Diagnostic and Advisory Service for Neuromyelitis Optica (NMO)
Oxford University Hospitals NHS Foundation Trust

Annual Report September 2018

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Positive feedback from patients seen in 2017

• Everyone was very compassionate, understanding & extremely helpful. Helped me to learn a lot about my condition.

• Very friendly team, explained everything very well and at a level that I could understand. The OT team were also very friendly and compassionate.

• After 30 years living with this condition, I finally feel that I am getting really useful information and that people (doctors) are trying to help to properly diagnose what I have.

• Very fortunate to have access to such a fantastic centre of clinical excellence - thanks to everyone involved!
1. Service Overview

The Diagnostic and Advisory Service for NMO at the Oxford Radcliffe Hospital (herein referred to as the “NMO Service”) with the Walton Centre in Liverpool, combines a specialist laboratory with a dedicated clinical service to offer a multidisciplinary service for patients across England and Scotland [funded by highly specialised services] and the rest of the UK [directly charged].

The NMO team comprises of:

**Clinical team**

- **Dr Jackie Palace**  Consultant Neurologist (Service Lead)
- **Dr M Isabel Leite**  Honorary Consultant Neurologist, Senior Clinical Research Fellow
- **Dr Saleel Chandratre**  Consultant Paediatric Neurologist
- **Miss Srilakshmi Sharma**  Consultant Medical Ophthalmologist
- **Dr Silvia Messina**  NMO Clinical Fellow
- **Rosie Everett**  NMO Specialist Nurse
- **Sandra Reeve**  NMO Specialist Nurse
- **Alix Platt**  NMO Service Coordinator
- **James Moore**  NMO Admin Assistant
- **Kay Day**  NMO Occupational Therapist
- **Nina Eagle**  NMO Physiotherapist
- **Julia Goodgame**  Clinical Service Manager

**Laboratory Team**

- **Dr Patrick Waters**  Senior Postdoctoral Scientist/Co-director of the Laboratory
- **Dr Sarosh Irani**  Associate Professor/Co-director of the Laboratory
- **Dr Mark Woodhall**  Postdoctoral Scientist

The service performs around 613 patient activities per year, in a combination of outpatient, inpatient and day case episodes, depending on clinical need. Patients are offered a full multidisciplinary experience when they come to clinic, with assessments from neurologists, ophthalmologists, specialist nurse and a team of therapists. For patients who are unable to attend (possibly due to disability) remote advice from the relevant team specialist is offered to local neurologists and GPs, as well as an advice email and phone line for patients to call with any queries.

To ensure ease of access, the service aims to ensure all appointments and investigations are completed within one visit. All patients are discussed within a multi-disciplinary meeting attended not only by clinicians, but also by laboratory and administrative staff to ensure a holistic and thorough assessment as well as a good communication to patients about appointments.

The service has the ability to admit patients who require urgent review to a dedicated neurosciences unit, with access to specialist therapies such as plasma exchange. A “relapse” (or exacerbation) of NMO can be a medical emergency, so the team liaise closely with bed managers to ensure rapid admission and treatment.

Most patients are on long term oral medication, but the few who need intravenous medication can be admitted as a day case to the neuroscience investigation unit, where trained nurses can administer medication such as Rituximab. Education links have been developed between the NMO team and the ward staff to ensure continuity of care.

An important part of developing a truly national service is closely linking with our sister NMO team in Liverpool. This is done through a combination of face to face meetings, teleconferences and jointly hosting and attending conferences relevant to the field of NMO. At these meetings, collaboration can be fostered in a supported environment to ensure continual developments in standardised care and evidence based practice for NMO patients.

Our service has an international reputation which means we frequently have doctors from abroad working and learning with us, which enhances the service we offer to patients and helps raise awareness and
2. Service Objectives, Outcomes and Performance Measures

The purpose and goals of the service are set out in the service specification.

- To make a definitive clinical and laboratory based diagnosis of patients with suspected Neuromyelitis Optica Spectrum Disorder (NMOSD).
- To optimise NMO assay reporting time, this in turn speeds up the diagnostic process.
- To ensure that NMO patients are quickly started on the correct long term immunotherapy to reduce the likelihood of having further relapses. Preventing a relapse is associated with a much better outcome than treating a relapse after it has occurred.
- To involve patients in their own care and allow them to feedback on their experiences.
- Develop patient / healthcare professional information about the condition.

