/rank of the IBD service compared national performance metrics for KPI

KPI 2: Time to initiation of treatment following a diagnosis

Definition: Time to treatment is defined as weeks between a documented diagnosis of IBD in secondary care to commencement of disease modifying medical or surgical treatment.

- Documented diagnosis is defined as a formal documentation of a confirmed diagnosis of IBD in the patient's records

- Treatment is defined as oral or rectal mesalazine, thiopurines, biological therapies, small molecule drugs, steroids, IBD specific surgery, nutritional therapies and therapies pertaining to IBD specific clinical trials.

Proposed process for audit

- IBD services will be invited to collect defined metrics as part of the KPI.

- Data may be collected prospectively at the point of first initiation of treatment or retrospectively at a later review.

- To facilitate comparability and benchmarking only patients with a new documented diagnosis of IBD made from a specified future date should be registered (date to be confirmed).

- A minimum of 25 newly diagnosed patients will be required to be registered per site for representative benchmarking. In order to avoid bias patients should not be pre-selected.

- A defined period of data collection is not needed as this will be a rolling QI metric with near-real time KPI reporting (once minimum dataset collected) .

- First treatment of IBD started during hospitalisation can be included in this KPI. However, a documented diagnosis of IBD should not have been made on that admission unless a prior referral to secondary care had been received for secondary care elective service.

Expected standard: Benchmark time to treatment for each IBD service in relation to national performance of IBD services.

IBD-UK standards define time to treatment from diagnosis as 48 hrs moderate to severe and within 2 weeks for mild to moderate IBD. There were based on surveys done nationally of IBD units and patients along with expert consensus agreement. Using these standards is an option for benchmarking. However, there is a paucity of published national data on what the current time from diagnosis to treatment of IBD interval is as well as what interval would be defined as an expected treatment standard based on clinical and patient centred outcomes. Furthermore, there would be a need to minimum proposed standards that would take in to account patients who do not

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

necessarily need to start treatment immediately for IBD (for example patients with asymptomatic isolated mild terminal ileal disease).

In view of this we propose that the first round of national audit should benchmark time to treatment intervals for each IBD service against national performance of IBD services. This initial exercise may also help define expected targets that would need to be achieved as part of future rounds of audits.

Proposed metrics to measure KPI:
- Date of a diagnosis (DD/MM/YYY)
- Date of commencement of IBD specific treatment (DD/MM/YYY)

Reported benchmarking outcome measures:
- Median weeks between a documented diagnosis of IBD to commencement of IBD specific treatment by the IBD service being audited
- Percentile score/rank of the IBD service compared national performance metrics for KPI

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

KPI 3: Excess steroid use

Brief summary

Corticosteroids are the mainstay of treatment for rapid induction of remission in patient with active IBD. Its use is however limited in view of its inability to maintain remission and significant side effect profile (17). The BSG IBD and ECCO guidelines define steroid excess as two or more courses of corticosteroids in a 12 month period (2, 18). Steroid dependency is defined as an inability to wean below 10mg of prednisolone or 3mg of budesonide within 3 months of starting, or disease flare within 3 months of stopping steroids. A multicentre patient reported UK audit found that 14.8% of IBD patients had steroid dependency or excess in the UK (19, 20). Potentially half of these cases were avoidable with a number of service and patient level factors independently correlating with risks of excess steroid exposure. Following quality improvement interventions, that included patient and physician education and rapid access flare clinics, there was a significant reduction in risk of steroid dependency and excess for patients with CD and UC. Importantly the group demonstrated that an online assessment tool could easily and robustly be used to measure steroid excess in clinical practice. Collectively there is a strong case for excess steroid use as a KPI and will enable benchmarking of service based on clinical outcomes and provide targets for improvements.

