EXECUTIVE SUMMARY

Strategic Highlights
- To deliver high quality care closer to home
- Reducing hospital admissions

Activity Highlights
- Improvement in choice of service
- Delivery of specialist clinics
- Set-up and application of electronic resources to deliver care
- Biologics audit results above national average

Looking Ahead
- Seamless interface between primary and secondary care
- Early patient education for supported self-management
- Implementing IBD-surveillance policy
- Incorporating new Biosimilar drugs
- Framework for integrating research into the service structure
INTRODUCTION

Delivering high quality care for IBD patients has been the focus of the service over the last year. Quality in healthcare refers to care that is timely, safe, effective, patient centred and associated with a good experience. In order to do so we challenged the traditional model of care where all patients are monitored in hospital irrespective of their clinical state. We recognised the need to adopt a modern model of care to reflect patient feedback, break the constraints within the health service, broaden the workforce that delivers care, destroy barriers between primary and secondary care and harness the potential of modern technology. We pursued our goals through the help of service improvement experts, clinical team, commissioners and above all patients. We are privileged to have an IBD patient panel as well as two dedicated patients at the forefront of our service design.

This report describes our achievements as well as our future aspirations of the service. 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.

Our achievements would not have been possible without the support of our colleagues in endoscopy, nutrition, cancer services and stoma care. A special word of thanks to the Trust Executive team who supported our efforts and CLAHRC team who funded our Quality Improvement Project. We are indebted to them for the confidence in our ability to deliver better care to our community and to maintain our reputation as a centre of excellence.

Finally, I would like to acknowledge staff who helped with collating the data for this report: Phillip Oppong (telephone clinic), Ravi Misra (rapid access clinic), Susan Osborne and Tracey Tyrrell (IBD MDT), Rishi Fofaria (transfer to telephone clinics, high cost drugs payments), Stephen Hiles (Virtual Biologic Clinic), Uchu Maede and Anneliese D’Souza (biologics switch), Kay Crook (IBD biologics audit) and Abigail Livermore (high cost drugs payments). I hope you are inspired by the dedication and hard work shown by the clinical team and our valued patient members without whom none of this would have been possible.

Naila Arebi
Director IBD Service
December 13, 2017
WHO WE ARE

The IBD clinical Team is made of:

3 Gastroenterologists Naila Arebi, Ayesha Akbar & Ailsa Hart  
2 Colorectal Surgeons Omar Faiz & Janindra Warusavitarne  
2 IBD Pharmacists Uchu Maede & Anneliese D’Souza  
1 IBD Lead Clinical Nurse Specialist Tracey Tyrrell  
5 IBD Clinical Nurse Specialists Monica Chan, Jitka Adio,  
  Pineshwari Naek-Boooluky, Guia Grande & Sheryl Azana  
4 IBD Nurses April Mahinary, April An, Berbo Nancy,  
  Aranas Comfort & Onyechi Okpeh  
1 IBD Dietician Gabriella Poufou  
Supported by secretarial team and administrators.

The quality improvement team consisted of Naila Arebi, Susan Barber,  
  Tom Woodcock, Yewande Adeleke, Nik Kamperidis, Rishi Forfaria,  
  Denise Robinson, Tracey Tyrell, Howard Bluston (service user) and  
  Susan Bailey-Fee (service user).

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. IBD community nurse funded by Brent CCG will  
support the vision of seamless primary and secondary care interface.

Medical and surgical services

Each consultant offers a dedicated IBD clinic with dedicated times set  
aside or joint medical-surgical clinics. In addition other gastroenterologists  
may be referred patients with IBD and where complex internal referral may  
be instigated. Over the last year, there were 7260 out-patient medical clinic  
visits for IBD. There were 281 admissions for IBD between October 2016  
and November 2017. Future data capture will include number  
of surgical procedures.

New clinics/services

Post-operative Crohn’s disease clinic

The purpose is to ensure timely follow-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.

Biologics Clinic

The biologic service was set up to address all the activities needed to prescribe, administer, monitor and audit biologic drugs in one setting. All new referrals are seen in the multidisciplinary face to face clinics with subsequent follow ups to assess response to therapy through the virtual clinic.

