Inflammatory Bowel Disease (IBD) Nursing Team Annual Report
April 2016 – March 2017

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1
Introduction

This document provides a report of the activity of IBD nursing teams for the period of April 2016 to March 2017. The IBD Nursing team service continues to be the corner stone of the IBD Service at St. Mark’s and across LNWH NHS trust. It remains to be a productive and busy service which is well utilised by both patients and staff. The service is continuously changing and the team continues to work together with the wider IBD multi-disciplinary team to develop services by providing education and taking part in audit.

The IBD nursing team are looking forward to the next 12 months with the anticipated approval of business cases which will allow the service to grow, change and improve. This is included re-establishing the nursing service at Ealing hospital.

Thank you to all of the consultant, management and nursing staff for their support and encouragement of the service.

Tracey Tyrrell
Lead IBD CNS

Contact details:
Phone: 0208 235 4155 (Advice line- voicemail)
Office: 0208 869 5560
Fax number: 0208 869 5487
E-mail: t.tyrrell@nhs.net
Staffing

The IBD Nursing team has evolved over the year with some staff turnover but overall an expansion of the team to include 12 IBD nurses working as two teams: the IBD CNS team and IBD Biologics team. The team is supported by an administrator and a secretary. Names of staff members and their roles are listed below.

Table

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Employment Dates</th>
</tr>
</thead>
</table>
<pre><code>                  | Operational Head of Nursing (Corporate Nursing Team) - Secondment Oct 16 – Sept 17 |
</code></pre>
<p>| Tracey Tyrrell     | Lead IBD CNS                          | Nov 08, (Lead) Jan 15 – Present                                                  |
| Hannah Yarrow      | IBD CNS                              | Apr 11 - Resigned Jun 16                                                          |
| Kay Crook          | Paediatric Gastro CNS                 | Nov 13 - Present                                                                  |
| Monica Chan        | IBD CNS                              | Mar 14 - present Maternity Leave Sep 16 – April 17                               |
| Jitka Adio         | IBD CNS                              | Aug 17 - Present                                                                  |
| Pineshwari Naek-Boolukey | IBD CNS                          | Feb 17 – Present                                                                |
| Guia Grande        | IBD Nurse, IBD CNS                   | Feb 15, Mar 17 – Present                                                         |
| Sheryl Azana       | IBD Nurse, IBD CNS                    | July 15, Mar 17 – Present                                                        |
| Susan Osborne      | IBD CNS Team Secretary                | April 04 – Present                                                               |
| Sheenu Thomas      | IBD Nurse                            | Feb 16 – Resigned Dec 16                                                         |
| Prudence Basuil    | IBD Nurse                            | Jul 16 – Resigned Dec 16                                                         |
| April Mahinary     | IBD Nurse                            | Feb 17 – Present                                                                 |
| April An Berbo     | IBD Nurse                            | Feb 17 – Present                                                                 |
| Nancy Aranas       | IBD Nurse                            | May 17                                                                           |
| Comfort Onyechi Okpeh | IBD Nurse                             | June 17                                                                         |
| Androulla Hadjinicolau | IBD Day Unit Administrator           | Oct 13 – Present                                                                 |</p>

The IBD Nursing team at LNWH NHS trust remains one of the largest IBD teams. There have been a few changes over the past 12 months with Hannah Yarrow, Sheenu Thomas and Prudence Basuil moving on to new pastures to fulfil their aspirations elsewhere having contributed valuable work to the team. The team welcomes Guia Grande and Sheryl Azana as an IBD CNS following promotion in March 2017, having both worked within the IBD Day Care Unit. In addition, the team welcomes Jitka Adio (IBD CNS), Pineshwari Naek-Boolukey (IBD CNS) April Mahinary (IBD Nurse) and April An Berbo (IBD Nurse). We look forward to welcome two new members to the team in 2017. Nancy Aranas (IBD Nurse) and Comfort Onyechi Okeph (IBD Nurse). Nancy and Comfort will be working as part of the biologics nursing team.
IBD Nursing Team – IBD CNS Team (April 2017)

Marian O’Connor
Consultant Nurse IBD
Secondment Oct 16 – Sept 17

Tracey Tyrrell
Lead IBD CNS

Kay Crook
Paed Gasto Nurse

Monica Chan
IBD CNS

Jitka Adio
IBD CNS

Pineshwari Naeck- Boolauky
IBD CNS

Guia Grande
IBD CNS

Sheryl Azana
IBD CNS
IBD Biologics Nursing Team

April An Berbo  April Mahinary
IBD Nurse  IBD Nurse

IBD Nurse - Administration Team

Susan Osborne  Androulla Hadjincolaou
IBD CNS Secretary  IBD Day Unit Administrator
IBD Clinical Nurse Specialist Service

