INFLAMMATORY BOWEL DISEASE (IBD) NURSING TEAM

Annual Report
April 2018- March 2019
<table>
<thead>
<tr>
<th>Contents</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>2</td>
</tr>
<tr>
<td>Staffing</td>
<td>3</td>
</tr>
<tr>
<td>Overview of activity</td>
<td>9</td>
</tr>
<tr>
<td>IBD Clinical Nurse Specialist Services</td>
<td></td>
</tr>
<tr>
<td>1. Telephone and e-mail Advice Line Service</td>
<td>11</td>
</tr>
<tr>
<td>2. Nurse-Led Clinics &amp; Telephone Review clinics</td>
<td>12</td>
</tr>
<tr>
<td>3. Ealing Nursing Service</td>
<td>14</td>
</tr>
<tr>
<td>4. IBD Biologics Nursing Team</td>
<td>14</td>
</tr>
<tr>
<td>5. Immunosuppressant monitoring</td>
<td>15</td>
</tr>
<tr>
<td>6. Paediatric service</td>
<td>16</td>
</tr>
<tr>
<td>7. In-patient service</td>
<td>16</td>
</tr>
<tr>
<td>8. Audit &amp; Research</td>
<td>16</td>
</tr>
<tr>
<td>9. Team meetings</td>
<td>17</td>
</tr>
<tr>
<td>10. Open day and IBD Awareness Days</td>
<td>18</td>
</tr>
<tr>
<td>11. IBD Intranet page</td>
<td>20</td>
</tr>
<tr>
<td>Supporting Services</td>
<td></td>
</tr>
<tr>
<td>12. Dietician service</td>
<td>20</td>
</tr>
<tr>
<td>13. Pharmacy service</td>
<td>21</td>
</tr>
<tr>
<td>Professional development</td>
<td></td>
</tr>
<tr>
<td>14. Positions of responsibility</td>
<td>22</td>
</tr>
<tr>
<td>15. Training &amp; Development</td>
<td>22</td>
</tr>
<tr>
<td>16. Clinical Supervision</td>
<td>22</td>
</tr>
<tr>
<td>17. Education</td>
<td>22</td>
</tr>
<tr>
<td>18. Visitors</td>
<td>24</td>
</tr>
<tr>
<td>Service Development</td>
<td></td>
</tr>
<tr>
<td>19. Current development</td>
<td>24</td>
</tr>
<tr>
<td>20. Service Income</td>
<td>25</td>
</tr>
<tr>
<td>21. Patient feedback</td>
<td>26</td>
</tr>
<tr>
<td>Appendix</td>
<td></td>
</tr>
<tr>
<td>Appendix 1 -Presentations</td>
<td>27</td>
</tr>
<tr>
<td>Appendix 2- Academia</td>
<td>32</td>
</tr>
<tr>
<td>Appendix 3- Publications and Posters list</td>
<td>33</td>
</tr>
<tr>
<td>Appendix 4- Patient feedback</td>
<td>34</td>
</tr>
</tbody>
</table>
Introduction

This document provides a report of the activity of IBD Nursing team for the period of April 2018 to March 2019. The IBD Nursing team service continues to be the cornerstone of the IBD Service at St. Mark’s Hospital and across LNWH NHS trust.

It remains 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 through the weekly IBD business meeting. The team continues to provide education as well as participating in research and audit.

The IBD Nursing team are looking forward to the next 12 months with new leadership, the outsourcing of the biologics service and development of the IBD Advanced Nurse Practitioner role.

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

Tracey Tyrrell
Lead IBD CNS (Stepped down March 2019)

IBD Advanced Nurse Practitioner

E-mail: t.tyrrell@nhs.net
Staffing

The IBD Nursing team continues to evolve to include 11 IBD nurses working as two teams: the IBD Clinical Nurse Specialist (CNS) team and IBD Biologics team. The IBD Nursing team at LNWH NHS trust remains one of the largest IBD teams in the UK. The team is supported by an IBD Day Unit administrator and a part-time secretary.

The team said goodbye to Monica Chan (IBD CNS) who relocated to North Devon NHS trust who still remains to work in the speciality of IBD. Aprill Mahinary (IBD Biologics Nurse) left to take on a new role as IBD CNS in St. Mary’s Hospital Paddington. Tracey Tyrrell stepped down as Lead IBD CNS to take on a new role as IBD Advanced Nurse Practitioner based at Central Middlesex Hospital. We wish them all the best in their new roles and may they continue to grow and develop the role of IBD Nursing in the UK.

