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Annual Report Lead for IBD Clinical Service

Reporting on the period
December 2017 to December 2018

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Executive Summary

Strategic Highlights

- High quality care closer to home
- Staff expansion for service improvement

Activity Highlights

- Three awards in recognition of patient-centred care
- New services – new diagnosis clinic
- Early patient education for supported self-management
- Easier access to specialist care

Looking Ahead

- Outsourcing the biologics service
- Switching to new Adalimumab Biosimilar drugs
- Set-up and application of electronic resources to deliver care
- New strategy to embrace team vision

Naila Arebi

Lead IBD Clinical Service

April 23, 2019

Introduction

This report describes the activities of the IBD team over the year 2017/2018 as well plans to develop the service further with ongoing improvements. It covers staff recruitment, new services, redesign of failing services, primary and secondary care interface and working as multi-professional teams as well recognising the need to embrace the service across 3 sites of the Trust.

IBD continues to be a busy sub-speciality facing the similar challenges for delivery of high-quality care as other long-term illnesses. Over the last year we have seen staff expansion with two new consultants, and two new Clinical Research Fellows posts. Our Lead IBD nurse Tracey Tyrell has been promoted to a new post as IBD Advance Nurse Practitioner to support out-of-hospital care making room for us to welcome Madhour Ramden as the new Lead IBD CNS.

I would like to acknowledge staff who helped with collating the data for this report Rishi Fofaria (transfer to telephone clinics), Uchu Maede/Anneliese D'Souza (high cost drugs), Stephen Hiles (Biologic Clinic and telephone clinics).

As the IBD team continues to grow we will continue to work towards a uniform service across the three sites by linking out-of-hospital care monitoring as well as IBD MDT.

Naila Arebi

Lead IBD Clinical Service

Who we are

The IBD clinical team is made up of five Gastroenterologists (Ayesha Akbar, Naila Arebi, Ailsa Hart, Nik Kamperidis and Ravi Misra), three colorectal surgeons (Omar Faiz, Phil Tozer, Janindra Warusavitarne), two IBD pharmacists (Uchu Maede, Anneliese D'Souza), one IBD Advanced Nurse Practitioner (Tracey Tyrrell) one IBD Lead Clinical Nurse Specialist (Madhour Ramden), five IBD Clinical Nurse Specialists (Susie Wen, Jitka Adio, Pineshwari Naek-Boooluky, Guia Grande, Sheryl Azana), four IBD nurses (April Mahinary, April An Berbo, Nancy Aranas, Comfort Onyechi Okpeh) and one IBD dietician (Gabriella Poufou) supported by secretarial team and administrators.

Services

Nursing services

These are covered in detail in the nursing report and include telephone and e-mail advice line Service, Nurse-Led Clinics & Telephone Review clinics, IBD Day Care Unit, Immunosuppressant monitoring, Paediatric service, transition and In-patient bleep service.

Dietetics Services

We have one dedicated IBD dietician. Full activities are outlined in the nursing service reports. A business case for additional dietician is underway.

Biologics Service

The biologic service was set up to address all the activities needed to prescribe, administer, monitor and audit biologic drugs in one setting. As of Dec 2018, there were 946 prescribed biologic drugs. The types and number of patients on specific biologic drugs are shown below.

Ustekinumab 96

Vedolizumab 199

Infliximab 335

Adalimumab 311

Golimumab 5

Face to Face multi-disciplinary biologic clinics

The clinic takes place on Thursday mornings between 9.30 and 12.30 alongside the virtual clinics. The service started in 6 July 2017 and continues to be busy. The activities for the multi-disciplinary face to face clinic include consent (for database registration, submission of funding applications to CCGs and prescriber-patient agreement), review of medical history and drug therapy, scoring disease activity, review of vaccination status and travel history, counselling patients on the various drug options before finally prescribing.

Activity summary

Between 1 Jan and 31 Dec 2018, 225 referrals were received of which there were 38 non-attenders.

Virtual biologics clinic

These are run by IBD CNS and IBD Registrar on Thursday mornings between 9.30 and 12.30 with input from an IBD consultant as needed. The purpose for these clinics is two-fold:

- i. Twelve-month reviews to determine need to continue therapy and submit funding applications.
- ii. Post-induction reviews to determine and diagnose primary non-responders and detect secondary LOR. Both states indicate a change in therapy or withdrawal of the drug.

Activity summary

Between 1 Jan and 31 Dec 2018, 216 twelve-month review appointments were booked of which only 173 answered the call. The majority were for funding application renewals. Post-induction review appointments were 129 in total and only 99 appointments were completed.

Future of the biologics service

The exponential rise in the number of patients on biologic drugs prompted a demand and capacity review of the biologic administration service. A business case for a novel partnership with a homecare company to administer the drugs was approved by the Trust board. Meetings are underway to ensure safe transition of the service expected to start 15 May 2019.

Specialists clinics

New diagnosis clinic

In October we started a new diagnosis clinic whereby education and treatment plans are offered early on in the disease course. New structured patient education programme to meet patient needs at different points of their journey will support the early diagnosis stage.

Joint medical and surgical clinics

Each consultant offers a dedicated IBD clinic with dedicated times set aside for joint medical-surgical clinics. In addition, other gastroenterologists may be referred patients with IBD and where complex internal referral may be instigated.

Post-operative Crohn's disease clinic

The purpose is to ensure timely follow-up of all patients undergoing ileo-colic resection in line with agreed pathway. The clinic is led by IBD nurse specialist on Monday mornings supported by a medical and surgical consultant. All patients undergoing surgery are booked for an initial 6-week follow-up and further visits and investigations depending on risk factors.