1. Telephone & email – Advice line

The aim of the advice line is to provide patients (adult and paediatric) with a point of access for advice regarding their condition and/or information regarding their disease and treatment. The telephone service continues to work on a voicemail system and patients are advised to only call when they are able to wait for us to call them back with advice. On returning the patient’s call the IBD CNS will assess the patient over the telephone (accessing the CIS records) and advise the patient to manage their symptoms, or where necessary, provide the patient with an urgent clinic review with their consultant.

Calls made to the advice line which avoid attendance at hospital (A&E or clinic) are recorded on the ICS system under the clinic code (NPIBD15D – adult, NPIBD15PAE- Paediatric) which generates £27.00 per call (Pbr tariff, DOH 2010).

All calls are documented live (at the time of call) onto the contracts tab on the patients clinical information system (CIS) record, which ensures patient safety, continuity of care and access for the wider MDT to view this record.

The generic e-mail LNWH-tr.idbnurse@nhs.net aims to provide patients with e-mail access for basic queries which can be dealt via e-mail.

The table below is a breakdown of activity and outcomes of the calls, split into those managed by advice alone, an urgent appointment made and those admitted to hospital.

<table>
<thead>
<tr>
<th>Total calls received</th>
<th>Advice given</th>
<th>Clinic appointment made</th>
<th>Admitted to hospital</th>
<th>Total e-mails received</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,874</td>
<td>558</td>
<td>1,316</td>
<td>16</td>
<td>4,114</td>
</tr>
</tbody>
</table>

Number of calls logged onto the ICS has reduced over the last 12 months. This is due to reduced opening hours owning to change of staff and training of new staff. More clinic appointments have been made then advice given due to the complexity of calls and lack of IBD experience of the staff running the advice line. The advice line will be audited in 2017 to obtain a deeper understanding of this discrepancy from previous years.

2. Nurse-Led Clinics and Telephone Review Clinics

It is important to highlight that during the last 12 months the biologics service was prioritised due to an increase in referrals and change of staff. This had an impact on both the advice line and nurse led clinics. The IBD nursing team currently provides a total of 3 weekly clinics across the trust, which is a decrease from 12 clinics (2015/2016). This is owing to staff changes within the team and the need for training.
The Nurse-led clinics are ideal for the following patients (adult and paediatric):

- Newly diagnosed patients or those requiring further information and education
- Stable IBD who require 6 or 12 month follow up (offer patients the opportunity to be reviewed over the phone rather than attending clinic)
- Patients who require a clinic review following commencement on immunosuppressant medications, particularly in the case of dose escalation for example. Otherwise patients can be reviewed by phone in the immunosuppressant clinic (see below).

Patient referred into the nurse led clinics are allocated a 30 minute clinic appointment which allows for adequate support and education to be given regarding their needs.

The telephone review clinic provides follow-up for patients with stable IBD and can alternate with their planned 12 monthly follow-up in out-patients as a means of reducing the number of follow-up appointments in the consultant’s out-patients clinics.

The telephone immunosuppressant clinic is undertaken with patients being contacted via the telephone in the event of abnormal blood test if they are being monitored by our database (see section below).

The biologics telephone review clinic stopped in June 2016 as the IBD Biologics team felt it was not meeting its purpose due to a high DNA rate and overlapping with face to face clinics.

The following table shows the total number of patients seen in these clinics over the past 12 months.

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Clinic Code</th>
<th>April 2016 – March 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Led Clinic SMH (Monday am)</td>
<td>NPGASTRO1Y</td>
<td>Suspended (Re-open 15/5/2017)</td>
</tr>
<tr>
<td>Nurse Led Clinic CMH (Monday pm)</td>
<td>CSHAAM1PN/COBRMS1PN</td>
<td>Suspended May 16 (Re-open May 2017) 11</td>
</tr>
<tr>
<td>Nurse Led Clinic SMH (Tuesday pm)</td>
<td>NPGASTRO2Y</td>
<td>Suspended June 16 (Re-open June 16) 47</td>
</tr>
<tr>
<td>Nurse Led Clinic SMH (Thursday am)</td>
<td>NPGASTRO4Y</td>
<td>Suspended April 16 – Feb 17 (Re-open Feb’17) 7</td>
</tr>
<tr>
<td>Nurse Led Clinic SMH (Friday am)</td>
<td>NPGASTRO5Y</td>
<td>Suspended Feb 17 (Re-open May 17) 107</td>
</tr>
<tr>
<td>Telephone review clinic (Monday pm)</td>
<td>NPGO1PF</td>
<td>Reduce to one clinic a month (Since June’17) 81</td>
</tr>
<tr>
<td>Telephone IMS Clinic (Wednesday am)</td>
<td>NPIMS15D</td>
<td>96</td>
</tr>
<tr>
<td>Paediatric Nurse Led Clinic (Monday pm)</td>
<td>NPIBD1P</td>
<td>173</td>
</tr>
</tbody>
</table>
Paediatric telephone review clinic (Monday pm) | NPPIBD1PT | 41
Paediatric Nurse led clinic (Thursday am) | NPPIBD4A | 243