Aim

Monitor and benchmark excess steroid use and steroid dependency in patients with IBD

Definition: Steroid excess is defined as the prescription of 2 or more course of steroids over a 12 month period or use of steroids for greater than 3 months over a 12-month period.
- Steroids would include any class of oral corticosteroids given for any indication.
- A course of corticosteroids is defined as a minimum of at least 7 days of consecutive use

Proposed process for audit
- IBD services will be invited to collect defined metrics as part of the KPI.
- Data may be collected by IBD services from patients as a retrospective snapshot of the prior 12 months their steroid history. This would be repeated every other year.
- Steroid use will include those obtained through secondary care and primary care prescriptions as well as home supplies.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

- A minimum of 50 patients being prescribed steroids will be required per site for representative benchmarking.

Expected standard: Proportion of patient's prescribed steroids with steroid excess not exceeding 50%.

The two multicentre UK audits exploring steroid excess has consistently identified that 50% of patients with IBD had avoidable or potentially avoidable steroid excess. With the audit recruiting patients from geographically and clinically diverse centres in England, Wales and Scotland with a mix of district general and teaching hospitals, we expected this standard to be generalisable for IBD centres across UK. Furthermore, as steroid prescriptions for non-IBD indications were found in less than 3%, for ease of reporting, this KPI measurement would include steroid use for all indications.

Proposed metrics to measure KPI:
- Total number of courses of steroids in the last 12 months
- Total duration of steroid use in the last 12 months (weeks)

Reported benchmarking outcome measures:
- Proportion of patients with excess steroid use (numerator: total number of patients with excess steroid use; denominator: total number of patients prescribed steroids).
- Percentile score/rank of the IBD service compared to national performance metrics for KPI

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

KPI 4: Biologic and immunomodulator pre-screening and assessment

The biological therapies KPI is part of the ongoing IBD Registry's audit and quality improvement programme. (7) This initially originated in the RCP IBD program prior to its transition to the Registry in 2016 – 2017. These KPIs monitored three points during a patient's biologics treatment - initiation on biological therapy (pre-treatment checks), post induction review and a 12-month review. This KPI was chosen by the RCP's Transition Steering Group to focus on the findings and recommendations in the IBD biological therapies audit report published in 2016 with the aim to measure the efficacy, safety and appropriate use of biological therapies. IBD services participating in submitted to the registry received quarterly report benchmarking performance to national data, including subgroups based on demographics, disease phenotype, consent levels and biologics usage. Since start of data collection in May 2015, 74 sites have participated. Work is ongoing in understanding outcomes of the benchmarking process around quality improvement by participating clinical teams.

With the licensing of newer biological therapies (and small molecules) for the treatment of IBD, the biologics pre-screening and response monitoring is likely to be an effective metric for facilitating safe and effective use of these drugs (2). The potential of regular reporting of individual service benchmarking with patient outcomes will help drive a reform in pathways that facilitate recognition of primary non-response and need for early optimisation of biological therapies.

Aim

Benchmark proportion of patients screened prior to initiation and monitoring during the course of treatment with biological therapies at induction.

Definition: Proportion of patients meeting standards for pre-screening prior to initiation of biologics and immunomodulators and assessment of efficacy and safety after induction of therapy and at one year.

- Biological therapies and immunomodulators include any monoclonal antibodies used for treatment of IBD and for the purposes of the KPI includes small molecule drugs. Thiopurines and methotrexate will not be included within this definition.
- Pre-screening for infections prior to commencement of biologics is defined in both BSG and ECCO guidance and includes HBV, HCV and HIV (and may include VZV if no history of chickenpox, shingles or varicella vaccination and TB). This may have been performed at any timepoint in

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

patient's recent history. The interval prior to repeating these tests would be based on the clinical team's discretion.

- Assessment of efficacy and safety following induction can be any documented review of patients between week 8 to week 20 after commencement of biological therapies. This review should consider both safety and clinical and objective assessment of disease activity and will only include patients who are on ongoing treatment with that biologic at that timepoint.

- Assessment of efficacy and safety at one year can be any documented review of patients between month 10 to month 14 after commencement of biological therapies. This review should consider both safety and clinical and objective assessment of disease activity and will only include patients who are on ongoing treatment with that biologic at that timepoint.