Rapid Access Clinic

The clinic was set up in 2017 to provide a rapid service to the patient with known IBD with symptoms of a disease flare or with complications of treatment. The aim is to treat patients with active IBD in a timely manner, avoiding disease progression and the requirement for inpatient admission.

The RAC currently takes place on Tuesday mornings in the St. Mark's outpatient department between 0930am – 12.30pm with six 30-minute time slots. The clinic is staffed by a fellow/registrar working within the IBD Team.

Activity summary

Between Jan and Dec 2018, 132 referrals were received of which with 14 did not attend.

Telephone Clinics

Medical telephone clinics

The purpose of the medical telephone clinic is to support patients for their results and to assess response to therapy early on. The clinic runs on Tuesday mornings in the St. Mark's outpatient department between 0930am – 12.30pm with six 30-minute time slots. The clinic is staffed by a fellow/registrar working within the IBD Team. Over the last year 275 appointments were given with 47 failed to answer the call.

Transfer of stable patients from medical clinics to nurse-led telephone clinics

Patients fulfilling clinical criteria for stable remission with low risk of complications were encouraged to utilise nurse-led telephone clinic follow up (NPGOL1PF) for out-of-hospital monitoring.

Activity summary

From 362 eligible patients 115 (32%) were transferred to this clinic. At 6 months 88% continued to be followed up in clinic with good clinical outcomes, 100% normal activity and very few hospital admissions (2.6%).

Surgical procedures

Over the year period a total of 447 surgical procedure with primary code as IBD were performed at the Northwick/St Mark's site. Of these 106 were emergency interventions.

Meetings

IBD MDT

The IBD MDT is held weekly on Wednesday mornings between 8 and 9am. The meeting offers the opportunity to discuss service updates and improvements as well as a wealth of cases with learning opportunities.

Over the last year a total of 474 cases were discussed including radiology cases, dysplasia cases, in-patients and out-patients.

IBD Business meeting

The business meeting is held weekly with the aim of addressing issues related to the service. The meeting is attended by consultants, nurse leads, dietician, pharmacists and IBD registrars.

Audit

The service participates in the national IBD biologic audit. There was no data from 2018 due to upgrading of the IBD database and technical difficulties with extracting the data. We are awaiting confirmation of named IT technical support administrator to help with data extraction for future years.

Electronic resources

Expansion of the electronic tools to improving patient care and communication across disciplines.

Electronic referrals

New internal electronic referral systems on ICE to facilitate and track internal referrals included surgical referral, additional high cost drugs, new diagnosis clinic and IBD MDT.

IBD Database Patient Management System (PMS)

The IBD PMS database is in use by the biologic team to fulfil the national audit requirements and facilitate the delivery of the biologic service. Future applications of this platform will require an IT administrator to support the team and maintain the technical aspects of the system.

High-cost drugs management system – Blueteq

Blueteq continues to be used for high cost drugs case management system to support the funding approval of biologic drugs.

IBD Intranet

The IBD intranet page is modernisation is near complete. Information covering all the aspects of IBD with patient information leaflets, pathways and protocols was updated.

Supporting Activities

Policies/protocols/clinical pathways

New policies, protocols and clinical pathways: Ustekinumab policy, Management of loss of response and primary non-response, vaccination checklist.

NEW patient information leaflet: biologics in pregnancy

Patient Education Resources

We continue to work with the PIF to improve access to patient information. Following on from last year's work the 7 steps to a perfect information journey we are working on signposting patients to Crohn's and Colitis UK PIL depending on the stage of their disease. Over the next year we will apply the flare card and study the impact on patient care.

Pharmacy-led switch from originator drug Humira to biosimilar

The availability of biosimilars for Adalimumab will lead to switching and the team is poised to deliver a switch strategy.

High cost drugs funding challenges

Administration of biologic drug (high cost drugs) is delayed by the need to confirm funding approval by relevant CCGs. The burden to funding application continues exert huge burden on the team as it is required each time a patient starts therapy, changes dose of therapy, switches to another drug and every 12 months to confirm therapy for the next year.

As at Dec 2018 there were 445 patients with expired biologic funding and 118 where funding was due to expire in the next 2 months. It is anticipated that these figures reduce once patients are transferred to external company for drug administration and monitoring. A temporary post of administrator will also facilitate the process.

Teaching and training courses

The team delivered the following in house courses and educational events.

1. Prescribing biologics in IBD – 29 March 2018
2. IBD open day – 20 May 2018
3. Trust open day – 1 July 2017
4. Nurses biologics course – 8 September 2017

Research

The research activities are reported in the IBD annual research report 2018 created by R&D department. Each consultant has their own research team with individual research portfolio.

Awards for the Service

In 2018, the team received three awards for delivery of high-quality patient centred care:

April 2018 Brian Turley Award, May 2018 Highly commended BMJ Award, Nov 2018 LNWUH R&D award.



NIHR CLAHRC London Brian Turley Award Winners 2018
'Patient and Carer Involvement'



BMJ Awards Highly Commended
Patient Partnership Team of the Year

Our future direction

Our vision for the future of the service will be collated in an IBD strategy whereby all team members will be encouraged to contribute. The strategy will focus on embarking innovative approaches to care for IBD patients as well as aligning with the direction of key NHS strategies. This include enhancing patients centred care and using artificial intelligence and electronic tools to deliver care differently and efficiently.