Monica’s Leaving drinks (Dec 2018) Left to right: Gabriela Poufou (IBD Dietitian), Androulla Hadjinicolau (IBD Day Unit Administrator), Comfort Okeph (IBD Biologics Nurse), Kay Crook (Paediatric Gastro Nurse), Tracey Tyrrell (Lead IBD CNS), Monica Chan (IBD CNS), Jitka Adio (IBD CNS), Sheryl Azana (IBD CNS), Guia Grande (IBD CNS), April Mahinary (IBD Biologics Nurse), Nancy Aranas (IBD Biologics Nurse).

In January 2019 the team welcomed Susie Wen who joined the trust as new IBD CNS. Susie has previously worked as an IBD CNS at Princess Alexander Trust.

In February 2019 the team welcomed Madhoor Ramdeen who joined the trust as new Lead IBD CNS. Madhoor has 8 years of IBD Nursing experience previously leading a team at Epsom and St. Helier.

Names of staff members and their roles are listed on the next page.
<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Employment Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>IBD CNS TEAM</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Madhoor Ramdeen</td>
<td>Lead IBD CNS</td>
<td>Feb 19 – Present</td>
</tr>
<tr>
<td>Kay Crook</td>
<td>Paediatric Gastro CNS</td>
<td>Nov 13 - Present</td>
</tr>
<tr>
<td>Monica Chan</td>
<td>IBD CNS</td>
<td>IBD Nurse March 2014 – 2015</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Maternity Leave Sep 16 – April 17</td>
</tr>
<tr>
<td></td>
<td></td>
<td>IBD CNS 2015 – Dec ‘18 (Resigned)</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Dates</td>
</tr>
<tr>
<td>-----------------------</td>
<td>------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Jitka Adio</td>
<td>IBD CNS</td>
<td>Aug 16 - Present</td>
</tr>
<tr>
<td>Pineshwari Naeck-Boolauky</td>
<td>IBD CNS</td>
<td>Feb 17 – Present</td>
</tr>
<tr>
<td>Guia Grande</td>
<td>IBD CNS</td>
<td>IBD Nurse Feb 15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>IBD CNS Mar 17 – Present</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Notes</td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Sheryl Azana</td>
<td>IBD CNS</td>
<td>IBD Nurse July 15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>IBD CNS Mar 17- Present</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Maternity leave July 17 to April 18</td>
</tr>
<tr>
<td>Susie Wen</td>
<td>IBD CNS</td>
<td>Feb 19 – Present</td>
</tr>
<tr>
<td>IBD BIOLOGIC NURSING TEAM</td>
<td></td>
<td></td>
</tr>
<tr>
<td>April Mahinary</td>
<td>IBD Biologics Nurse</td>
<td>Feb 17 – Mar 19 (Resigned)</td>
</tr>
<tr>
<td>Name</td>
<td>Role</td>
<td>Dates</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----------</td>
<td>------------------------------</td>
</tr>
<tr>
<td>April An Berbo</td>
<td>IBD Nurse</td>
<td>Feb 17 – Present</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Maternity leave Aug 17 to May 18</td>
</tr>
<tr>
<td>Nancy Aranas</td>
<td>IBD Nurse</td>
<td>May 17 – Present</td>
</tr>
<tr>
<td>Comfort Okeph</td>
<td>IBD Nurse</td>
<td>June 17 – Present</td>
</tr>
<tr>
<td>Susan Osborne</td>
<td>IBD CNS Team Secretary</td>
<td>April 04 – Present</td>
</tr>
<tr>
<td>--------------</td>
<td>------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Androulla Hadjinicolaou</td>
<td>IBD Day Unit Administrator</td>
<td>Oct 13 – Present</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IBD Advanced Nurse Practitioner</th>
<th>IBD Advanced Nurse Practitioner Based: CMH</th>
<th>IBD CNS Nov 08 – Dec 14</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Lead IBD CNS Jan 15 – Feb 19</td>
</tr>
<tr>
<td></td>
<td></td>
<td>IBD Advanced Nurse Practitioner Mar 19 - Present</td>
</tr>
</tbody>
</table>
### Overview on IBD Nursing Service activity April 2018- March 2019