Biologics telephone review clinic (Monday pm) | NPGOL1PBT | Suspended
Biologics telephone review clinic (Thursday pm) | NPGOL4PBT | Suspended

Total reviewed in N/L clinics (face to face) | 588
Total reviewed in Telephone clinics | 329

Referral to any of the nurse led clinics can be done by marking clearly on the Green outcome form in clinic for an appointment to be made with the IBD Nurse clinic and copy the clinic letter to the IBD CNS team for information.

3. IBD Biologics Nursing Team

Telephone: 0208 869 5488
E-mail: LNWH-tr.ibdbiologics@nhs.net
Fax: 0208 869 5487

The IBD Day Unit is a three-chaired unit (located on the physiology corridor, level 4, STM) which open 5 days per week, from 08:30am until 7pm daily.

Admission times are staggered, allowing for 10 - 12 patients to be treated daily providing access to biologics therapies (Infliximab, Vedolizumab and Ustekinumab) and IV Iron (ferinject). In addition, a clinic room in the physiology department is also utilised two days per week to provide treatment to patients requiring sub-cutaneous therapies (Adalimumab, Golimumab, Methotrexate and Ustekinumab injections).

Admissions continue to grow with approximately an extra 500 admissions to the day unit in compared to 2015/2016.

The following table shows the total number of patient’s admissions to the IBD Day Unit in the past year, along with a breakdown of the numbers of patients on each therapy.

<table>
<thead>
<tr>
<th>Total number of day care admissions</th>
<th>April 2016- March 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of patients on Infliximab</td>
<td>286</td>
</tr>
<tr>
<td>Total number of patients on Vedolizumab</td>
<td>115</td>
</tr>
<tr>
<td>Total number of patients on Adalimumab</td>
<td>230</td>
</tr>
<tr>
<td>Total number of patients on Golimumab</td>
<td>3</td>
</tr>
<tr>
<td>Total number of patients on Ustekinumab</td>
<td>4</td>
</tr>
<tr>
<td>Total number of patients on Methotrexate</td>
<td>12</td>
</tr>
</tbody>
</table>
4. Immunosuppressant monitoring

The immunosuppressant monitoring service provides patients with a safe means of having their blood test monitored whilst on immunosuppressant therapy (including Azathioprine, Mercaptopurine, Methotrexate, Tacrolimus and Ciclosporin), in the situation that the GP is unable to do so. The service is run using the database system, Therapy Audit Monitor.

Five hundred and seventy four patients are currently being monitored using the system. The database system Therapy Audit Monitor is used in the department to monitor blood test results for patients taking these immunosuppressant medications. This system works by flagging the abnormal blood tests for patients (parameters are set in accordance with the protocols for each of the medications) and is checked on a twice weekly basis by the IBD CNS team. The IBD CNS team will then contact the patient via telephone to discuss any abnormal blood test result and arrange for a change of dose of their immunosuppressant and/or repeat blood test (as per protocol). Secondly this system highlights the patients who have not attended for regular monitoring and generates a letter which is sent to the patient with a blood test request form to remind them to attend St. Marks or Central Middlesex out-patients department for their blood tests.

To refer any patients to this service please e-mail us or send us a copy of your patient’s clinic letter.

5. Paediatric & Transition services

The paediatric IBD Service continues to be run by Dr Warren Hyer and CNS Kay Crook caring for approximately 120 paediatric patients with IBD.

The paediatric IBD Nursing service mirrors the adult service, providing access for children and their parents via the IBD telephone advice line and e-mail service, two nurse led clinics per week, and access to biologic and Iron therapies are offered via the Paediatric day unit.

