Making No Headway

An investigation into the Government's failure to support neurology services

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Executive Summary

Neurology covers conditions of the brain and central nervous system, including Parkinson's disease, Epilepsy and Multiple sclerosis. I have undertaken a great deal of research in this area, publishing a report in 2000. This report updates that research, showing the current state of neurology services in the NHS.

The main findings were:

- On average, patients have to wait 19 weeks for a neurology outpatient appointment. This is over five months.

- Waiting times are being kept artificially lower than they otherwise would be by central funding. When this one-off funding is withdrawn, the waiting times will get much longer.

- Acutely ill patients should be seen by a consultant within 24 hours. One in five acutely ill patients with neurological conditions is not seen by a consultant neurologist in the first 24 hours of admission to hospital. This rises to one in four in southern England.

- There is a chronic shortage of neurologists. The number of specialist registrars has increased by 3 and senior house officers has fallen by 19 between 1997 and 2001. Even if no consultant were to retire it will take until 2043 to increase the number of neurologists to levels considered ideal by the profession and patients groups.

- While more NHS Trusts are bidding for funding to establish consultant posts, fewer bids are proving successful. This suggests that the preparation of the National Service Framework on Long Term Medical Conditions is blighting any attempts at meeting existing demand or developing services.

1. Introduction

1.1 Neurology is an overlooked service within the NHS. Yet as many as 10 million people in the UK suffer from a neurological condition[1] and as many as one in five admissions to medical wards are the result of acute neurological cases[2]. Neurology covers conditions of the brain and central nervous system, including Parkinson's disease, Epilepsy and Multiple sclerosis.

1.2 After investigating this issue in 1999 and 2000, it was obvious from parliamentary questions that even the Department of Health had a very limited picture of neurological services across the country. This lack of information prompted my own survey of NHS Trusts in England and Wales. The findings where published in autumn 2000 and were the subject of a parliamentary debate in 2001[3].

1.3 The 2000 survey forms a baseline against which progress can be measured. Since the publication of my first report the Department of Health has announced that a National Service Framework (NSF) on Long Term Medical Conditions will be produced. The NSF is expected to be published in 2004 for implementation from 2005 onwards.

1.4 With work on the NSF underway it seemed a good time to take stock of the current state of play with a further survey. What foundations exist on which the NSF can build? How long do people have to wait to see a neurologist, how many neurologists are there, what is the funding like? In order to ensure a fair comparison with the results of the 2000 survey I have repeated the questions used then. Within this report where comparisons are made between 2000 and 2003 results we have used results only from Trusts who responded to both surveys.

1.5 Access to a neurologist is only one aspect of effective treatment and good care of people with neurological conditions. However, early confirmation of diagnosis is critical to the way in which an appropriate response from health and social care services is tailored to meet the need.

2. Main Findings

2.1 On average, patients have to wait 19 weeks for a neurology outpatient appointment. This is longer than the NHS Plan's 'average' wait of seven weeks, longer than the planned 2004 16 week wait and longer than the planned 2005 three months wait. Waiting times are likely to lengthen after the funding for short-term waiting list initiatives ceases.

2.2 One in five acutely ill patients with neurological conditions is not seen by a consultant neurologist in the first 24 hours of admission to hospital. This rises to one in four in southern England. Delays in diagnosis and specialist care hamper effective treatment and the prospects for recovery and rehabilitation.

2.3 There is a chronic shortage of neurologists. Since the last survey there has been a worsening of the position. The pool of qualified staff available in the UK for appointment to consultant grade has shrunk since Labour came to power. On present trends of training it will take until 2020 to increase the number of neurologists from the current 350 to 600.

2.4 While more NHS Trusts are bidding for funding to establish consultant posts, fewer bids are proving successful. This suggests that the preparation of the National Service Framework on Long Term Medical Conditions is blighting any attempts at meeting existing demand or developing services.

3. What are neurological conditions?

3.1 Whilst there is no simple definition of neurological disorders, the following are conventionally regarded as being neurological conditions:

- All structural disorders of the central nervous system (the brain and spinal cord).
- All structural disorders of the peripheral nervous system (the nerves in the face, trunk and limbs).
- Disorders involving muscle.
- Certain common conditions, which are not necessarily caused by structural disease (such as many varieties of headaches).
- Other conditions (such as epilepsy, fainting and dizziness), which are often caused by disorder physiology, rather than abnormal anatomy[4].

Disorders include Alzheimer’s disease/dementia, brain tumour, cerebral palsy, vCJD, Epilepsy, Motor Neurone Disease, Multiple sclerosis, Parkinson’s disease and Stroke.

4. Waiting times

> *I have completed your form but have not given the current waiting times because these, at the moment, are entirely artificial. In order to reduce the Neurological Out Patient waiting list Consultants and SpRs in Neurology have been paid huge sums of money to do extra clinics. Hence the waiting list has fallen. So when these centrally funded payouts cease then the waiting lists will revert to the very long one preceding this initiative. None of this money is being diverted into improving the infrastructure of our Neurology Unit here, but when the figures are produced for our waiting list it will appear that there has been an improvement in the Service which we will provide.*
>
> **Consultant Neurologist**
> **North of England**

