NHS
Nottingham
University Hospitals
NHS Trust

Via email

Tuesday 18 January 2022

Dear Councillor Power,

Thank you for your letter of the 8th December, which was passed on to me as Head of Service for Neurology at Nottingham University Hospitals. Please accept my apologies that my response to your letter has been delayed.

Our Neurology service serves not only the people of Nottingham and Nottinghamshire, but also those in Mansfield, Leicester, Derbyshire and Lincolnshire accepting primary care referrals from these areas.

Neurology is predominantly an outpatient specialty, and our neurologists provide long term care for patients with neurological conditions which are frequently chronic, incurable and in many cases very debilitating. Fortunately, an increasing number of these conditions are now treatable. The use of modern therapies, many of which have a profound effect upon the nervous system requires specialist knowledge and regular outpatient appointments to ensure their safe and effective delivery and monitoring. This can only be provided by Neurologists, often working in and supervising multi-disciplinary teams. At NUH, we have large cohorts of patients with conditions including Parkinson's disease, Multiple Sclerosis, Epilepsy, Myaesthenia Gravis and Motor Neurone Disease, as well as smaller numbers of patients with chronic nerve or muscular disorders which need regular monitoring. The demands that the care of patients with long term disorders places upon a Neurology department are formidable.

Our service had challenges even before the pandemic with patients frequently waiting more than 18 weeks to receive an outpatient appointment, which often meant a delay in diagnosis for some diseases, such as Parkinson or Motor Neurone Disease. With our current capacity we are able to see patients with Parkinson's disease at a minimum of 7 month intervals, and for epilepsy and multiple sclerosis the figure is closer to 12 months. This is not the service we want to be able to provide for our patients.

New referrals would historically come to the general Neurology clinic through a system called "Choose and Book", which effectively let GPs book patients directly into slots in general Neurology clinics. We are unable to predict the types of new outpatient referrals we might expect to receive, but our Neurology department receives over 150 such referrals a week. With our current complement of Neurology consultants, each of whom will deliver, on average, two general Neurology outpatient clinics per week, we are able to offer in the region of 60-70 appointments per week. As you can see the capacity doesn't quite meet the needs hence the historical (over 18 week) waiting times for a Neurology Outpatient appointment.

In 2019 the National Institute of Health and Care Excellence (NICE) produced some helpful guidance for primary care physicians about when they should, and when they should not, refer patients with "neurological symptoms" (NG127[1]). For example referrals for symptoms such as tremor, speech difficulties or focal muscle wasting would have a high chance of being correlated with an underlying neurological diagnosis, other symptoms, such as headache, fatigue and subjective sensory disturbance (tingling fingers, numb face etc.) have a very low chance of being associated with an underlying neurological disease. Similarly, whilst, historically, conditions like chronic headache, chronic neuralgic pain (conditions which are <u>not</u> caused by structural <u>disease</u> of the nervous system) and e.g. restless legs symptoms might have populated Neurology outpatient clinics, there are now very clear pathways for the treatment of such symptoms, and these can, and indeed should, be instituted in primary care in line with the NICE guidance.

Whilst it is certainly true that all patients are deserving of having their case evaluated, with a proper history and examination, there are some symptoms for which further investigation is not necessary, and others where there are very clear, pre-referral management steps that can and should be undertaken in primary care (simple blood tests, lifestyle measures, initial therapy where this is supported by NICE guidance, monitoring and reassurance).

To take again the example of chronic headaches (that is daily or near-daily headache), the commonest cause is due to the overuse of analgesics. Using the NHS rightcare guidance for headache/migraine[2] in primary care means that we save that 30 minute appointment with a Neurologist for a patient that needs our expertise.

The NHS rightcare guidance for headache/migraine[2] is just one example of a resource which empowers GPs to manage chronic symptoms in primary care, and the advice that we are feeding back to GPs invariably draws upon and makes reference to this and similar guidelines and treatment algorithms. The aim of these guidelines is not to obstruct the path to a Neurologist, but it is to recognise that when Neurologists see patients with such complaints they follow almost to the letter the guidance enshrined in such documents. Thus the "added value" of a Neurologist's input in many cases is negligible. To make our small department run efficiently and well, our goal has therefore been to maximise the "added value" that Neurologists can provide.