<table>
<thead>
<tr>
<th>Service</th>
<th>April 2017-March 2018</th>
<th>April 2018- March 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advice &amp; Email support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advice line</td>
<td>Messages: 3250</td>
<td>Messages: 4,335</td>
</tr>
<tr>
<td></td>
<td>Chargeable: 2301</td>
<td>Chargeable: 2215</td>
</tr>
<tr>
<td>Clinic appointments made</td>
<td>728</td>
<td>1,041</td>
</tr>
<tr>
<td>Admitted to hospital</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>Emails</td>
<td>5,484</td>
<td>6,372</td>
</tr>
</tbody>
</table>

| Nurse led clinics (Adult)     |                       |                        |
| Face to face                 | 428                   | 628                    |
| Including MDT               |                       |                        |
| Biologics                    |                       |                        |
| Telephone                    | 366                   | 758                    |
| Including                    |                       |                        |
| Biologics telephone IMS clinics |                 |                        |

| Biologics Service            |                       |                        |
| IBD Day Unit & IBD Day Clinic| 2,936                 | 3,231                  |
| Virtual SC Clinic (Nurse & Pharmacist) | 99       | 102                    |

| In-patient review            |                       |                        |
| Nurse review                 | 120                   | 242                    |
## Service

<table>
<thead>
<tr>
<th>Service</th>
<th>April 2017- March 2018</th>
<th>April 2018 –March 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse led Clinics Paediatric Gastro</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Face to face</td>
<td>467</td>
<td>490</td>
</tr>
<tr>
<td>Telephone</td>
<td>40</td>
<td>39</td>
</tr>
<tr>
<td>Advice line</td>
<td>40</td>
<td>51</td>
</tr>
<tr>
<td>Email Service</td>
<td>959</td>
<td>1204</td>
</tr>
<tr>
<td>IMS Service</td>
<td>45</td>
<td>51</td>
</tr>
<tr>
<td>Biologics (IV &amp;SC)</td>
<td>18</td>
<td>19</td>
</tr>
<tr>
<td>Ferinject (IV)</td>
<td>0</td>
<td>17</td>
</tr>
</tbody>
</table>

## Academia

<table>
<thead>
<tr>
<th>Academia</th>
<th>April 2017- March 2018</th>
<th>April 2017- March 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presentations</td>
<td>47</td>
<td>38</td>
</tr>
<tr>
<td>Posters</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Publications</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Master/Degree Module</td>
<td>?</td>
<td>9</td>
</tr>
<tr>
<td>Visitors</td>
<td>10</td>
<td>6</td>
</tr>
</tbody>
</table>
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 call only 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 how to manage their symptoms, or where necessary, provide the patient with an urgent clinic review with their consultant or in the rapid access clinic.

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.ibdnurse@nhs.net aims to provide patients with e-mail access for basic queries, which can be dealt with via e-mail. This work is not tariffed. This has been highlighted to management.

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>Year</th>
<th>Total calls received (Audit figures)</th>
<th>Advice given (Logged on ICS)</th>
<th>Clinic appointment made</th>
<th>Admitted to hospital (Advised A&amp;E)</th>
<th>Total e-mails received</th>
</tr>
</thead>
<tbody>
<tr>
<td>2017-2018</td>
<td>3,250</td>
<td>2301</td>
<td>552 (via Advice line)</td>
<td>16</td>
<td>5,484</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>176 (via email)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2018-2019</td>
<td>4,355</td>
<td>2215</td>
<td>1,041</td>
<td>2</td>
<td>6,372</td>
</tr>
</tbody>
</table>

Overall the number of calls to the advice line has increased by 1,105 in the last 12 months. However this has not been reflected in the number of chargeable calls logged onto the ICS. What has been noted is that the number of clinic appointments made has increased by 313 requests. The number of patients admitted is low and it is recognised that not all patients that are admitted come through the advice line.

The number of emails has again increased in the last 12 months. To help manage this activity the IBD CNS timetables has now dedicated time slots to answer email queries. It is important to recognise that these sessions are not generating income. The email service was audited for one month to establish how it is being utilised by patients and staff however due increase clinical work this was not completed. It has been highlighted to management and we are currently in talks about getting this work tariffed.
2. Nurse-Led Clinics and Telephone Review Clinics

The IBD Nursing team currently provides a total of 13 clinics per week across the trust. This includes 6 face to face clinics (1 MDT clinic) and 7 telephone clinics covering, biologics, immunosuppressants, and support/education. The IBD Nursing team reviewed an additional 395 patients in telephone clinics in 2017/2018.

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).

Patients 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 (x 2 Adult clinics per week) 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 (x2 Adult sessions per week) 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 clinic is a multidisciplinary clinic supported by the IBD Nursing team. Currently the nursing team attend two clinics SIBDIO4A (Face to Face) and SIBDBIO4NT (Telephone).