These are measured using the following outcomes:

**Activity levels**
- Number of new and follow up outpatient episodes, day cases and inpatient stays
- Number of AQP4 antibody tests performed in the laboratory

**Performance indicators**
- Remote Support
- Time to report NMO assay
- Certainty of diagnosis
- Annual relapse rates
- Mortality rate
- Patient feedback questionnaires

**Miscellaneous**
- Geographical access to the service
- Time from the service receiving the referral to being offered a clinical consultation
- Outreach clinics
- Service discharge
- CQUIN

**Activity Levels**
The service activity is monitored and recorded on a monthly basis so that the centre can meet the demands of a shifting patient demographic and case load.

**Clinical Services Activity:**
Basic activities are demonstrated in Appendix 1.

From 1st April 2017 to 31st March 2018 the service performed 150 new patient assessments from eligible areas. A large proportion of the patients seen in the outpatient setting are followed up at the centre on an annual basis, whilst visiting their local neurologist in between.

For financial year 01/04/2017 to 31/03/2018, the service has increased the number of outpatient clinic slots from 507 last year to 581 this year, to cope with increased demand. We continue to have adult out-patient clinics every week, we’ve increased paediatric clinics to six times per year and have increased the number and locations of remote clinics.

The clinical service activity for 2017-18 was 61% over annual plan for new patients seen, 44% over annual plan for follow up patients seen, 14% under annual plan for day case admissions and inpatient events were 8% over annual plan.

The annual plan for inpatient spells was reduced from 40 to 12 in 2016/17 because there had been fewer admissions than in previous years. 13 inpatient spells this year meant we were much closer to target
Remote support

1. Telephone support

Table 1a. Number of calls to nurse advice line 2017-18, from patients and professionals

<table>
<thead>
<tr>
<th>Remote advice</th>
<th>Calls 2017 /18 01.04.17 - 31.03.18</th>
<th>Calls 2016 /17 01.04.16 - 31.03.17</th>
<th>Percentage change 2016/17 – 2017/18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient/carers</td>
<td>812</td>
<td>659</td>
<td>+23.2%</td>
</tr>
<tr>
<td>Professionals</td>
<td>175</td>
<td>112</td>
<td>+56.3%</td>
</tr>
<tr>
<td>Total</td>
<td>987</td>
<td>771</td>
<td>+28.0%</td>
</tr>
</tbody>
</table>

The total number of calls with patients and professionals have continued to increase this year. The numbers of calls has been steadily increasing each year.

Table 1b. Call complexity grading to nurse advice line 2017-18

<table>
<thead>
<tr>
<th></th>
<th>Calls 2017/18 01.04.17 - 31.03.18</th>
<th>Calls 2016/17 01.04.16 – 31.03.2017</th>
<th>Percentage change 2016/17 – 2017/18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td>14</td>
<td>8</td>
<td>+75.0%</td>
</tr>
<tr>
<td>Level 2</td>
<td>262</td>
<td>155</td>
<td>+69.0%</td>
</tr>
<tr>
<td>Level 3</td>
<td>511</td>
<td>433</td>
<td>+18.0%</td>
</tr>
<tr>
<td>Level 4</td>
<td>25</td>
<td>63</td>
<td>- 60.3%</td>
</tr>
<tr>
<td>Total</td>
<td>812</td>
<td>659</td>
<td>+23.2%</td>
</tr>
</tbody>
</table>

Call grading:
Level 1 = simple admin
Level 2 = simple patient contact/discussion
Level 3 = more complex discussion, e.g. medication or investigations, follow-up required
Level 4 = relapse management, urgent response required, complex care/planning.

There was a small increase in Level 1 calls from 2016/17 to 2017/18 but the admin team were not recording their calls during this time period. Admin calls are now being recorded and we expect these calls to increase next year.

Level 2 calls increased significantly in 2017/18 and level 3 calls, which form the majority of nurse phone calls were slightly increased.

