IBD Registry

The Inflammatory Bowel Disease (IBD) Registry Biologics Audit (2017/18)
Statement of purpose, scope and requirements

Background

The IBD Registry Biologics Audit is a continuation of the National IBD Biological Therapies Audit previously funded by NHS England and managed by the Royal College of Physicians. As of January 2017 this Audit has become part of the IBD Registry Programme, which is managed by the British Society of Gastroenterology (BSG).

NHS England and the Welsh Government has decommissioned IBD as part of the NCAPOP however participation in the IBD Biologics Audit remains part of the Quality Accounts reporting requirements for Trusts in 2017/18. In the absence of NHS England funding, the BSG is obliged to recover a proportion of the costs through a small annual subscription from participating Trusts.

Quality Improvement Aims

Patient perspective – All patients with IBD receiving biological therapy should be adequately screened before initiation and the safety and effectiveness of the therapy reviewed post-induction and each year. Patients should be asked to consent to their data being submitted to the Registry.

Clinical Team perspective – The IBD Clinical Team should have a safe, efficient and secure electronic system for recording and accessing the key demographic and clinical data on all patients receiving biological therapy. The team should be resourced to ensure the minimum data is routinely entered.

Management and Governance perspective - Trust management and Commissioners should be able to review key demographic and clinical data on the use of biological therapies on a regular basis to assure quality and value for money. They should have access to national benchmarking on key indicators at least annually.

Relevant Clinical Standards:

NICE TA 187, TA 329 and European Crohn's Colitis Organisation (ECCO) Guidelines

Scope of data collection

Data collection has been reduced to the minimum necessary to report the key clinical indicators which are compliance with ECCO guidance on pre-treatment screening and compliance with NICE recommendations for follow-up review of patients receiving biological therapies. All patients starting or receiving biological therapy for IBD in the period April 2017 to March 2018 should be included. Data collection is prospective and continuous with quarterly uploads of data to NHS Digital. The data Includes a minimum of patient identifiable demographics to enable linkage of the Audit data by NHS Digital to routine HES data when this is published.

Related documents:

(1) Report of the IBD Biological Therapies Audit (September 2016)

(2) Rationale and description of the IBD Registry Biologics Audit KPIs (2017/18)

Audit reporting

Participating Trusts will receive feedback reports on their performance against the KPIs following each quarter, and during the course of the year the Registry will provide benchmarking to all other Trusts that have submitted data. An Annual Report will be published following the final data collection in March 2018.

To support the Quality Improvement aims the Registry is developing near-real-time online data visualisation tool to show up-to-date performance against the KPIs. This will initially be piloted on the IBD Registry Web Tool.

Participation requirements

Technical - IBD teams will need access to an electronic system that captures the key demographic and clinical data. This system will need to be capable of exporting the relevant data in the format required by NHS Digital. (cf. The IBD Registry Data Submission Framework)

Trusts may develop their own EPR system to capture and export the data and the Registry has set out the technical requirements in the IBD Registry Data Specification Framework. Alternatively, Trusts can purchase one of the commercially-available IBD Patient Management Systems that is IBD Registry-compliant.

For Trusts without a suitable EPR, the IBD Registry provides a Web Tool. This tool not only captures and exports the Biologics Audit data, but also provides a clinical management system for all IBD care. The BSG is obliged to make a partial cost-recovery charge to use the Registry Web Tool which is currently £1,000 per year for each Trust database.

Further information about EPR system choices is available on the IBD Registry website.

Information Governance – Some patient-identifiable demographic data is included in the Audit dataset and NHS Digital require the Trust Caldicott Guardian to confirm the Trust has authorized submission of this data before access is granted to their Clinical Audit Platform. The IBD Registry is committed to offering patients the opportunity to formally consent to submission of their data. Progress towards this objective is one of the Audit KPIs.

Data entry resource – it is important that adequate resource is provided to the IBD team to undertake the routine entry of the required audit data.

Annual Trust subscription – In order to maintain the IBD Registry Biologics Audit, the BSG is obliged to charge participating Trusts a small subscription. This fee is currently £2,500 (plus VAT) payable to the BSG from 1st April 2017. For context, biological therapy for one IBD patient costs between £5,000 and £10,000 per year, and one of the key objectives of the Medicines Optimisation Programme is the safe switching of patients to biosimilars.

NB. The BSG is offering a 40% discount for Trusts that place a Purchase Order before 15th March 2017. The Purchase Order should be addressed to The IBD Registry, BSG, 3 St Andrew's Place, Regents Park, London NW1 4LB. (Fax 020 7487 3734; email: support@ibdregistry.org.uk)

Further information

Additional information about the IBD Registry is available at www.ibdregistry.org.uk and on the Biological Therapies Audit and Quality Accounts at www.ibdregistry.org.uk/qualityaccounts

For any queries, please email the IBD Registry at support@ibdregistry.org.uk

The IBD Registry is owned and managed by the British Society of Gastroenterology
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