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>2017-2018</th>
<th>2018 –2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Led Clinic SMH (Monday am)</td>
<td>NPGASTRO1Y</td>
<td>Open Sept ‘17 11</td>
<td>96</td>
</tr>
<tr>
<td>Nurse Led Clinic CMH (Monday pm)</td>
<td>CSHAAM1PN/COBRMS1PN</td>
<td>Re-open May ‘17 88</td>
<td>Closed September 2018 74</td>
</tr>
<tr>
<td>Nurse Led Clinic SMH (Tuesday pm)</td>
<td>NPGASTRO2Y</td>
<td>Suspended Jun ‘16 11</td>
<td>Remains closed 0</td>
</tr>
<tr>
<td>Nurse led Clinic EALING (Wednesday pm)</td>
<td>EHTIBD3P</td>
<td>Open Jan ‘18 11</td>
<td>123</td>
</tr>
<tr>
<td>Nurse Led Clinic SMH (Thursday am)</td>
<td>NPGASTGRO4Y</td>
<td>Suspended Jun ‘17 33</td>
<td>Remains closed</td>
</tr>
<tr>
<td>Nurse Led Clinic SMH (Friday am)</td>
<td>NPGASTRO5Y</td>
<td>Re-open May’17 107</td>
<td>128</td>
</tr>
<tr>
<td>Telephone review clinic (Monday pm)</td>
<td>NPGOL1PF</td>
<td>80</td>
<td>227</td>
</tr>
<tr>
<td>Telephone review clinic (Monday pm)</td>
<td>NPGOL1P1T</td>
<td>0</td>
<td>Open Apr ’18 162</td>
</tr>
<tr>
<td>Telephone IMS Clinic (Wednesday am)</td>
<td>NPIMS15D (Nurse &amp; Pharmacist)</td>
<td>195</td>
<td>157</td>
</tr>
<tr>
<td>Paediatric Nurse Led Clinic (Monday pm)</td>
<td>NPPIBD1P</td>
<td>180</td>
<td>193</td>
</tr>
<tr>
<td>Paediatric telephone review clinic (Monday pm)</td>
<td>NPPIBD1PT</td>
<td>40</td>
<td>39</td>
</tr>
<tr>
<td>Paediatric Nurse led clinic (Thursday am)</td>
<td>NPPIBD4A</td>
<td>287</td>
<td>297</td>
</tr>
<tr>
<td>Virtual SC biologics telephone clinic (Monday pm &amp; Wednesday pm )</td>
<td>NPIBDIOT NPIBDPHAT</td>
<td>71 28</td>
<td>64 38</td>
</tr>
<tr>
<td>Biologics Clinic (MDT)</td>
<td>SIBDBIO4A SIBDBIO4NT</td>
<td>178 91</td>
<td>207 212</td>
</tr>
<tr>
<td>Total reviewed in N/L clinics (face to face)</td>
<td></td>
<td>902</td>
<td>1,123 (DNA: 127)</td>
</tr>
<tr>
<td>Total reviewed in Telephone clinics</td>
<td></td>
<td>477</td>
<td>899 (DNA: 90)</td>
</tr>
</tbody>
</table>
Referral to any of the nurse led clinics can be done by marking clearly on the outpatient 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.

4. Ealing Nursing Service

Guia Grande has been appointed as the IBD CNS at Ealing hospital currently working on site on a Wednesday. Since January 2018 a nurse led clinic has been set up (EHTIBD3P) for patient education and support and over the last year 123 patients was reviewed in this clinic. Immunosuppressant service is available with currently 73 patients (Increase from 40) patients on azathioprine and methotrexates are being monitored via TA monitoring. Ealing patients are currently having their infusions at St. Mark’s IBD Day Unit. This includes 37 patients on IV biologics (Infliximab and Vedolizumab) and 40 on subcutaneous treatment (Adalimumab, Golimumab& Ustekinumb) Ward education has been set up and given to nurses on 6North. Guia carries out adhoc ward reviews.

3. IBD Biologics Nursing Team

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. 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 295 admissions to the day unit in compared to 2017/2018.

The following table shows the approximate 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>
<th>April 2017- March 2018</th>
<th>April 2018- March 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of day care admissions</td>
<td>2, 615</td>
<td>2, 936</td>
<td>3,231</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, Ciclosporin , in situations where the GP is unable to do so. The service is run using the database system, Therapy Audit (TA) Monitor.
682 patients are currently being monitored using the system. This is an increase of 20 patients from 2017/2018. 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 and IBD Pharmacist. The IBD CNS/IBD Pharmacist 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 refer via ICE – IBD Immunomodulator monitoring service

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. The email advice line is much more popular with parents (1204 emails responded to) and telephone calls are now practically non-existent (51).