Proposed process for audit

- IBD services will be invited to collect defined metrics as part of the KPI.

- Data may be collected by IBD services both prospectively and retrospectively (case note reviews) and should include patients having commenced biological therapies from Jan 2021

- Each of the proposed biologics KPIs will be collected as a 'Yes' or 'No' response.

- A minimum of 25 patients will be required per site for representative benchmarking and will be part of the same process of the Biologics Audit currently being delivered by the IBD Registry.

Proposed expected standard:

- **The standard for minimum expected proportion of patient's being pre-screened prior to initiation of biologics is set at 95%.**

- **The standard for minimum expected proportion of patient's being assessment following induction is set at 90%.**

- **The standard for minimum expected proportion of patient's being assessment at one year after commencement of biological therapies is set at 90%.**

At present there is no defined nationally expected standard for biologics pre-screening and monitoring. However, both BSG and ECCO guidelines make strong recommendations towards this. We therefore propose a minimum expected standard for these KPIs which would help continue to ensure there are robust protocols and pathways locally for safe effective use of these therapies.

Proposed metrics to measure KPI:

- Was the patient screened for infections before starting on a biological therapy?

- Was there a documented assessment of efficacy and safety between week 8 and week 16 after commencement of biologics in patients with ongoing use?

- Was there a documented assessment of efficacy and safety between month 10 and month 14 after commencement of biologics in patients with ongoing use?

Reported benchmarking outcome measures:

- Proportion of patients pre-screened prior to biologics use

- Proportion of patients with a documented assessment following induction of biological therapy

- Proportion of patients with a documented assessment at one year following commencement of biological therapy

- Percentile score/rank of the IBD service compared national performance for each of the biologics KPI

References

1.   Kapasi R, Glatter J, Lamb CA, Acheson AG, Andrews C, Arnott ID, et al. Consensus standards of healthcare for adults and children with inflammatory bowel disease in the UK. Frontline Gastroenterol. 2020;11(3):178-87.

2.   Lamb CA, Kennedy NA, Raine T, Hendy PA, Smith PJ, Limdi JK, et al. British Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults. Gut. 2019;68(Suppl 3):s1-s106.

3.   Louis E, Dotan I, Ghosh S, Mlynarsky L, Reenaers C, Schreiber S. Optimising the Inflammatory Bowel Disease Unit to Improve Quality of Care: Expert Recommendations. J Crohns Colitis. 2015;9(8):685-91.

4.   Melmed GY, Siegel CA, Spiegel BM, Allen JI, Cima R, Colombel JF, et al. Quality indicators for inflammatory bowel disease: development of process and outcome measures. Inflamm Bowel Dis. 2013;19(3):662-8.

5.   IBD Standards Group. Standards for the healthcare of people who have inflammatory bowel disease, IBD standards, 2013 update. Available online at www.ibdstandards.org.uk

6.   IBD audit programme 2005–2017. Review of events, impact and critical reflections. Royal College of Physicians 2018.

7.   IBD Registry Biological Therapies Audit Statement of Purpose, Scope and Requirements. Available online https://ibdregistry.org.uk/.

8.   Kaplan GG, Windsor JW. The four epidemiological stages in the global evolution of inflammatory bowel disease. Nat Rev Gastroenterol Hepatol. 2020.

9.   IBD UK National Report (To be published) - https://ibduk.org/.

10.   Kennedy NA, Hansen R, Younge L, Mawdsley J, Beattie RM, Din S, et al. Organisational changes and challenges for inflammatory bowel disease services in the UK during the COVID-19 pandemic. Frontline Gastroenterol. 2020;11(5):343-50.

11.   Lee DW, Koo JS, Choe JW, Suh SJ, Kim SY, Hyun JJ, et al. Diagnostic delay in inflammatory bowel disease increases the risk of intestinal surgery. World J Gastroenterol. 2017;23(35):6474-81.