There are currently 54 paediatric patients maintained on Immunosuppressant therapy who attend the Paediatric out-patients department regularly for blood tests. This is due to their local GP services either do not undertake Paediatric patient’s blood tests or do not monitor azathioprine in the surgery. These patients are being followed up safely using the Therapy Audit database monitoring system as above which Kay can then action according to paediatric protocol.

Infliximab therapy is used to maintain 15 Paediatric patients through the Paediatric day care unit, supported by Kay. 5 patients have switched to Remsima with 2 still on Remicade and are now due to switch following discussion with patient and family. 16 children (3yrs +) have received Ferinject infusions in the past 12 months following the development and audit of a paediatric pathway.

Recent developments

The Transition clinic continues to be held on a Friday afternoon once a monthly with Professor Hart, Dr Hyer & Dr Akbar and Kay attending. There will soon be a dedicated transition adult nurse to support the service. The service will then be compliant with national transition guidelines and standards offering better support to this group of young adults through their transition to adult care/services. Over the last year 30 adolescents were transitioned into the young adult IBD clinics, with approxi-
mately 83 patients who have moved through transition and are now being seen routinely in the young adult IBD clinics.

The **Paediatric Sedation Endoscopy Service** continues on a Tuesday/Friday morning providing a transition from GA endoscopy to sedation endoscopy for patients with IBD or Polyposis. Over the past year, 10 IBD patients have been through this pathway with lists held every 1-2 months. The service is currently being re-audited.

**Joint endocrine clinics** were established in February 2015 and occur every 3 months with Dr Hyer, Dr Massoud (Paediatric endocrinologist) and Kay. Fifteen patients are routinely seen in this clinic to date.

Following requests from patients and families Kay initiated an **Information event** aimed at the under 12 year old age group – ‘Crazy and Crafty Colitis and Crohn’s afternoon’. The event took place in July 2016, it was planned in collaboration with the children and focused on crafts and fun for the children to develop an IBD information board for the Paediatric Outpatient Department. Dr Hyer provided an educational element with a tour through the inflatable bowel. The event was very well received with 8 children (plus siblings) and 8 parents attending. Parents felt that the opportunity to meet other parents was very beneficial, all 16 participants would like to meet again to utilise the opportunity to support others and be supported themselves.

### 6. Audit and Research

**Audit**

- Biologics registry

The IBD nursing team within the IBD Day Unit supported by Kay Crook has been inputting data onto the IBD registry. To date 591 patients data have been entered, which included demographic data, medical and surgical disease history and previous and current biologic therapy.

**Research**

- FINS (Faecal Incontinence iNtervention Study)

In collaboration with Professor Hart, Professor Christina Norton and Dr. Lesley Dibley at Kings College London, the IBD CNS was involved until January 2017. Due to reduction in the IBD Nursing service it was agreed that the IBD CNS would be no longer involved in the research.

### 7. In-Patients services

At NPSM, the IBD Nurse can be contacted via Bleep 471 to see in-patients and ad-hoc out-patients, and we will endeavour to accommodate this around our scheduled clinical duties. At CMH an IBD Nurse is currently not available.

**One Hundred and sixty two (162)** in-patients were reviewed by the IBD Nursing team in the past 12 months.

**Ten (10)** ad hoc clinic reviews were also undertaken when bleeped to attend the out-patients departments.
8. Team Meetings

**IBD Multidisciplinary Team Meeting (MDM)**  
**Wednesday 8-9am**  
**Location: Lecture room F, Level 3, MEC**

Over the last 12 months the chairing of the meeting has including all members of the IBD MDM. The IBD CNS team coordinates the meeting. It occurs weekly with breakfast provided by a medical representative.

The format of this meeting is as follow;

@8am: Service Updates  
@8:10am  In-patient case review  
@8:30am  Clinical case review with radiology

This meeting provides the whole IBD team with the opportunity to discuss difficult or challenging clinical cases, in order to gain input from relevant disciplines and agree a management plan.

To refer any patients to the agenda for discussion please complete the referral form which is available on the IBD intranet page (under meetings) and e-mail us at LNWH-tr.ibdnurse@nhs.net

**IBD Nursing Team Meeting**  
**Friday 8.30-9am**  
**Location: Physiology Meeting Room**

The whole IBD Nursing team meets weekly on a Friday to ensure that the clinical service is managed effectively and safely, with the meeting being chaired by the Lead IBD CNS. This meeting is also an opportunity for any staff who have attended a clinical or educational meeting to feedback on learning to the wider team, which encourages sharing of that knowledge and ensures development opportunities of all members of the team.