There are currently 51 paediatric patients maintained on Immunosuppressant therapy who attend the Paediatric out-patients department regularly for blood tests. This is due to Azathioprine being an Amber drug and having no paediatric license for use in children with IBD therefore local GP services are not generally able to undertake monitoring also many surgeries do not take Paediatric patient’s blood tests. These patients are therefore being followed up safely using the Therapy Audit database monitoring system as above which Kay can then action according to paediatric protocol.

Infliximab (Remsima) therapy is used to maintain 19 Paediatric patients through the Paediatric day care unit, supported by Kay. 4 patients have now switched to Humira and we are awaiting the switch to Amgevita to take place. 17 children (3yrs +) have received Ferinject infusions in the past 12 months, as per paediatric guidelines with no issues.

Ongoing developments

The adolescent service has developed over the last year to accommodate young adults to the age of 25 as per NICE Guidelines. It continues to be lead by Dr Hyer, Professor Hart and Kay. The service runs on the first Friday afternoon of the month and is split into 2 elements – Transition clinic and Young adult clinic.

Whilst the transition element is well established, there are plans to continue to develop the Young Adult clinic, to open it up to all young adults within St Mark’s Hospital in line with national guidance and standards to offer better support to the young adults who are diagnosed at this difficult time in
their transition from child to adult. Over the last year 13 adolescents were transitioned into the 5 transition clinics that were held, with 43 adolescents followed up in the young adult clinic. Approximately 140 patients are now being seen routinely in the young adult 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, 19 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. 24 patients are routinely seen in this clinic. The clinic helps to ensure that medication is optimized and that the effect of IBD during this critical phase of development has minimal effect on growth and puberty.

7. In- Patients services

At NPSM, the IBD CNS can be contacted via Bleep 471 to see in-patients and time is allocated for 3 sessions per week. Ad-hoc out-patients visits will depend on availability on the day but we endeavour to accommodate this around our scheduled clinical duties. At CMH an IBD CNS is not available. At Ealing an IBD CNS is available on Wednesday mornings. 242 (increase from 120) in patients were reviewed by the IBD Nursing team in the past 12 months.

8. 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

The team has a named nurse that attends the research meeting regularly. The named nurse feedbacks to the whole teams on current research projects this helps with potential patients.

Kay Crook has been successfully involved in the “Being me with IBD: young people and social interactions” recruiting 21/121 patients into the study. The aim of the study will increase understanding of how IBD affects young people’s friendships during the key transition periods of adolescence and young adulthood. This will provide insight to how they think other people, including health professionals, could better support their wellbeing.
8. Team Meetings

**IBD Multidisciplinary Team Meeting (MDM)**  
Wednesday 8-9am  
Location: Varies

Over the last 12 months **305 patients (474)** have been discussed at the IBD MDM. The chairing of the meeting has included 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 from 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 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 has 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.

**IBD Patient Panel Meeting (PPM)**  
Trimonthly 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 IBD CNS’s currently Kay Crook and Guia Grande 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 IBD Open Day which occurs every two years.

10. Open Day Events

**IBD Open Day**

Plans are in place for the next IBD Open Day on Saturday 18th May 2019.
Trust Open Day

Over the last two years the IBD Nursing team have taken part in the LNWH Trust Open Day. This has been a great opportunity for the team to create awareness of IBD and the service available at LNWH.

World IBD Day 2018

Along with the support of the IBD Patient Panel the team went purple for World IBD Day on the 19th of May 2018. The team had two stalls one at St. Mark’s and one at Northwick Park entrances. The trust communication team completed a small write up in the inbrief and twitter on the “tip tops for patients for managing IBD.”
Nurses Day 2018

On 12th of May 2018 the IBD Nurses celebrated “Nurses Day”

Service Development Away Day

On the 20th April 2018 both the IBD Nursing Team and Pharmacy team had an away afternoon to take time out to review the current service and developments for the year ahead. This meeting was attended by the Divisional Head of Nursing Helen Hardy.
11. IBD Intranet Page

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 able to find information on all aspects of the IBD Nursing service, along with relevant protocols, guidelines and patient information sheets. Lead IBD CNS Tracey has been working with the trust communications to develop the IBD Intranet page. It was giving a new look and is continuously kept up to date.