Face to Face Multi-disciplinary 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. 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
83 Referrals  (6 Jul to 30 November 2017)

Disease Phenotype
61/83 CD
22/83 UC
12 Perianal CD
1 Unconfirmed (IBS)

Reasons for Referral
47/83 Biologic naive
23/83 Switch biologic
(loss of response and 3/83 switch adverse drug reaction)
2 Repeat 12 month funding
3 Repeat failed funding
(after drug holiday and 2/83 drug holiday for previous response)
1 Dose escalation
2 Not recorded
Outcomes of Referrals

Biologic drug prescribed or adjusted:
- 24/83 Adalimumab
- 22/83 Infliximab
- 13/83 Vedolizumab
- 7 Dose escalation of IFX (instead of drug switch)
- 6 Ustekinumab, 2 Golimumab
- 6 Biologic drug not needed

Virtual biologics clinic

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

(i) Twelve month reviews to determine need to continue therapy and submit funding applications. At the start of the year there were a large group of patients receiving therapy without funding approval.

(ii) Post-induction reviews to determine and diagnose primary non-responders and detect secondary LOR. Both state indicate a change in therapy or withdrawal of the drug.

Activity summary

6 July to 7 December 2017

Appointment Reviews

The majority were funding application renewals.

A full report on these outcomes will be collated for the Biologics Registry.
Rapid Access Clinic

The purpose of this clinic is 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.

Patients may be referred to the clinic via the IBD clinical nurse specialists (via the patient advice line), from clinicians within the trust (via the clinician advice line) or from LNWH Gastroenterology Consultants’ secretaries. 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
73 Referrals with 5 DNA’s (8 June to 28 November 2017)

Disease Phenotype
52 UC
15 CD
1 IBDU

Waiting time
47/68 Within a week
None greater than 2 weeks

Management in clinic
38/68 Steroids (commence/continue)
14/68 5-ASA (commence/continue)
11/68 No management change
3 Other 2 Biologic (commence)
0 Admission

Initial results of patient satisfaction

<table>
<thead>
<tr>
<th>Patient satisfaction</th>
<th>Very dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Neutral</th>
<th>Somewhat satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied with how quickly the appointment was arranged?</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Satisfied with your concerns answered by the doctor?</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Satisfied with the consultation?</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>9</td>
</tr>
</tbody>
</table>

Impact on services

<table>
<thead>
<tr>
<th>Impact on services</th>
<th>Yes</th>
<th>No</th>
<th>Already attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have we prevented you from seeing GP?</td>
<td>5</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Have we prevented you from visiting A&amp;E?</td>
<td>7</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>
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 117 appointments were given with 8 DNA.

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

In March 2017 (phase 1), the quality improvement team analysed the numbers of low risk/remission IBD patients attending 3 Consultant Clinics (Drs Nightingale/Donnelly, Pitcher and Jacyna). Suitable patients were identified by the IBD Pathway Coordinator. Eligible patients were given a questionnaire at their clinic appointment and if they indicated a preference for out of hospital (OOH) monitoring and were in remission they were transferred to telephone clinic follow up (NPGOL1PF).

Outpatients analysed
693 IBD appointments from 3 Consultant Clinics (April-Oct 2017)

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low risk</td>
<td>130</td>
</tr>
<tr>
<td>Returned questionnaire</td>
<td>74/130</td>
</tr>
<tr>
<td>Monitoring</td>
<td>42/74</td>
</tr>
<tr>
<td>Potential transfers</td>
<td>29</td>
</tr>
</tbody>
</table>

Patients identified as having low risk disease and in remission for consecutive appointments (eligible population).

57% Patients returned a follow up preference questionnaire of which 57% Opted for OOH monitoring and were transferred to telephone clinic, accordingly.

Further patients were identified who could potentially be transferred but who were also on immunomodulators.

The total number of patients that were transferred were lower than expected, but this was mainly because of a i) low rate of questionnaire returns and ii) strict criteria for inclusion.

In phase 2, all clinicians will be responsible for discussing telephone clinic follow up for eligible patients directly in clinic, obviating the need for a preference questionnaire. Patients who have not attended their face to face appointment (“DNAs”) and meet eligible criteria for transfer will also be included. Patients who have been stabilised on immunomodulators for 12 months may also be allowed to transfer with individual Consultant agreement.
**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 838 cases were discussed of which 465 were with radiology and 193 were in-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 a consultant, nurse leads, dietician, pharmacists and IBD registrars.