Level 4 calls reduced significantly; this may indicate patients are having less relapses and less complex issues, and their needs and questions may be addressed in clinics and in our improved and expanding patient information materials.

Being able to contact the NMO nurses is greatly valued by our patients, who receive prompt
2. **Email support 01.04.17 - 31.03.18**

**Table 2: Email advice from the NMO team to patients and professionals 2017-18**

<table>
<thead>
<tr>
<th></th>
<th>Emails 2017/18 01.04.17 - 31.03.18</th>
<th>Emails 2016/17 01.04.16 - 31.03.17</th>
<th>Percentage change 2016/17-2017/18</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Existing Patients</strong></td>
<td>367</td>
<td>238</td>
<td>+54.2%</td>
</tr>
<tr>
<td><strong>Potential Patients</strong></td>
<td>69</td>
<td>62</td>
<td>+11.2%</td>
</tr>
<tr>
<td><strong>Professional Queries</strong></td>
<td>585</td>
<td>177</td>
<td>+230.5%</td>
</tr>
<tr>
<td><strong>Total Emails</strong></td>
<td>1021</td>
<td>477</td>
<td>+114%</td>
</tr>
</tbody>
</table>

There was 54.2% increase in emails from patients already known to the service from 2016/17 to 2017/18.

We received 11.2% more emails from patients not previously known to the service.

These included emails from European countries Norway, Slovakia & Germany and internationally from USA, Australia, Hong Kong, Israel, Pakistan, Malaysia, Nigeria & Columbia.

Email queries from professionals increased by 230.5%.

There was an overall increase in emails of 114%.

**Laboratory Activity:**

A more detailed breakdown of the laboratory activity is shown in Appendix 2.

For the period April 2017 to March 2018 the Autoimmune Neurology Laboratory team for the Diagnostic and Advisory Service for NMO (Oxford John Radcliffe Hospital) tested a total of 8025 samples (this is the total of all samples received from eligible and non-eligible countries worldwide) of which 7981 samples were received from the United Kingdom (7817 samples) and other NHS eligible overseas EEA member countries (164 samples) under the testing remit of the service. Of these 8025 samples, 6651 were new patient serum/CSF samples from which 91 (1.4%) were reported positive for AQP4 antibodies [see Appendix 3].

**Turnaround times**

We aim to report all samples within 5 days even though the number of samples tested has increased by 5.0% this year. During April 2017 to March 2018, 93.0% of all assays were reported within 5 days with the remaining (468/6651) being reported within 13 days [Appendix 3]. This year the current turnaround time is 97.3% of assays reported within 5 days [Appendix 3] and 92.9% reported within 2 days from April 2018 to August 2018.

**End-point titres to follow serum antibody levels**

As well as providing the routine AQP4 antibody test we also provide AQP4 titrations on request for individual patients. Dr. Woodhall has completed serial AQP4 titrations on over 500 patients who are either seen within the service or are receiving remote advice from the service. Refer to Appendix 4 for a summary of the AQP4 titrations completed over the last service year. Although titrations are labour intensive [now 3-6 assays reduced from 6-12 assays to obtain 1 patient end-point titre], the benefits of being able to follow a patient’s AQP4 titres over the course of their disease can be invaluable for assessing the effectiveness of treatment regimens for example. An important use of the AQP4 titres was highlighted in 2017 when a patient accidentally stopped taking their mediation. This resulted in an increase in their AQP4 titres that alerted the Oxford medical team to investigate.
Definite Diagnosis

Fig. 2a Diagnosis of new patients; numbers of patients and their diagnosis
MS = Multiple Sclerosis, TM = Transverse Myelitis, ON = Optic Neuritis, OSD = Opticospinal Demyelination
ADEM = Acute Disseminated Encephalomyelitis, MOG = Myelin Oligodendrocyte Glycoprotein
Other e.g. subacute combined degeneration, syphilis

Fig. 2b Diagnosis of follow-up patients; numbers of patients and their diagnosis
Of our follow-up NMO patients and of the recently seen mimics, only 4 patients (1.3%) remain with an