To access the IBD intranet page:

*Click on the main InwhIntranet icon >Clinical Departments and Corporate> Inflammatory Bowel Disease*

10. IBD Dietitian Service

*Gabriela Poufou*, IBD Dietitian remains extremely 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
### CLINIC

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietitian Clinic review</td>
<td>244</td>
<td>690</td>
<td>299</td>
</tr>
<tr>
<td>Dietitian Telephone consultations</td>
<td>154</td>
<td>186</td>
<td>253</td>
</tr>
<tr>
<td>Ad-hoc opd reviews (bleeped by staff)</td>
<td>497</td>
<td>n/a</td>
<td>914</td>
</tr>
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<td>Total number of all outpatients seen</td>
<td>895</td>
<td>690</td>
<td>1213</td>
</tr>
<tr>
<td>Total number of in-patient reviews</td>
<td>585</td>
<td>591</td>
<td>728</td>
</tr>
<tr>
<td>Total number of contacts</td>
<td></td>
<td></td>
<td>2032</td>
</tr>
</tbody>
</table>

In-patients: Please note that we weren’t able to identify the ad-hoc (bleeped by staff) reviews due to system error.

### 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. Anneliese works together with the IBD nurses in the immunosuppressant clinic. She has recently become an Independent Prescriber and will be using this new qualification in the immunosuppressant clinics. The IBD pharmacists’ team currently leads on the Adalimumab prescription screening and homecare supply two afternoons a week, alongside support from the IBD nurses. 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 works as part of the Biologics MDT clinic, which takes place every Thursday morning. The homecare role is to coordinate across all 3 sites within the trust ensuring we are Hackett compliant and looking at how we can reduce waste and standardise how we work. As well as being part of the IBD MDT,
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 writing clinical protocols.

12. Positions of responsibility

**Tracey Tyrrell** is currently the special project coordinator for the Royal College of Nursing (RCN) IBD Network group which aims to have nurse representation at national and internal committees. Tracey continues to be a peer reviewer for Gastrointestinal Nursing (GIN).

**Kay Crook** is currently the vice chair of the IBD RCN/BSPGHAN (British Society of Paediatric Gastroenterology, Hepatology and Nutrition) Nurses Group. Kay is 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 IBD UK committee which is continuing to improve the quality in IBD services. She also is a member of the IBD PMS (Patient Management System) User group working to improve the functionality of the IBD registry.

13. Training & Development

**Tracey Tyrrell** (Feb 2018 – January 2019) completed two master modules including physical assessment of the adult patient and non-medical prescribing at Buckingham New University.

**Jitka Adio & Monica Chan** (August – October 2018) completed GI Anatomy and Physiology and GI Abdominal Care (Degree) modules

**Nancy Aranas & Comfort Okeph** (January – March 2019) completed the IBD Degree Module at Salford University

Full list of completed courses at Masters and Degree level listed in Appendix 2

All team members have a shared opportunity to attend pharma sponsored study days and national & international congress including ECCO & BSG.

14. Supervision

All team members have access to clinical supervision with Dr. Yoram Inspector on a weekly basis. All team members are also encouraged to seek individual supervision with a senior healthcare professional within or outside the trust.

15. Planned Education

**Presentations & Publications**

In total the IBD Nursing team has given 38 individual presentations. The presentations have been given mainly to an in-house audience with 5 local and 1 international presentations delivered. 2 publications and 2 collaborative posters were completed by the team. For the full list of the team’s presentations and publications undertaken within the past 12 months, see appendix 1 & 3.
Monthly Journal club

Monthly Journal club continues. Each nurse has an opportunity to present findings on a recent nursing/medical article.

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 Nursing Team Study Days

On the 7th September 2018 the IBD Nursing team held their first IBD Nursing Service Study Day. The day included talks from all IBD CNS’s on different aspects on the IBD Nursing Service. 19 delegates attend with overall excellent feedback. The team plan to continue this as annual study day – IBD Masterclass. This will be held with the support of Jennie Burch (Head of Gastrointestinal Nurse Education)
Stoma Care Course (MSc/BSc)

Previously, known as the Moor Park Stoma Care Course now takes place at the Royal Plaza in Acton Lane. The IBD Nursing Team present on this course once every 4 months. This presentation is shared amongst the IBD CNS team.

GI Nursing Study Day

The IBD Nursing Team presented at this annual study day.

16. Visitors

The IBD CNS team has received 6 visitors to the unit to observe and learn from the IBD Nursing service. This is a reduction from 10 visitors in 2017-2018. Visitors travelled from Belgium, Israel, Switzerland, Leicester and Nottingham.

17. Current developments

- IBD Advanced Nurse Practitioner

As part of the CLAHRC project led by Dr. Arebi a business proposal was placed and accepted by Brent CCG for a community IBD Nurse post. Unfortunately this funding was refused in November 2018. However, the trust has agreed to support the role. Therefore the IBD Advanced Nurse Practitioner
role was developed. Tracey Tyrrell was successful candidate. Tracey will be working at Central Middlesex Hospital creating additional Nurse Led Face to face and virtual telephone clinics. The role will also look at bridging the links with primary care by offering GP education in Brent, Harrow and Ealing. Tracey will also be completing a research project which will coincide with her Masters Dissertation module.