At NUH, we have adjusted how we process referrals to the department. Referrals are now triaged by a team of five Consultant Neurologists in rotation. Each referral is read in detail, and any previous correspondence and investigations related to the patient's case reviewed. The Consultant will then triage the referral to either a general Neurology clinic (video or face-to-face depending upon the nature of the presentation), a specialist clinic (for example, the movement disorders clinic in a patient suspected of having Parkinson's disease) or, if they feel that, there are simple management steps that can be undertaken first in primary care, or the referral is otherwise unsuitable for the Neurology outpatient clinic they will respond to the GP with a bespoke letter explaining the reasons, and outlining their recommendations. I would stress that we are not deviating from the guidance laid out by NICE in NG127, and the main difference is that we are now applying these guidelines correctly, when historically we may not have. We do not currently copy these letters to patients, but this is something that we can review in light of the issues that you raise.

We have not made any changes in our service lightly, but have made these changes recognising that we must focus our collective expertise where it is really needed. We have been in contact with senior colleagues in General Practice that have been very supportive of our approach. Dr. Matt Jelpke is a senior GP at the St. George's Medical Centre in West Bridgford, and editor of the clinical design authority of the Nottinghamshire CCGs, and we have been in close liaison with him to ensure we are providing a service geared to the needs of primary care. We continue to work with Primary Care further to develop our network of advice and guidance, and hope in the future to integrate teaching about the pre-hospital management of common "neurological" presentations.

I hope that this, and the data in the charts at the end of this letter, provides you with information about our Neurology service to address the concerns you have raised. To re-iterate, we are not doing less work, and we are not seeing fewer patients. We are, as a department re-aligning what we do to prioritise time for patients with a higher probability of an underlying neurological disease. These patients will be seen, diagnosed and treated far more promptly than they would have otherwise been. Similarly, making these changes has allowed us to continue to see for follow-up our large cohorts of patients with debilitating long term neurological conditions, many of whom are exceedingly vulnerable, on a regular basis.

I will raise your enquiry and concerns with my colleagues and share this response. I will raise the possibility of copying patients in to the advice and guidance letters sent to GPs when an appointment is not offered.

I and my team would be happy to look into any specific complaints that have been raised with you if those individuals consent to your doing so.

Yours sincerely,

Dr. Jonathan Evans MBBchir MA MRCP PhD
Consultant Neurologist and Head of Service for Neurology, NUH

References

[1]Suspected neurological conditions: recognition and referral
NICE guideline [NG127] Published: 01 May 2019 last updated: 04 July 2019
https://www.nice.org.uk/guidance/ng127. Last accessed 30/12/2021
[2]https://www.england.nhs.uk/rightcare/products/pathways/headache-and-migraine-toolkit/ Last accessed 21/12/2021.

Additional information:

Figure 1: Monthly referrals for Neurology OPA from 2017 onwards. Note the reduction in early 2020 coincident with the peak of the Covid-19 pandemic response, and subsequent increase.