**Virtual Biologics Meeting (VBM)**  
**Fridays 9.30-11am**  
**Location: Physiology Meeting Room**

This meeting is coordinated by the IBD Biologics Team, attended by Consultant Gastroenterologists, IBD Clinical fellow, register and pharmacy.

From December 2016 to March 2017 this meeting was on hold due to staff changes within the biologics nursing team.

The aim of this meeting is to discuss:

- **New Starters:** Final case review of patients cases prior to commencing biologics
- **Loss of response:** Review any patients whom appear to be losing response to therapy and make a plan for escalation of therapy (identified by the IBD CNS team in the IBD Day Care Unit)

- **Issues with treatment:** Monitor tolerance, side effects and use of concomitant immunosuppressant’s

- **12 month reviews:** All patients need to have a 12 month review form completed for ongoing anti-TNF therapy if this is deemed appropriate by their consultant Gastroenterologist. This should be completed when the patient is reviewed in the outpatient’s clinic with their consulting team and a decision made to continue treatment beyond 12 months (if the clinic appointment ties in with the end of therapy).

**IBD Patient Panel Meeting (PPM)**

Tri-monthly Tuesday evenings
Location: Medical Education Centre

The patient panel meets every 3 months and is attended by a group of 5 regular patients who provide feedback on current or new IBD Services. Two members of the IBD CNS team attend this meeting as a means of providing a link between this patient group and the team. The IBD Patient panel and the IBD team continue to arrange an annual IBD Open Day.

**IBD Open Day**

The IBD Open day did not take place in November 2016. This was due to lack of funding and changes within the IBD nursing team. It was agreed by the patient panel to delay the day until further funding was secured. Plans are in place to host the event on 20th of May 2017.

**9. IBD Intranet Page (Currently under review)**

To access the IBD intranet page:

*Click on the main Inwh(Intranet icon >Clinical Departments and Corporate> Inflammatory Bowel Disease*

The IBD Intranet page provides a great resource of information accessible to all members of the team across the trust. Within the IBD Intranet page you will be find information on all aspects of the IBD Nursing service, along with relevant protocols, guidelines and patient information sheets.

**10. IBD Dietitian Service**

Evi Kyriakidou, IBD Dietitian remains busy with a consistently high numbers of referrals to clinics and in-patient reviews.

The following table is the data for the numbers of patients seen by the Dietitian over the last 12 months:

<table>
<thead>
<tr>
<th>CLINIC</th>
<th>2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietitian Clinic review</td>
<td>244</td>
</tr>
<tr>
<td>Dietitian Telephone consultant</td>
<td>154</td>
</tr>
<tr>
<td>Ad-hoc opd reviews (bleeped by staff)</td>
<td>497</td>
</tr>
</tbody>
</table>
### 11. Pharmacy

Anneliese D’Souza started as the St Mark’s IBD Pharmacist in February 2017. The role is part time IBD and part time homecare. The pharmacist will work together with the IBD nurses in the immunosuppressant clinic. In the future, this clinic may be run by the pharmacist. The pharmacist currently leads on the Adalimumab prescription two afternoons a week (currently Monday and Thursdays). As well as working within the IBD team, the pharmacist will provide specialist support and training to the other junior pharmacists within the trust. The pharmacist will work as part of the MDT and attend the weekly VBM. The homecare role will be across all 3 sites within the trust ensuring we are Hackett compliant and looking at how we can reduce waste. The pharmacist will also work as part of the St. Mark’s pharmacy team carrying out daily tasks required within the team such as screening high-cost drugs and homecare parenteral prescriptions.

### 12. Positions of responsibility

**Marian O’Connor** is currently on a secondment (October 16 – October 17) within the LNWH trust working within the Corporate Nursing Team, as **Operational Head of Nursing, Midwifery and AHP Standards**.

Marian continues as a committee member for **ICHOM (International Consortium for Health Outcome Measures)** which is aims to identify a standard set of Outcome measures for IBD. This is in its final stages at present, with a pending publication in GUT.

Marian continues to be a **member of the Global Nurses Forum** (previously known as the International IBD Nurses steering committee) and the chair of the **UK IBD Nursing Academy**, both of which aim to develop IBD Nursing internationally & nationally.

Marian is also a **Trustee for the charity, IBD2020**, which aims to work globally to improve the quality of care for patients with IBD, in collaboration with Simon Travis & Richard Driscoll.