Relapse rate

Relapse rate before service started 2.83 relapses pre-service (ARR calculated in 2013 on a group of 160 patients
seen since the service was commissioned).
Annualised Relapse Rate 2016/7 0.1
Annualised Relapse Rate 2017/8 0.1
Relapse rates remain reduced after patients are seen in service.
Note: Patients are more likely to be kept under our care if their disease is active or they are under active
Relapses of all active patients and by antibody group

For 01/04/2017 - 31/03/2018

<p>| | |</p>
<table>
<thead>
<tr>
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</tr>
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<tbody>
<tr>
<td>Total Active Patients:</td>
<td>326</td>
</tr>
<tr>
<td>Total Relapses:</td>
<td>23</td>
</tr>
<tr>
<td>n pts who relapsed:</td>
<td>19</td>
</tr>
<tr>
<td>Overall % who relapsed:</td>
<td>6%</td>
</tr>
<tr>
<td>Mean Overall ARR:</td>
<td>0.1 (median 0.08)</td>
</tr>
<tr>
<td>n AQP4:</td>
<td>126</td>
</tr>
<tr>
<td>AQP4 Relapses:</td>
<td>14</td>
</tr>
<tr>
<td>n AQP4 pts who relapsed:</td>
<td>10</td>
</tr>
<tr>
<td>AQP4 % who relapsed:</td>
<td>8%</td>
</tr>
<tr>
<td>Mean AQP4 ARR:</td>
<td>0.1 (median 0.08)</td>
</tr>
<tr>
<td>n MOG:</td>
<td>81</td>
</tr>
<tr>
<td>MOG Relapses:</td>
<td>8</td>
</tr>
<tr>
<td>n MOG pts who relapsed:</td>
<td>8</td>
</tr>
<tr>
<td>MOG % who relapsed:</td>
<td>9.8%</td>
</tr>
<tr>
<td>Mean MOG ARR:</td>
<td>0.08 (median 0.08)</td>
</tr>
</tbody>
</table>

Table 3. Number of relapses 01.04.17 – 31.03.18

Additional info; time to diagnosis at Oxford

![Fig. 3. Time to diagnosis at Oxford](image)

There has been an increase in the number of patients over time but a steep decrease in time to diagnosis.
## Mortality rate

There were four deaths in year 01.04.2017 – 31.03.18

The table below shows the age, gender, cause of death and relevant clinical background for these patients.

<table>
<thead>
<tr>
<th>Age, sex</th>
<th>Cause of death</th>
<th>Relevant background</th>
</tr>
</thead>
<tbody>
<tr>
<td>63, F</td>
<td>Myocardial infarction</td>
<td><strong>AQP4 +ve NMOSD</strong>&lt;br&gt;- Onset of severe TM Feb 16; paraplegic.&lt;br&gt;- MMF &amp; Pred; no further attacks.&lt;br&gt;Ischemic heart disease (stent 2005)&lt;br&gt;Renal cancer (nephrectomy 2015),&lt;br&gt;Type II diabetes&lt;br&gt;Hypertension</td>
</tr>
<tr>
<td>71, F</td>
<td>Sepsis</td>
<td><strong>AQP4 +ve NMOSD</strong>&lt;br&gt;- Onset 1998; 4 attacks of TM 98-2000&lt;br&gt;- Wheelchair bound with suprapubic catheter&lt;br&gt;- Mitox, then AZA (stopped in 2005 due to side-effects and patient chose no further immune suppressant therapy&lt;br&gt;2012-3 viral myocarditis &amp; pulmonary embolism&lt;br&gt;2015 pyelonephritis &amp; renal calculi and osteoporosis</td>
</tr>
<tr>
<td>56, F</td>
<td>Myocardial infarction</td>
<td><strong>AQP4 +ve NMOSD</strong>&lt;br&gt;- Onset 2004; ON not treated with poor recovery&lt;br&gt;- AZA &amp; Pred&lt;br&gt;Hypothyroidism (anti-TPO Ab +ve)&lt;br&gt;Myasthenia gravis (AChR Ab +ve); pyridostigmine (1983) &amp; thymectomy (1984)&lt;br&gt;Depression &amp; anxiety, premature menopause, generalised joint pain.</td>
</tr>
<tr>
<td>61, M</td>
<td>Myocardial infarction with severe coronary artery disease</td>
<td><strong>AQP4 +ve NMOSD</strong>&lt;br&gt;- Onset severe TM Mar 16; paraplegic.&lt;br&gt;- MMF then Ritux &amp; pred.&lt;br&gt;Hypertension, hyperlipidaemia, glaucoma, steroid-related avascular necrosis.</td>
</tr>
</tbody>
</table>

**Table 4 : Clinical details of the patient deaths**

These patients were discussed at the CQUIN meeting and the combination of factors that contributed to the mortality of these patients was acknowledged.