- **Outsourcing of biologics**

The team have been working with management and Mckesson in outsourcing intravenous biologics into a “community setting”. The mobile unit will help with current capacity issues in the IBD Day Unit. Pictured below is the mobile unit. The aim is to go live on 1st May 2019.

- **Paediatric Business case**

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 Managers to improve the services for Paediatric patients with IBD. Kay also arranged a peer review of the paediatric IBD service in 2015 which validates the proposed business case. Current plans are underway to move the paediatric IBD service from Paediatrics into the St Mark’s directorate.

- **PKB**

IBD Advanced Nurse Practitioner will be working with the trust IT team and PKB to see if this can be re-launched in IBD.
19. Patient Feedback

**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 have received 5 star reviews from patients, following seeing them in nurse led clinics. Over the last 12 months 3 nurses have received in total 13 positive comments from patients/service users. To view all feedback please go to: https://www.iwantgreatcare.org/nurses

**Complaints**

In the last 12 months we have completed 11 DATIX forms (reduced from 26) which have been investigated at a local and divisional level. There have been 3 formal complaints via PALS from patients. 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, biologics clinic and medication error. All of these complaints have been addressed with the patients and team and are working with management to address the on-going capacity issues in the IBD day unit.

**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. 2,415 patients have provided feedback over the last 12 months, with the majority of patients stating that they are extremely likely or likely to recommend the unit. See appendix 3 for breakdown of FFT data from April 2018 – March 2019.
Appendix 1

presentations & chair 2018-2019

tracey tyrrell presentations

26 april 2018
GI nursing course
post grad room, level 6, st. mark’s hospital
presentation entitled: anatomy & physiology of inflammatory bowel disease (IBD)

22 june 2018
Grand rounds, the clore

14 August 2018
Meeting with Brent CCG
Physiology room, level 5, St. Mark’s Hospital
Presentation entitled: Community Inflammatory Bowel Disease (IBD) Service

22 August 2018
Team teaching
Seminar room 3, medical education centre, NPH
Presentation entitled: Methotrexate in IBD

7 September 2018
St. Mark’s Nurse Education - “What is an Inflammatory Bowel Disease Nursing Service?” A study day for IBD Nurses by IBD Nurses
Seminar room 1, medical education centre, NPH
Presentation entitled: History of IBD nursing service at St. Mark’s Hospital

7 September 2018
St. Mark’s Nurse Education - “What is an Inflammatory Bowel Disease Nursing Service?” A study day for IBD Nurses by IBD Nurses
Seminar room 1, medical education centre, NPH
Presentation entitled: Service Development

4 October 2018
Ward teaching
Post Grad Room, Level 6, St. Mark’s Hospital
Presentation entitled: Management of Inflammatory Bowel Disease (IBD)

8 October 2018
Advanced Approach to Stoma Care Management Programme
Park Plaza, Park Royal
Presentation entitled: Inflammatory Bowel Disease (IBD)
29 November 2018
Frontiers
Post Grad Room, Level 6, St. Mark’s Hospital
Presentation entitled: Innovations in Inflammatory Bowel Disease (IBD)

22 December 2018
Master course –Non-medical prescribing
Buckinghamshire New University, Uxbridge
Presentation entitled: The use of Azathioprine and Mercaptopurine in Inflammatory Bowel Disease (IBD)

22 March 2019
GI Nursing Course
Medical Education Centre, Level 6, St. Mark’s Hospital
Presentation entitled: Looking after IBD patients on the ward

Tracey Tyrrell Meeting Chair

7 September 2018
St. Mark’s Nurse Education – “What is an Inflammatory Bowel Disease Nursing Service?” A study day for IBD Nurses by IBD Nurses

18 November 2018
Crohn’s and Colitis UK –Patient Education Programme Event
The Wesley Euston

15 March 2019
St. Mark’s Nurse Education - Understanding Inflammatory Bowel Disease
St. Mark’s Hospital

Kay Crook Presentations

18 May 2018
Patient Education Programme, The Wolsely Hotel, Euston
Presentation entitled: The Role of Transition in Paediatric IBD

22 June 2018
Grand Round, Clore, level 6, Medical Education Centre

7 September 2018
IBD Nursing Study Day, Seminar room 1, Medical Education centre
Presentation entitled: ‘Emails – Controlling the Beast’

7 September 2018
IBD Nursing Study Day, Seminar room 1, Medical Education centre
Presentation entitled: Transition – Teens move forward

15 March 2019
IBD Nursing Study Day – Understanding IBD – Seminar room 1, Medical Education centre
Presentation entitled: Paediatric Transition