Marian also regularly peer reviews articles for GIN (Gastrointestinal Nursing), British Journal of Nursing (BJN), Journal of Crohn’s and Colitis and IANHC.

Following the successful development of the **Monthly Ward Teaching in January 2016**, Marian handed over responsibility of this to Jennie Burch (Head of GI Nurse Education) whilst she is on secondment.

**Tracey Tyrrell** stepped down as chair of the IBD RCN Network London and South East region in September 2016. In March 2017 she was elected IBD RCN Special projects co-ordinator for the national committee. This ensures that an IBD Nurse has representation on the main the IBD projects at a national level. Tracey continues to be a peer reviewer for GIN.

**Kay Crook** is currently the vice chair of the IBD RCN/BSPGHAN (British Society of Paediatric Gastroenterology Hepatology and Nutrition). Kay was a member of the working party that produced the quality standards for paediatric gastroenterology, hepatology & nutrition which have been launched by the Royal College of Paediatric and Child Health (RCPCH). Kay is currently on the working party for the improve IBD alliance which is continuing the IBD quality in IBD services.
13. Planned Education

For the full list of the team’s presentations and publications undertaken within the past 12 months, see appendix 1 & 2.

Weekly teaching Session

Weekly teaching Sessions for the IBD Nursing Team took place from August to November 2016. This will be restarted in May 2017.

Monthly Ward Education

The IBD Nursing team take part in the monthly ward education sessions co-ordinated by the Head of GI Nursing Education Jennie Burch. This is aimed at the nursing and healthcare assistant staff from Frederick Salmon, out-patients department, Sainsbury ward, IFU and Fletcher wards to provide education and updates on all aspects of GI care.

Burdett scholar

The IBD Nursing team continues to support the Burdett scholarship programme. Over the last 12 months the team have supported two scholars.

IBD Nurse Biologics Study Day

In May 2016 the IBD Nursing team co-ordinated a day of talks and discussion the next study day is planned for September 2017.

Moor- Park Stoma Care Course (MSc/BSc)

The IBD Nursing Team present on this course once every 4 months.

GI Nursing Study Day

The IBD Nursing Team present at this annual study day.

14. Visitors

The IBD CNS team has received 6 visitors to the unit to observe and learn from the IBD Nursing service and develop best practice, over the past 12 months. The visitors came from South Africa, Egypt and the UK.

15. Current developments

Business cases

- Community IBD Nurse
As part of the CLARCH project led by Dr. Arebi a business proposal was placed and accepted by Brent CCG for a community IBD Nurse post. The post is for a band 8a IBD Nurse who will be working based in a GP practice. This is going through its final stages.

- **Expansion of the IBD Day Unit**

A business case was drawn up and presented to the Business case review panel in March 2017. The case is to expand the current 3 bed IBD Day Unit to a 6 bedded Unit. This is currently with finance. In the meantime the IBD Nursing team have been using the Rheumatology unit every Friday to help with the current waiting time (6-8 weeks) to start on biologics.

- **Paediatric**

Following the IBD Audit which was completed in 2014 for the Paediatric department and the development of a Quality Improvement Plan (QIP) Kay continues to work on a business case with Dr. Hyer and Paediatric managers to improve the services for Paediatric patients with IBD. Kay also arranged a peer review of the paediatric IBD service which validates the proposed business case.

- **PKB**

PKB is on hold until September 2017.

### 16. Estimated IBD Nursing Service Income April 2016- March 2017

<table>
<thead>
<tr>
<th>Clinic Name</th>
<th>Volume</th>
<th>Estimated Tariff</th>
<th>Estimated Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>IBD Telephone Advice line</td>
<td>1,874</td>
<td>£27</td>
<td>£50,598</td>
</tr>
<tr>
<td>Nurse led clinics</td>
<td>107</td>
<td>£128</td>
<td>£13,761</td>
</tr>
<tr>
<td>Paediatric clinics</td>
<td>416</td>
<td>£128</td>
<td>£53,248</td>
</tr>
<tr>
<td>All Telephone review clinics</td>
<td>329</td>
<td>£27</td>
<td>£8,883</td>
</tr>
<tr>
<td>IBD Day Care Unit</td>
<td>2,615</td>
<td>£483</td>
<td>£945,956</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td><strong>£1,072,446</strong></td>
</tr>
</tbody>
</table>

### 17. Patient Feedback

**Friends and Family Test (FFT)**

In May 2016, the IBD Day Care Unit was registered on FFT in order to allow patients to provide feedback on their experience of the unit. Over 400 patients have provided feedback, with the majority of patients stating that they are extremely likely or likely to recommend the unit.