Following this review the teams from both centres are working together to look at these factors, including cardiac risk factors on steroid treatment and infections on immunosuppression.
Patient feedback
The service should be geared towards the needs of the patients and should be sensitive to any suggestions or complaints that are made. Patients are asked to complete anonymous questionnaires focusing on their experiences of receiving an appointment through to being seen in clinic. An example of this questionnaire can be seen in Appendix 5.

The results from completed questionnaires for the last financial year April 2017 – March 2018 can be seen in Appendix 6.

Patients gave very positive feedback about the care they received; over 95% were completely satisfied with their interactions with the clinical team and the information they received prior to their appointment. Over 90% were completely satisfied with the explanations and information they were given about their condition. 92.9% would recommend this service to their family and friends (for the remaining 7.1% this question was unanswered) and most patients felt they were involved in decisions about their care. The lack of parking at the hospital received the most complaints.

Patient feedback from the outreach clinics can be seen in Appendix 7. Only 10 patients completed this questionnaire but the feedback is mostly positive. All the patients found it easier to get to the outreach hospital than coming to Oxford and most were satisfied with their consultation.

Patient Geographic’s
As a national service for NMO, Oxford aims to offer equal access to the diagnostic and management expertise at the centre to patients from across the South of England. However, many patients cite transport costs as a limiting factor in their decision to attend the Oxford clinic. In cases where the patients are physically unable to attend an outpatient clinic, a remote advice service is offered to their local clinician regarding diagnosis and management. The expansion of outreach clinics has also helped with this.

Please see Appendix 8 for a breakdown of Patient Geographic’s for patients seen by the NMO Service in clinics and those given remote advice from April 2017 to March 2018.

In addition to this we also deal with international enquiries. This year we have had emails or phone calls from Ireland, USA, Northern Ireland, Norway, Hong Kong, Israel, Nigeria, Malaysia, Australia & Slovakia.

Referral to consultation time
NMO can be a devastating disease if left undiagnosed and untreated. This can be compounded further by incorrect diagnosis. Therefore the service aims to assess and diagnose patients as rapidly as possible. This is more important in AQP4 antibody positive patients, particularly those not on a stable therapeutic dose of immunosuppressant medication.

To ensure that all relevant correspondence and imaging from the referring centre has been transferred to the NMO service, a timeframe of approximately 8 weeks from receiving referral to assessing the patient was agreed.

Since the 1st April 2017 to date all new patients that have been referred to the service have been offered appointments within 8-10 weeks of their referral being received by the service. Some of the patients however have chosen to be seen at a later date. More urgent appointments are also offered when patients are untreated and immunosuppression is indicated and the team also liaises with the referring clinician in the interim.
18 Joint Outreach Clinics/ year

Current:
- Joint clinic with Dr Cheryl Hemmingway and Dr Ming Lim at Great Ormond Street Hospital (GOSH) twice per year.
- Joint clinic with Mr Eoin O’Sullivan/ Dr Peter Brex/ Dr Victoria Williams at Kings College Hospital four times per year.
- Joint clinic with Dr Christopher Halfpenny at Southampton General Hospital twice per year.
- Joint clinic with Dr Camilla Blain/ Dr Arani Nitkunan/ Dr Ruth Dobson at St Georges Hospital twice per year.
- Joint clinic with Dr Leonora Fisniku/ Dr Sarah Cooper at the Princess Royal Hospital, Brighton twice per year.
- Joint clinic with Dr Roswell Martin at Gloucestershire Royal Hospital, Gloucester twice per year.
- Joint clinic with Professor Jeremy Hobart/ Dr Apostu at Derriford Hospital, Plymouth twice per year.
- Joint clinic with Dr Ruth Dobson at St Barts Hospital, London.