**AUDIT**

The service participates in the national IBD biologic audit. Data from the last year shows room for improvement with the administration of biologic drugs. Much of this will be delivered with the new IBD service and the new IBD database.

**Audit results**

549 Registered patients (period to 30 June 2017)

<table>
<thead>
<tr>
<th>Disease</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD</td>
<td>419</td>
</tr>
<tr>
<td>UC</td>
<td>108</td>
</tr>
<tr>
<td>Unclassified</td>
<td>9</td>
</tr>
</tbody>
</table>

**IBD biologic audit**

From 549 patients registered:
- 419 CD
- 108 UC
- 9 unclassified
### Key performance indicators
1 April 2016 to data submission deadline 30 June 2017

#### Pre-treatment checks and initiation

<table>
<thead>
<tr>
<th></th>
<th>Your Trust</th>
<th>National average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the patient screened before starting on a biological therapy?</td>
<td>58/112 (51.8%)</td>
<td>300/615 (48.8%)</td>
</tr>
<tr>
<td>Was a formal assessment of disease activity recorded at the point the decision was made to commence biological therapy?</td>
<td>42/112 (37.5%)</td>
<td>101/615 (16.4%)</td>
</tr>
<tr>
<td>Is there a record of Registry consent?</td>
<td>72/112 (64.3%)</td>
<td>170/615 (27.6%)</td>
</tr>
</tbody>
</table>

#### Post-induction review (approx 3 months after date of initial treatment)

<table>
<thead>
<tr>
<th></th>
<th>Your Trust</th>
<th>National average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did a post-induction review take place (visit recorded)?</td>
<td>47/112 (42%)</td>
<td>214/615 (34.8%)</td>
</tr>
<tr>
<td>Was a formal assessment of disease activity recorded at this time?</td>
<td>35/112 (31.3%)</td>
<td>&lt;6/615 (N/A%)</td>
</tr>
</tbody>
</table>

#### 12 month review (approx 12 months after date of initial treatment)

<table>
<thead>
<tr>
<th></th>
<th>Your Trust</th>
<th>National average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did a 12 month review take place?</td>
<td>21/112 (18.8%)</td>
<td>24/615 (3.9%)</td>
</tr>
<tr>
<td>Was a formal assessment of disease activity recorded at this time?</td>
<td>18/112 (16.1%)</td>
<td>&lt;6/615 (N/A%)</td>
</tr>
</tbody>
</table>

All the results were below expected standards but well above national average. It is anticipated that the biologic clinic will drive up the standards of outcomes.
A number of electronic tools were introduced with the aim of improving patient care and communication across disciplines.

**Electronic referrals**

We set up internal electronic referral systems on ICE to facilitate and track internal referrals. There is a referral for the biologic clinic and immunosuppressant clinic.

**IBD MDT outcomes**

The outcome of the cases discussed at the IBD MDT are uploaded live on the Clinical Information System (CIS) for future audit and to track the discussions. Over the last year a total of xx cases were discussed.

**IBD Database Patient Management System (PMS)**

We successfully implement the first phase of the IBD PMS database between Feb 2016 and November 2017. This involved the purchase of the system, interface with the Trust operating systems, transferring data from the web registry, examining the quality of the data and testing of the system.

The second phase (December 2017 to December 2018) will involve training and use of the system by the biologic team to fulfil the national audit requirement and facilitate the delivery of the biologic service as well as agreement on a policy for the use of the database for research purposes.

The third phase will involve IT interface for routine clinic care and training of staff involved in delivering care for IBD.

**High-cost drugs management system**

Blueteq

The Pharmacy team successful implemented the use of Blueteq high cost drugs case management system to support the funding approval of biologic drugs. All patients starting biologic drugs in the biologic clinic had application forms submitted online with immediate funding approval in many cases. Furthermore, Blueteq was instrumental in recover drug costs for the Trust, whereby hundreds of patients on biologic drugs continued to receive therapy without approved funding.