12.   Zaharie R, Tantau A, Zaharie F, Tantau M, Gheorghe L, Gheorghe C, et al. Diagnostic Delay in Romanian Patients with Inflammatory Bowel Disease: Risk Factors and Impact on the Disease Course and Need for Surgery. J Crohns Colitis. 2016;10(3):306-14.

13.   Kang HS, Koo JS, Lee KM, Kim DB, Lee JM, Kim YJ, et al. Two-year delay in ulcerative colitis diagnosis is associated with anti-tumor necrosis factor alpha use. World J Gastroenterol. 2019;25(8):989-1001.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

14.   Jones GR, Lyons M, Plevris N, Jenkinson PW, Bisset C, Burgess C, et al. IBD prevalence in Lothian, Scotland, derived by capture-recapture methodology. Gut. 2019;68(11):1953-60.

15.   Blackwell J, Saxena S, Jayasooriya N, Bottle A, Petersen I, Hotopf M, et al. Prevalence and duration of gastrointestinal symptoms before diagnosis of Inflammatory Bowel Disease and predictors of timely specialist review: a population-based study. J Crohns Colitis. 2020.

16.   Inflammatory bowel disease Quality standard [QS81]. National Institute for Health and Care Excellence. .

17.   Ford AC, Bernstein CN, Khan KJ, Abreu MT, Marshall JK, Talley NJ, et al. Glucocorticosteroid therapy in inflammatory bowel disease: systematic review and meta-analysis. Am J Gastroenterol. 2011;106(4):590-9; quiz 600.

18.   Gomollon F, Dignass A, Annese V, Tilg H, Van Assche G, Lindsay JO, et al. 3rd European Evidence-based Consensus on the Diagnosis and Management of Crohn's Disease 2016: Part 1: Diagnosis and Medical Management. J Crohns Colitis. 2017;11(1):3-25.

19.   Selinger CP, Parkes GC, Bassi A, Limdi JK, Ludlow H, Patel P, et al. Assessment of steroid use as a key performance indicator in inflammatory bowel disease-analysis of data from 2385 UK patients. Aliment Pharmacol Ther. 2019;50(9):1009-18.

20.   Selinger CP, Parkes GC, Bassi A, Fogden E, Hayee B, Limdi JK, et al. A multi-centre audit of excess steroid use in 1176 patients with inflammatory bowel disease. Aliment Pharmacol Ther. 2017;46(10):964-73.

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

Demographics of panellists participating in Round 1 of Delphi consensus survey

A total of 106 individuals were invited of whom 60 completed the Delphi survey. The nature of Stakeholder representative panel selection meant that nearly all the clinical respondents were based in teaching hospitals or large district general hospitals. The responses requested were meant to be generic and based on national feasibility (as opposed to local feasibility). A breakdown of description / affiliation of the respondents is as shown in Table 1:

Table 1 – Delphi panellists	Count of Speciality
IBD Clinical Nurse Specialists	**2**
Barts Health NHS Trust	1
Nottingham University Hospitals NHS Trust	1
Gastroenterologists	**38**
Aintree University Hospital	1
Barts Health NHS Trust	2
Cambridge University Hospitals	2
County Durham and Darlington NHS Foundation Trust	1
Glasgow Royal Infirmary	1
Guy's & St Thomas	1
Hull University Teaching Hospitals	1
Leeds Teaching Hospitals NHS Trust	1
Newcastle Hospitals NHS Foundation Trust	4
Queen Elizabeth University Hospital, Glasgow	1
Royal Devon and Exeter NHS Foundation Trust	1
Royal Liverpool Hospital	1
Royal Liverpool University Hospital	1
Salford Royal NHS Foundation Trust	1
Sheffield Teaching Hospitals NHS Foundation Trust	1
Shrewsbury and Telford NHS Foundation Trust	1
South Tyneside And Sunderland NHS Foundation Trust	1
St Mark's Hospital	1
Stockport NHS Foundation Trust	1
The Pennine Acute Hospitals NHS Trust	1
The Royal Wolverhampton NHS Trust	2
The Royal Bournemouth Hospital a	1
Ulster Hospital	1
University College London Hospitals	2
University Hospital of North Tees, Stockton-on-Tees	1
University Hospital of Wales	1
University Hospital of Wales	1
University Hospitals Bristol NHS Foundation Trust	1
University Hospitals Southampton NHS Foundation Trust	1
Western General Hospital	2
Paediatrics	**3**
Nottingham University Hospitals NHS Trust	1