Service discharge
After NMO clinic assessment and review, those with other demyelinating conditions, such as MS, ADEM or idiopathic transverse myelitis are discharged for local neurology management.

CQUIN
Annual CQUIN meetings are held with our sister NMO team in Liverpool. At these meetings, collaboration can be fostered in a supported environment to ensure continual developments in standardised care and evidence based practice for NMO patients. A meeting was held this year on 29th June 2018 and the next one is scheduled for 28th June 2019. Minutes from the meeting held on the 29th June 2018 [see Appendix 9].

3. Financial Update
To be presented by the OUH Financial team lead by Carol Ann Gourlay, Neurosciences Finance Manager.

4. Service Developments current and future
a) Review of Clinical Outcome Measures
   Patient Questionnaires:
   - Quality of Life – Euroqol EQ-5D
   - Mood (HADS)
   - Pain – (BPI)
   - Fatigue – (MFIS & VAS)
   - Visual QoL (eyesight & vfq25)
   - Bladder/Bowel severity (new)

   Clinic assessments:
   - Tinetti
   - T25FW
   - Edmus
   - BMI
   - OCT
   - Cognitive assessment

The nurses and therapists at Oxford have started to review their clinical activity in order to identify the key therapy/nursing needs of NMO patients, ensure their knowledge and skills are up to date and best evidence based practice is used [see Appendix 10].
b) Ongoing projects in 2017-18

NMOSD and atypical or opportunistic infections. Lead investigator Dr Isabel Leite

MRI and OCT as biomarkers to determine the prognosis of diseases with an inflammatory background: differences between AQP4, MOG and MS. Lead investigator Silvia Messina and Romina Mariano.

Genetic and Functional Analysis of NMO and MS. To try to identify and study genetic factors important in the demyelinating diseases NMO and MS. Lead investigator Calliope Dendrou.

Seasonality of attacks in NMO (Giordani Passos).

Association of fatigue and pain (BPI), QoL, & mood (HADS). Lead investigator Ron Yeo and Rosie Everett.

c) Research projects planned for forthcoming year:

MOG & preceding headache; is this a feature of MOG disease that can help identify cases earlier? (MIL, RE, SR)

Hearing loss in NMO; a few cases of hearing loss in NMO have been noted, is this due to high expression of AQP4 in this area? Plan to investigate and write-up cases (MIL, RE, SR)

Steroid-induced avascular necrosis (SM, DW, SH, MIL)

Optic Neuritis in older adults as 1st presentation of AQP4 disease. Lead investigator Dr Isabel Leite

Co-morbidities and cardiac risk factors in patients with NMOSD (SM, DW, SH, MIL)

d) How our research helps people with NMO

Treating rare neurological conditions is always challenging as many questions are still unanswered. The NMO team is involved in many different aspects of research. One of our aims is to try to answer those questions we face in our everyday practice.

A great number of different clinical projects have been carried out thanks to the data collected from the NMO tissue bank. This includes investigating the cause and impact of on-going symptoms (e.g. fatigue and pain), the effectiveness of NMO treatment and the role of environmental and genetic factors in the disease process. We have also been exploring the use of OCT measures as markers of long-term visual outcome. These studies have enabled us to provide evidence-based recommendations on the treatment and management of NMO.

In recent years one of our research aims has been to identify the role of MRI techniques that contribute to our ability to distinguish between NMOSD and MS. After the identification of MOG disease as a condition different from NMOSD and MS, we have been interested in identifying MRI measures that can help to differentiate the three conditions. We believe that studying NMOSD and MOG-disease and contrasting them to MS is important to shed light into the pathogenesis of these diseases. This helps us to provide accurate diagnosis for patients with these conditions. In addition, publications in high impact journals and talks by the NMO team about our research and clinical practice help to educate healthcare professionals and increase awareness of NMO.
e) Regional Patient Events ‘NMO on Tour’

The NMO team at Oxford organised two regional patient events (similar to the annual patient day but on a much smaller scale), with the aims:
- To update patients/carers re: NMO treatment & research.
- Provide opportunity to meet other people with the condition and share experiences.