**IBD Intranet**

The IBD intranet page is undergoing modernisation to enable easy access to relevant information. There is a wealth of information covering all the aspects of IBD with patient information leaflets, pathways and protocols.
Policies/protocols/clinical pathways

Over the last year the team developed new pathways, protocols and policies as well as updated the old documents.


Updated pathways and protocols: Acute severe colitis, Infliximab protocol and Ciclosporin protocols.

An operational policy has been drafted and is awaiting for administrative support for completion.

Patient Education Resources

There are several patient information leaflets (PIL) on the intranet most are linked to Crohn’s and Colitis UK webpage in addition to others in preparation to meet the needs of the service. The team created the following new PIL to support our current policies and services: Biologics service and IBD Surveillance.

Through a series of workshops with the Patient Information Forum (PIF), we tracked IBD patient journey to create a checklist for patient information needs at different time-points of their journey. We continue our work with the PIF to explore new information resources to encourage supported self-management.

Pharmacy-Led switch
From originator drug Remicade to biosimilar Remsima

The team agreed a project time line with patient engagement to switch all patients from the originator drug to a biosimilar drug with cost savings to CCGs. A total of 145 patients were switched over 6 months with savings of £375,000. A 50:50 gain share supported the post of an IBD Pharmacist at the Trust. The coming year will see the marketing of the biosimilar for Adalimumab. The team in poised to deliver a similar switch strategy should there be a significant difference in costs.

High cost drugs funding challenges

The process by which patients prescribed biologic drug (high cost drugs) receive therapy involves a funding application sent to the CCG for funding
approval. Therapy is only administered after funding is approved and costs for the drug are recovered from respective CCGs. However, once treatment is started there is a lack of robust process to ensure that approval for repeat funding. This has led to a large number of patients continuing to receive therapy without CCG funding approval. These costs are met by the Trust until CCG agree to fund the therapy. The team set out to deal with the outstanding 320 patients with expired funding forms at a cost of £305,000. Through the virtual biologic clinic and enhanced ‘bonanzas’ sessions we were able to reduce the number to 190 with a deficit of £191,000 as of December 2017. This initiative will continue through the virtual biologic clinic.

Teaching and training courses

The team delivered the following in-house courses and educational events:

1. Prescribing Biologics in IBD (29 March 2017)
2. IBD Open day (20 May 2017)
3. Trust Open day (1 July 2017)
4. Nurses Biologics course (8 September 2017)
5. Drugs, Bugs and Hugs (14 September 2017)

The research activities are reported in the IBD ANNUAL RESEARCH REPORT 2017 created by R&D department.
OUR FUTURE DIRECTION

As the IBD population continues to grow, we face huge challenge in maintaining a high-quality service. The aims of the development plan set out in 2016 have been largely achieved with setting up of specialist clinics with new clinic codes for the medical, surgical, nursing and pharmacy teams as well as offering care closer to home for patients with stable disease through community and telephone clinics. The appointment of a community IBD nurse will be critical to the success of this venture. The successful implementation of the IBD database will drive improvement of the KPIs for biologic therapy with plans for a gradual roll out for clinical services in Phase 3 and integration of service, audit and research in Phase 4.

The future service strategy will be discussed at a review meeting scheduled for 26th January with clinical teams, commissioners and service users. The vision is to register all IBD patients on the database at the point of referral with triaging to clinic according to expertise. All newly diagnosed patients are to be seen in a multi-disciplinary 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 point of their journey will support the early diagnosis stage. To achieve our aspirations the service needs to expand and restructure the working patterns of the current team to support new patient referrals, outpatient specialist clinics, biologic clinic to incorporate a strategy to withdraw biologic therapy where appropriate and IBD-cancer surveillance clinics. All these activities and embraced in the booking policy which now warrants implementation.

A well-structured clinical service represents a huge opportunity for national and international collaborative research. A framework to integrate research into service is in development underpinned by the need to acknowledge front-line clinical staff who set up and deliver clinical care. Without a service infrastructure, recruitment efforts are more difficult and a mutually beneficial policy will encourage stronger collaborative outputs.
Tracey Tyrrell  Lead Nurse, IBD Clinical Nurse Specialist
Dr Nailing Arebi  Director of IBD Services, Consultant Gastroenterologist