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

Southampton General Hospital	1
Royal Hospital for Children	1
Patient representatives	**7**
Crohns and Colitis UK	2
Patient representative	5
Primary Care	**1**
Primary Care	1
IBD Registry	**1**
Registry	1
Specialist registrar	**2**
Cambridge University Hospitals	1
St Mark's Hospital	1
Surgeons	**6**
Cambridge University Hospitals NHS Foundation Trust	1
Newcastle Royal Victoria Infirmary	1
Sheffield Teaching Hospitals NHS	1
St Mark's Hospital	1
University Hospitals Leicester	1
Worcester Acute Hospitals NHS Trust	1
Grand Total	**60**

Summary results from Round 1 of Delphi consensus survey based on the initial QI proposal

Statements are presented with the median value of responses to the 5-point Likert scale (5- strongly agree, 4 - agree, 3-neither agree nor disagree, 2 - disagree, 1 - strongly disagree) along with an interquartile range (IQR). An IQR of 2 or more suggests high level of polarity in responses.

KPI 1 –Time from primary care referral to diagnosis in secondary care

Statement	Median; IQR
Time to diagnosis is defined as weeks between referral from primary care to a documented diagnosis of IBD in secondary care.	4; 1
Documented diagnosis is defined as a formal documentation of a confirmed diagnosis of IBD in the patients' records	4; 1
Date of documented diagnosis should be left to the discretion of the clinician rather than be prescriptive based on an investigation	4; 1
Time from symptom onset to diagnosis is an important metric to measure and should form part of this KPI	4; 3
Patients diagnosed following hospitalisation should be included if a prior referral to secondary care had already been made from primary care. Data from these patients will be reported separately as an additional outcome measure for this KPI.	4; 0.5
Time from referral to time to treatment has more value as a KPI and should be preferred over KPI 1 and KPI 2. Individual IBD units will then be responsible for exploring underlying reasons for possible delays within their service.	4; 3
Delays in time to diagnosis of IBD following referral to secondary care is associated with poor clinical outcomes and quality of life measures.	4; 1
Improving time to diagnosis means that patients do not experience life changing symptoms for prolonged periods without treatment.	4; 1
Improving time to diagnosis of IBD is an important clinical priority in the current era of managing IBD.	5; 1
A minimum of 25 newly diagnosed patients is sufficient for representative benchmarking.	3; 1
A minimum of 50% of all new diagnosis should instead be used per site for representative benchmarking.	3; 2
Benchmarking time to diagnosis of IBD in secondary care can adequately represent specific modifiable organisational factors within an IBD service.	4; 0

There are no established national standards for time to diagnosis of IBD that can adopted for benchmarking	4; 1
Benchmarking diagnostic times for each IBD service in relation to national performance of IBD services is appropriate for the first round of audit	4; 1
The proposed reporting outputs of the benchmarking process is appropriate for this KPI	4; 0.75
The proposed process for QI is the appropriate for measuring and monitoring time to diagnosis from referral	4; 1
The proposed metrics (date of referral and date of documented diagnosis) are sufficiently representative for this KPI.	4; 0
There are no significant confounding factors that would impact its analysis / interpretation	2; 1
The audit process outlined is undemanding and robustly deliverable by IBD services across UK	3; 2
A defined period of data collection is not needed as this will be a rolling QI metric with near-real time KPI reporting (once minimum dataset collected) .	4; 1
Improving pathways that lead to reduction in time to diagnosis is an effective use of resources	5; 1
Reduction in time to diagnosis is feasible by IBD services across UK	4; 1
Reduction in time to diagnosis following referral will improve patient safety and outcomes	4; 1
Reduction in time to diagnosis will not negatively impact equitable access to care	4; 1.75