Monica Chan Presentations

Date: 16 May 2018
Stoma Course by Dansac
Presentation entitled: Overview of IBD

22 June 2018
Grand Rounds, The Clore
Presentation entitled: What a difference a year makes (Team presentation)

7 September 2018
IBD Nursing Service Study Day
Presentation entitled: Advice Line

7 September 2018
IBD Nursing Service Study Day
Presentation entitled: Transition Clinic (with Kay Crook)

2 October 2018
RSO Induction
Presentation entitled: IBD Nursing Service

Jitka Adio Presentations

22 June 2018
Grandround, Clore, level 6, Medical Education Centre
Presentation entitled: Immunosuppressant Monitoring. What a difference a year makes (Team presentation)

7 September 2018
IBD Nursing Service Study Day, Level 6, Medical Education Centre
Presentation entitled: Post-operative CD “Where is recurrence”

29 November 2018
IBD Nurse Meeting, Florence, Italy
Presentation entitled: IBD Nurse - the English experience

15 March 2019
Understanding IBD, level 6, Medical education centre
Presentation entitled: Surgical treatment in IBD
Pineshwari Naeck-Boolauky Presentations

3 April 2018
Gastrointestinal HCA Study Day
Presentation entitled: IBD

7 September 2018
IBD Nursing Service Study Day
Presentation entitled: Nurse led clinic – The values of Nurses

22 October 2018
Gastrointestinal HCA Study Day
Presentation entitled: IBD

15 March 2019
Understanding IBD, level 6, Medical education centre
Presentation entitled: Understanding IBD

30 March 2019
Takeda Preceptorship
Presentation entitled: Role of IBD Nurse @ St. Mark’s

Guia Grande Presentations

2nd May 2018
Biologics prescribing, St Mark’s Academic Institute
Presentation entitled: Delivering and Monitoring Biologics

6 June 2018
Ealing Hospital Ward Teaching, Ward 6 North, Ealing Hospital
Presentation entitled: Nursing considerations in caring for in-patients with Inflammatory Bowel Disease

26 October 2018
IBD Nursing Team Journal Club, Physiology room, Level 5, STM
Presentation entitled: Vaccinations in IBD

6 December 2018
St. Mark’s Nurse Education, Post Grad room, level 5
Presentation entitled: Medical management of IBD

15 March 2019
Understanding Inflammatory Bowel Disease Study Day, St Mark’s Academic Institute
Presentation entitled: Medical Management in IBD
Sheryl Azana Presentations

Date: 07 September 2018
IBD Nurses Study Day
Presentation entitled: Practical nursing with IV biologics therapies “it’s not just an infusion”

Date: 15 March 2019
Understanding IBD Study Day
Presentation entitled: What is IBD?

Date: 03 April 2019
Prescribing Biologics in IBD
Presentation entitled: Delivering and Monitoring Biologics

Anneliese D’Souza Presentations

7 September 2018
St Mark’s Nurse Education- What is an Inflammatory Bowel Disease Nursing Service? “A study day for IBD Nurses by IBD Nurses”
Presentation entitled: Immunosuppressant clinic “It’s more than a blood result”

15 March 2019
Understanding IBD study day
Presentation entitled: Medical treatment of IBD
Appendix 2 Academic courses

Tracey Tyrrell Completed courses

May 2018
Module: Physical Assessment of Adult (Msc)
New Buckinghamshire University

March 2019
Module: Non-Medical Prescriber (Msc)
New Buckinghamshire University

Monica Chan Completed courses

Aug 2018
Module: GI Anatomy and Physiology (Degree)
St. Marks and Birmingham University

Oct 2018
Module: GI Abdominal Care (Degree)
St. Marks and Birmingham University

Jitka Adio completed courses

Aug 2018
Module: GI Anatomy and Physiology (Degree)
St. Mark’s and Birmingham University

Oct 2018
Module: GI Abdominal Care (Degree) A/W accreditation of Advanced Diploma
St. Marks and Birmingham University

Guia Grande Courses completed

25th June 2018 – 28th January 2019
Leadership and Management Course
London North West University Healthcare NHS Trust

Comfort Okeph Courses Completed

February 2019
Module: IBD Module (Degree)
Salford University
Nancy Aranas Courses Completed
February 2019
Module: IBD Module (Degree)
Salford University

Anneliese D’Souza Courses completed
17 September 2018
Module: Independent prescribing course
Added onto the pharmacy GPHC registry 17/09/2018

Appendix 3
Publications list 2018 - 2019

Publications


Posters:

Appendix 4: Patient feedback