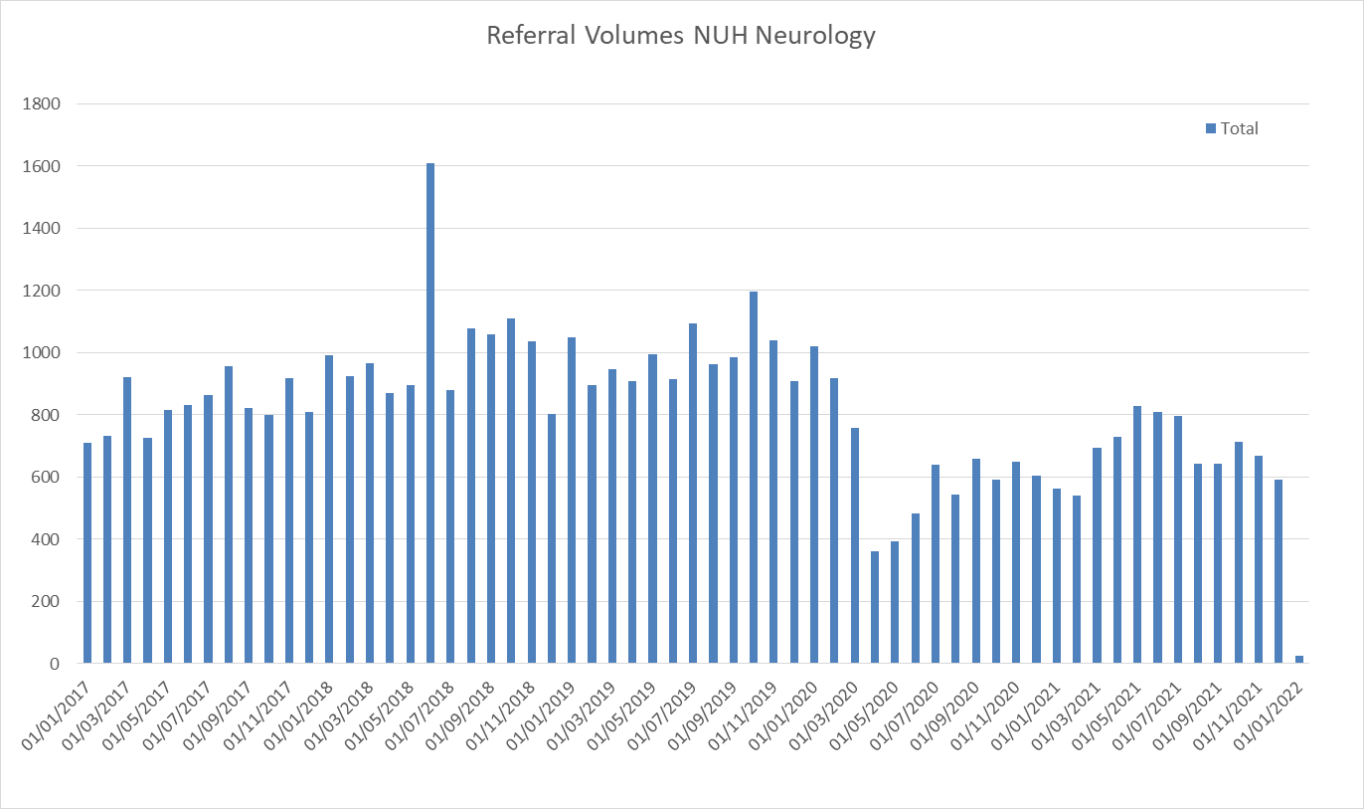

Figure 2 Monthly OPA capacity for NUH Neurology. Note reduction in capacity from April 2020 onwards due to social distancing requirements in clinic spaces, and also reduction in Consultant staffing levels.