KPI 2 –Time to treatment recommendation following a diagnosis

Statement	Median; IQR
Time to treatment is defined as weeks between a documented diagnosis of IBD in secondary care to commencement of IBD specific disease modifying medical or surgical treatment	4; 1
Treatment is defined as oral or rectal mesalazine, thiopurines, biological therapies, small molecule drugs, steroids, IBD specific surgery, nutritional therapies and therapies pertaining to IBD specific clinical trials.	4; 1
First treatment of IBD started during hospitalisation can be included in this KPI. However, a documented diagnosis of IBD should not have been made on that admission unless a prior referral to secondary care had been received for secondary	4; 1

care elective service.	
Delays in time to treatment following a diagnosis of IBD is associated with poor clinical outcomes and quality of life measures	4; 1
Reduction in time to treatment following a diagnosis of IBD is currently an important clinical priority.	4; 1
A minimum of 25 newly diagnosed patients will be required to be registered per site for representative benchmarking. In order to avoid bias patients should not be pre-selected.	3.5; 1
A minimum of 50% of all new diagnosis should instead be used per site for representative benchmarking.	3; 2
Benchmarking time to initiation of treatment following a diagnosis of IBD can adequately represent specific modifiable organisational factors within an IBD service	4; 0
Standards for time to treatment following diagnosis of IBD have recently been defined in the IBD UK national report should be adopted for benchmarking rather than against national performance	4; 1
Benchmarking time to treatment following diagnosis of IBD for individual service in relation to national performance of IBD services is appropriate for the first round of audit.	4; 1
The proposed reporting outputs of the benchmarking process is appropriate for this KPI	4; 0
The proposed QI process is appropriate for measuring and monitoring time to treatment.	4; 0
The proposed metrics (date of documented diagnosis and date of treatment commencement) are sufficiently representative for this KPI.	4; 0
Data on the class of treatment should be collected in order to control for inherent delays (such as pre-screening with biologics).	4; 0
A defined period of data collection is not needed as this will be a rolling QI metric with near-real time KPI reporting (once minimum dataset collected).	4; 1
There are no major confounding factors that would impact its analysis / interpretation	3; 2
The QI process outlined is undemanding and robustly deliverable by IBD services across UK	3; 2
Improving pathways that lead to reduction in time to treatment is an effective use of resources	4; 1

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

Reduction in time to treatment is feasible by IBD services across UK	4; 1
Reduction in time to treatment following diagnosis will improve patient safety and outcomes	4;1
Reduction in time to treatment will not negatively impact equitable access to care	4; 1

KPI 3 – Appropriate use of steroids

Statement	Median; IQR
Steroid excess is defined as the prescription of 2 or more steroid courses over 12 months or > 3 months over a 12-month period.	4;1
Steroids would include any class of oral corticosteroids	4;1
Steroid use would include any given indication rather than IBD alone.	2; 2
Steroid use should measure those obtained through secondary care and primary care prescriptions as well as home supplies.	4; 1
A course of corticosteroids is defined as a minimum of at least 7 days of consecutive use	4; 1
Excessive use of steroids in IBD is associated with poor clinical outcomes and quality of life	4.5;1
Reduction in steroid use is an important clinical priority in the current era of management of IBD	4;1
Reduction of excess steroid use would mean patients overall have better disease control with reduced risk of flares and corticosteroid related side effects.	4;1
Benchmarking excess steroid use can adequately represent specific modifiable organisational factors within an IBD service	4;1
The KPI standard defined as proportion of patient's with steroid excess not exceeding 50% is appropriate.	3;2
Benchmarking for this KPI should instead be done against national performance rather than a pre-defined standard of 50%.	3;1
The proposed reporting outputs of the benchmarking process is appropriate for this KPI	4; 0.75
The proposed process for data collection is the appropriate for measuring steroid excess in patients with IBD.	4; 0
A minimum of 50 patients being prescribed steroids will be required per site for representative benchmarking.	3; 2
Excess steroid use over a 12-month period should be measured prospectively rather	4; 1