We held an event for patients and carers in the Southampton area on 4th October 2017 and in London on 26th January 2018, funded by the charity NMO-UK.

Events included:
- Presentation/talk about an aspect of NMO
  (the London event included a medication workshop and the Southampton presentation was a general update on NMO as no one from this area had attended the patient day in Birmingham).
- Buffet & social time

f) Patient Information

1. MOG booklet is written and in use in draft format. Diagrams are with medical illustrations to allow the NMO service to reproduce their diagrams.
2. Exercise booklet written by Nina Eagle; in review.
3. Fatigue booklet updated by Kay Day; with printers.
4. Newly Diagnosed; practical help and advice by Kay Day.
5. NMO condition booklet under review and being updated to reflect diagnostic criteria and NMOSD (Rosie Everett).

MOG & Fatigue booklets are still pending approval due to delays with the review process at Oxford (discussed at CQUIN meeting).

Please see Appendix 14 for the NMO new patient introduction booklet and Appendix 15 for the NMO Advice line pamphlet.

g) Web based information

NMO Website  www.nmouk.nhs.uk
Approximately 800-1000 hits per month.

Charity NMO-UK research foundation
Website:  www.nmo-uk.org

The NMO charity NMO-UK is a non-profit charitable organisation which aims to raise awareness of NMO, support people living with the condition, provide financial support and legal advice. This was set
h) NMO Drug Trials

Abide pain study
Assessing the safety and efficacy of a new therapy administered orally in patients with pain associated with neuromyelitis optica spectrum disorders (NMOSD). Patients with myelitis-related neuropathic pain were recruited at Oxford and Liverpool. Rationale: Current pain medications have not produced satisfactory relief and living with this pain can have dramatic negative effect on quality of life. The trial is now closed to recruitment and results are being analysed.

Chugai Trial
A multicentre, randomized, addition to baseline treatment, double-blind, placebo-controlled, phase 3 study to evaluate the efficacy and safety of SA237 in patients with Neuromyelitis optica (NMO) and NMO spectrum disorder (NMOSD). Dr Palace is the lead investigator in the UK and we had one patient take part. The trial is now closed to recruitment and results are being analysed.

Alexion Trial
A randomized, double-blind, placebo-controlled, multi-centre trial to evaluate the safety and efficacy of eculizumab in patients with relapsing NMO is also closed to recruitment.

i) Meetings/Conferences

European NMO meeting; 18th & 19th January 2018
Neurologists and researchers from across Europe who have an interest in NMO met for 2 days in London to discuss and plan research into NMO. Topics covered AQP4 NMO, antibody negative NMO, MOG antibody disease, imaging and genetics. The two days consisted of short presentations, discussions and workshops and a European Network meeting.

NMO Patient Information Day; 13th & 14th April 2018.
This year’s patient information day was held over two days in Birmingham. The first day was more informal with a patient experiences workshop followed by a social event in the evening for patients and carers who stayed overnight. The second day consisted of talks by members of the NMO teams and interactive workshops. There was lots of opportunity for participants to meet other people living with NMO as well as discussions with the Oxford and Liverpool teams. The venue was the same this year as the previous three years because the feedback about the venue has been consistently positive. The patient charity NMO-UK research foundation attended the event again and presented awards to fundraisers and members of staff (Rosie & Kerry) for their contributions.

Please see Appendix 16a for the event programme and Appendix 16b for the feedback from the patient information day.

j) NMO scientific/medical publications

One of the best ways to inform other healthcare providers about work going on within the field of NMO is to publish journal articles. These articles often form the basis of a presentation to other HCP and scientists at various meetings. For publications please see Appendix 17.

k) NMO Team Presentations
The NMO team participate in the education of people affected by NMO and health care professionals around the UK about the disease. This includes patient meetings, education sessions with therapists and nurses, medical students, visiting doctors, and consultant talks at other UK neurology units and at national educational courses and meetings.
For a list of talks by the Oxford NMO team in 2017/2018 see Appendix 18.
## 5. Appendices

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<tr>
<td>Appendix 5.</td>
<td>NMO Patient Survey Form.</td>
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