See the attached breakdown of FFT data since May 2016 on the IBD DCU.

**I Want Great Care (IWGC)**

The IBD CNS team are registered on IWGC which provides each staff member with an individual webpage to collect feedback. Many of the IBD CNS staff has received 5 star reviews from patients, following seeing them in nurse led clinics.

**Complaints**
In the last 12 months we received five informal complaints from both patients and doctors. The main themes have been unable to get through on the advice line and not getting a schedule appointment in the IBD day care unit within the correct infusion interval. All of these complaints have been addressed with the patients and I am working with management to address the ongoing capacity issues in the IBD day unit.
Appendix 1

Marian O'Connor Presentations

22 April 2016
Takeda National IBD Meeting, London
Nursing perspective on considering the right patient for biologic therapy

22 April 2016
Takeda National IBD Meeting, London
Workshop; Exemplar of Business case

5 May 2016
Ward teaching, Med Education Centre, Seminar Room 5, L6, LNWH
Presentation entitled: Nursing considerations in caring for in-patients with Inflammatory Bowel Disease

13 May 2016
IBD Nurse Academy, London
Demonstrating the value of your service

13 May 2016
IBD Nurse Academy, London
Workshop; Business case development

21 May 2016
Napp Regional Meeting, Leeds
Motivational communication

15 June 2016
Ward teaching, Med Education Centre, Seminar Room 5, L6, LNWH
Presentation entitled: Nursing considerations in caring for in-patients with Inflammatory Bowel Disease

17 June 2016
UKCPA(UK Clinical Pharmacy Association) Clinical Pharmacists Masterclass, London
Developing Advance Practice Skills

5 July 2016
The Association of Coloproctology of Great Britain & Ireland. Edinburg, Scotland
The role of the IBD Consultant Nurse in IBD
14 July 2016  
Ward teaching, Med Education Centre, Seminar Room 5, L6, LNWH  
Presentation entitled: Nursing considerations in caring for in-patients with Inflammatory Bowel Disease

23 July 2016  
Takeda Nurse Steering Committee Meeting, London  
Presentation entitled: Education and networking opportunities for IBD Nurses

6 August, 2016  
Australian Nurses Meeting (IGNiTE), Sydney, Australia (via video link)  
Presentation entitled: IBD Nursing Activity Audits

6 August, 2016  
Australian Nurses Meeting (IGNiTE), Sydney, Australia (via video link)  
Presentation entitled: Shared care for patients on Immunosuppressant’s

8 September 2016  
Ward teaching, Med Education Centre, Seminar Room 5, L6, LNWH  
Presentation entitled: Nursing considerations in caring for in-patients with Inflammatory Bowel Disease

2 November 2016  
Birmingham City University, Moorpark  
Colorectal Cancer care for Advanced (MSc) Practice  
Presentation entitled: Demonstrating the value of your nursing service

22 November 2016  
Inaugural Nursing Frontiers, St Marks Hospital, London  
Presentation entitled: Demonstrating the value of your service

25 November 2016  
Crohn’s Disease Matters, Janssen sponsored, London  
Presentation entitled: Demonstrating the value of the IBD Nurse Service

6 December 2016  
Humira Forum, Chicago America  
Presentation entitled: Key role that the nurse plays in patient empowerment and self-management

Marian O’Connor Meeting Chair

2 Feb 2016  
Marian O’Connor Meeting Chair  
Abbvie Sponsored Sub-cut biologics Meeting, London
17 March 2016
Takeda Sponsored N-ECCO Symposium, Amsterdam, Netherlands

13 May 2016
MSD Nurse Biologics Study Day, London

13 & 14 May 2016
IBD Nurse Academy, London

23 July 2016
Takeda Nurse Steering Committee Meeting, London

**Tracey Tyrrell Presentations**

13 May 2016
St. Mark’s Nurse Biologics Study Day, Gyms Dyke Hotel, Harrow
Presentation entitled: Running a biologics service- A CNS perspective

22 July 2016
IBD Nursing team away day,
Presentation entitled: IBD Nursing Service – Changes

28 September 2016
IBD MDM, Level 3, Medical Education Centre
Presentation entitled: St. Mark’s IBD Nursing Team

13 October 2016
Ward teaching, Physiology room, St. Mark’s Hospital
Presentation entitled: Nursing considerations in caring for in-patients with Inflammatory Bowel Disease