Supplemental material

BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance placed on this supplemental material which has been supplied by the author(s)

Frontline Gastroenterol

than be a retrospective snapshot for individual patients	
The proposed metrics (steroid courses and steroid duration over 12 months) are sufficiently representative for this KPI	4; 0
There are no major confounding factors that would impact its analysis / interpretation	3; 2
The audit process outlined is undemanding and robustly deliverable by IBD services across UK	3; 2
Improving pathways that lead to reduction in steroid excess is an effective use of resources	4; 1
Reduction in steroid excess is feasible by IBD services across UK	4; 1
Reduction in steroid excess will improve patient safety and outcomes	4; 1
Reduction in steroid excess will not negatively impact equitable access to care	4; 1

KPI 4 – Advanced therapies pre-screening and assessment

Statement	Median; IQR
Biologic pre-screening is defined as prior screening of all patients prior to starting biological / small molecule drugs based on BSG / ECCO guidelines	5;1
Biologics assessment following induction is defined as a documented review of patients between week 8 to week 20 after commencement of biological therapies that include safety and clinical and objective assessment of disease activity	4;1
Biologics assessment at one year is defined as a documented review of patients between month 10 to month 14 after commencement of biological therapies. This includes safety and clinical and objective assessment of disease activity.	4;1
Recording of disease scores / indices should form part of the assessments at both these time points.	4;1
Patient reported outcome measures should form part of the assessments at both these time points.	4;1
Documented reviews at these time points should be done by clinicians within the IBD team.	4;1
Inadequate biologic pre-screening is associated with poor clinical outcomes and quality of life scores in patients with IBD	4;1
Inadequate biologic assessment following induction maybe associated with poor clinical outcomes and quality of life scores in patients with IBD	4;1
Inadequate biologic assessment at one year after commencement maybe associated	4;1

with poor clinical outcomes and quality of life scores in patients with IBD	
Improving compliance with biologic screening and timely assessment is an important clinical priority	4;1
Benchmarking biologic screening and monitoring in secondary care can help IBD services better understand structure of their clinical service including local flare pathways	4;1
Benchmarking biologic pre-screening and assessment following induction and at one year can adequately represent specific modifiable organisational factors within an IBD service	4;1
There are no established national standards for this KPI that can adopted for benchmarking	4;1
Setting a standard of 95% for minimum proportion of patients being pre-screened prior to initiation of biologics is appropriate.	4;0
Setting a standard of 90% for minimum proportion of patients being assessed following induction of biological therapy is appropriate.	4;1
Setting a standard of 90% for minimum proportion of patients being assessed following at 1 year after biologic initiation is appropriate.	4;0
The proposed QI pathway is the appropriate for measuring biologics pre-screening and assessment of patients with IBD	4; 0
A minimum of 25 patients will be required per site for representative benchmarking	4; 1
The proposed metrics are sufficiently representative for this KPI	4; 0
There are no major confounding factors that would impact its analysis / interpretation	4; 1
The audit process outlined is undemanding and robustly deliverable by IBD services across UK	4; 1
Improving pathways that lead appropriate biologics pre-screening and safety and efficacy monitoring is an effective use of resources	4; 1
Appropriate biologics pre-screening and timely safety and efficacy monitoring is feasible by IBD services across UK	4; 1
Appropriate biologics pre-screening and safety and efficacy monitoring will improve patient safety and outcomes	4; 1
Appropriate biologics pre-screening and safety and efficacy monitoring will not negatively impact equitable access to care	4; 1