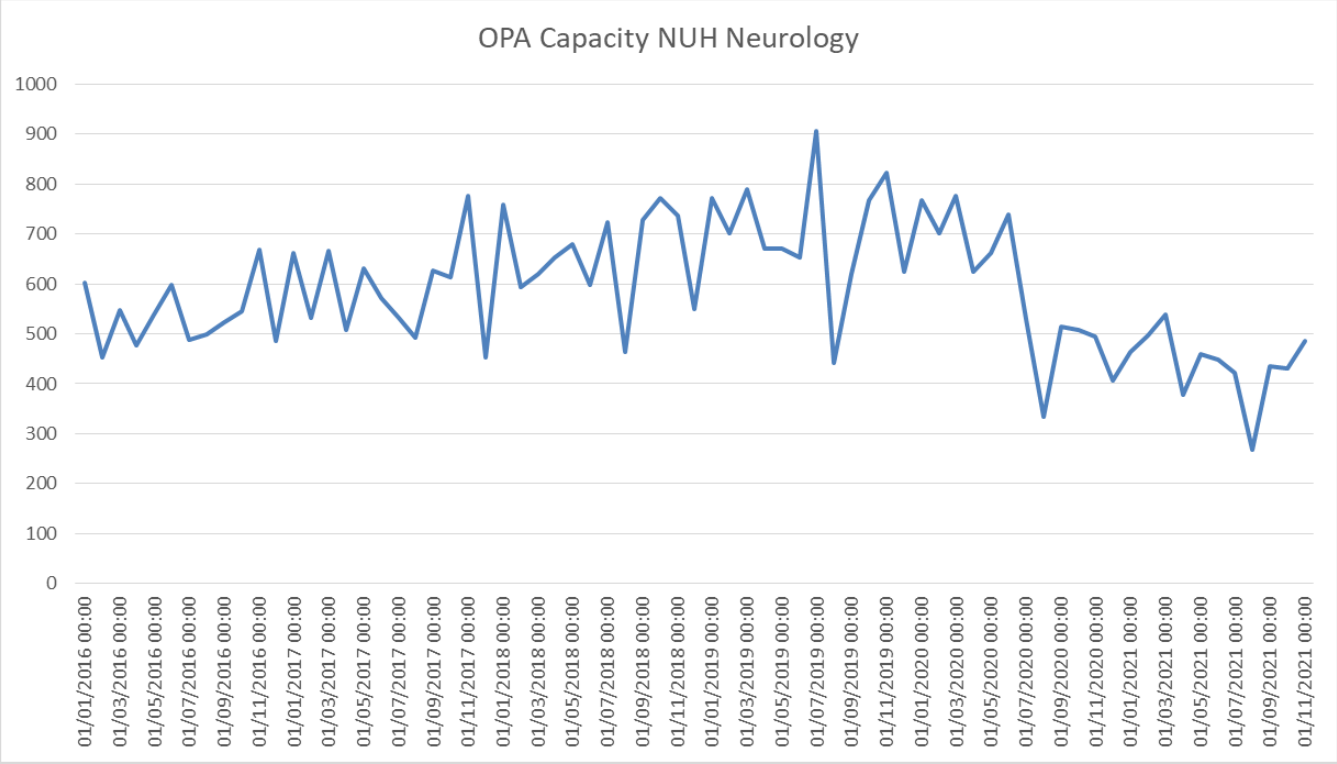

Figure 3: Wait times for Neurology OPA. Regrettably, the initial improvement due to enhanced advice/guidance and improved vetting has been offset in recent months by the loss of Consultants from the workforce. We anticipate that this will be remedied in a further round of recruitment, and our target is to have waits of no longer than 10 weeks for a Neurology OPC.

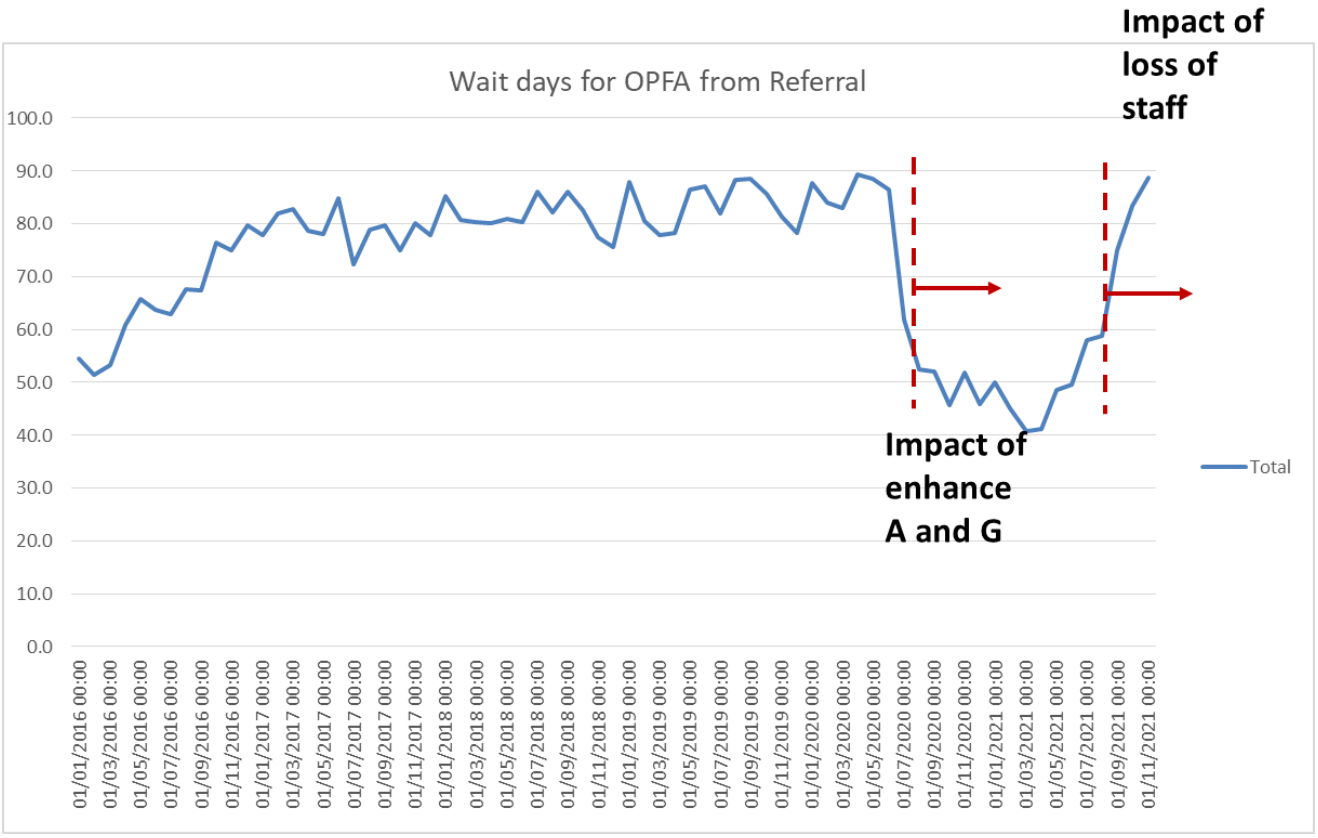

Figure 4: Return of Referral rates. Now that our system of vetting has been established we are returning on average 40-45% of referrals.