14 October 2016
IBD Nursing Team weekly teaching session, IBD Unit, St. Mark’s Hospital
Presentation entitled: Medical Management – Part 1

28 October 2016
IBD Nursing team weekly teaching session, IBD Unit, St. Mark’s Hospital
Presentation entitled: Scoring systems in IBD

21 October 2016
IBD Nursing Team weekly teaching session, IBD Unit, St. Mark’s Hospital
Presentation entitled: Medical Management – Part 2

02 November 2016
IBD Nursing Team – Biologics team, IBD Unit, St. Mark’s Hospital
Presentation entitled: Methotrexate in IBD

04 November 2016
IBD Nursing Team, IBD Unit, St. Mark’s Hospital
Presentation entitled: Support for IBD patients

10 November 2016
Ward teaching, Physiology room, St. Mark’s Hospital
Presentation entitled: Nursing considerations in caring for in-patients with Inflammatory Bowel Disease

04 January 2017
IBD MDE, Level 3, Medical Education Centre
Presentation entitled: IBD nursing team service

08 February 2017
Sainsbury ward teaching, Sainsbury, St. Mark’s Hospital
Presentation entitled: Infliximab and Vedolizumab

08 March 2017
LNWH Leadership Programme, Level 6, Medical Education Centre
Presentation entitled: Expansion of the Inflammatory Bowel Disease (IBD) Day Unit.

01 March 2017
Advanced approach to stoma care (level 6), Moor Park
Presentation entitled: Inflammatory Bowel Disease

T Tyrrell Meeting Chair

13 May 2016 (afternoon session)
St.Mark’s Nurse Biologics study day, Grimsdyke Hotel, Harrow

21 July 2016
IBD RCN network meeting, Radisson Blue Hotel, Euston

21 September 2016
IBD RCN network meeting, Radisson Blue Hotel, Euston

Kay Crook Presentations

12 May 2016
LNWH Nurses day
Presentation entitled: What has changed in the 2 decades since the first IBD Nursing post in the UK?

05 June 2016
St Mark’s Biologics Study Day, Grims Dyke Hotel, Harrow
Presentation entitled: Transition: How to manage with and without a dedicated CNS clinic
08 June 2016
Journal of Health Visiting Study Day,
Presentation entitled: The Developing Gut

21 July 2016
RCN IBD Nurse Network
Presentation entitled: Difficult Case

14 September 2016
Advanced approach to stoma care (level 6), Moor Park
Presentation entitled: Inflammatory Bowel Disease

29 September 2016
Growing together: Working together to improve the treatment of Crohn’s Disease in paediatric patients (ABBVIE)
Presentation entitled: Transition

07 October 2016
IBD Nurses teaching
Presentation entitled: Pathophysiology of IBD Nursing

**Monica Chan Presentations**

28 April 2016
Teaching Room, Endoscopy Department, St Mark’s Hospital
Presentation entitled: Clinical Manifestations of IBD

6 June 2016
Advanced approach to stoma care (level 6), Moor Park
Presentation entitled: IBD

**Jitka Adio Presentations**

08 September 2016
St’ Marks Hospital
Presentation entitled: Nursing considerations in caring for in-patients with IBD

13 October 2016
St’ Marks Hospital
Presentation entitled: Nursing considerations in caring for in-patients with IBD

31 March 2017
St’ Marks Hospital
Presentation entitled: Inflammatory Bowel Disease
Guia Grande Presentations

18 January 2017
IBD Module: University of Salford
Ustekinumab for the treatment of Crohn’s Disease,

29 March 2017
Prescribing Biologics St. Mark’s Hospital
Presentation entitled: Delivering Biologics

Sheryl Azana Presentations

18 January 2017
IBD Module: University of Salford
Presentation entitled: Infliximab induced lupus

Evi Kyriakidou Presentations

15 June 2016
Ward teaching session
Presentation entitled: The Importance of diet for IBD patients

23 June 2016
Pouch Masterclass
Presentation entitled: The role of a balanced diet with an ileo-anal pouch

14 July 2016
Ward teaching session
Presentation entitled: The Importance of diet for IBD patients

13 Oct 2016
Ward teaching session
Presentation entitled: The Importance of diet for IBD patients

10 November 2016
Ward teaching session
Presentation entitled: The Importance of diet for IBD patients
Appendix 2

Publications list 2016 - 2017

Kay Crook
RCPH/BSPGHAN (2017) Quality standards for specialist paediatric, gastroenterology, Hepatology and nutritional support
Appendix 3

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*Note: IBD Service started Friends and Family Test in May 2016*