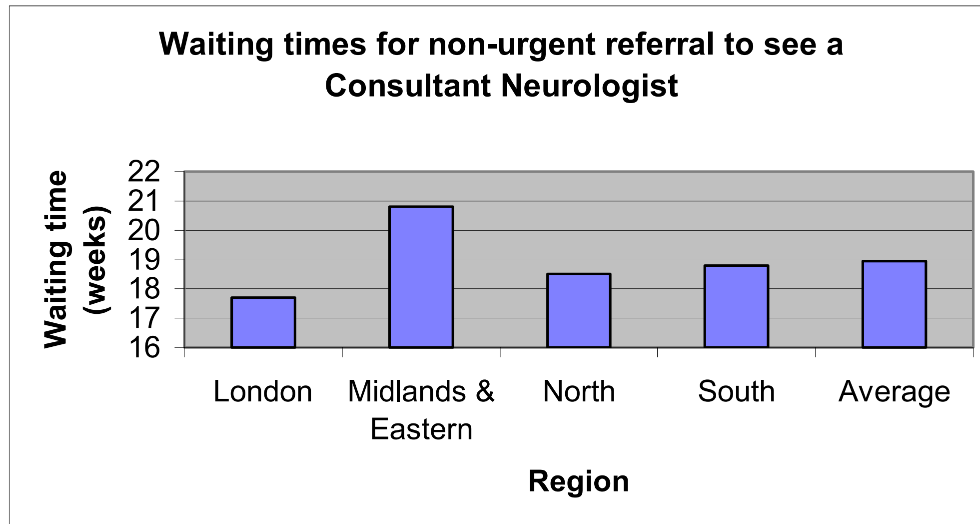
4.1 The NHS Plan states that by 2005 the maximum waiting time for a routine out-patient appointment will be three months[5]. It goes on to state that the average wait will be seven weeks[6]. In a written Parliamentary answer the Department of Health confirmed there are further targets to reduce waits to 16 weeks by 1 April 2004[7].

4.2 NHS Trusts were asked for the current length of urgent, average and non-urgent waiting times for out patient appointments with a consultant neurologist. With less than a year to go before the 16 week target is meant to be delivered the survey results show that no NHS region in England currently meets the target.

4.3 The average wait throughout England for a non-urgent referral to see a consultant neurologist now stands at 19 weeks which is down from the 2000 figure of 25 weeks. However, this figure has to be read with some caution given the use of one off waiting list initiatives.

4.4 According to the information received for outpatient neurological appointments, the **current 19 week wait is a lot longer than the 'average' wait for all conditions (seven weeks), longer than the planned 2004 16 week wait and longer than the planned 2005 three months wait.**

4.5 The three months wait translates into 12-13 weeks. As can be seen from the graph below such a waiting time remains a pipedream. London has the shortest wait, with an average of 18 weeks, **50% longer than the figure quoted in the Government's NHS Plan.** The Midlands and Eastern region has the highest waiting times in England, with the wait being **21 weeks**.



4.6 The scale of the task can be seen when it is measured in terms of the number of people who are waiting. Almost two-thirds of people wait between 13 and 25 weeks for a referral to a consultant neurologist.

4.7 According to the Association of British Neurologists, who represent the clinicians, **'all acutely ill patients with neurological illnesses, who do not require immediate intervention should be seen within 24 hours…'[8]. The 2003 survey found that as many as one in five emergency patients across England are not seen by a Consultant Neurologist in those first 24 hours. The number rises to almost one in four patients in the south of England.**

4.8 Without a specialist consultation within the first 24 hours of an emergency admission, the chances of the right diagnosis and correct future treatment being made is severely reduced. For example, with epilepsy and Transient Ischemic Attacks (warning stroke), the symptoms many only last a short time and the diagnosis of these by a specialist would enable the correct preventative treatment to begin straightaway. The shortages are not just limited to neurologists but extend to neurosurgery. According the British Brain and Spine Foundation[9] **UK patients have half the chance of waking up with a neurosurgeon at the bottom of their bed following a head injury or stroke than they do in the rest of the developed world.**

4.9 The length of time that a person waits to be diagnosed can cause symptoms of a neurological complaint to exist when in fact they are wholly preventable or curable. The Alzheimer's Society put it this way, "A diagnosis is essential to rule out other conditions that may have symptoms similar to dementia and that may be treatable. These include depression, chest and urinary infections, severe constipation, vitamin and thyroid deficiencies and brain tumours".[10]

4.10 Long waiting lists to see a consultant neurologist force patients to rely on GPs, who do not have the in-depth knowledge of neurological disorders necessary to provide the best possible treatment for patients.

4.11 For example in a survey of people with MS conducted by the Myelin Project[11], it found that 75% of respondents had discussed Beta Interferon with a GP or Neurologist. Out of that 75%, only 20% had discussed this with their GP. If the majority of people are discussing such treatments with a neurologist, then it is imperative that the waiting times for non-urgent outpatient appointments are reduced so that all avenues of treatment are explored. **An early consultation with an outpatient neurologist would improve the quality of life for many people living under the shadow of a neurological condition.** Even if there are no drugs that can be offered in order to combat a condition, the early advice or diagnosis would enable many patients to change their lifestyles in order to accommodate the problems they may face in the future and gain access to other treatments including physiotherapy and Occupational Therapy.

4.12 Specialist consultation is very important for getting the right diagnosis. Miss-diagnosis is a common problem with neurological disorders. The Government's Clinical Standards Advisory Group found that[1]:

"Diagnosing epilepsy is not easy. In a recent population-based study of epilepsy, it was found that, in about a third of new cases, a conclusive diagnosis could not be made. The mean time from the first seizure to diagnosis is over six months in 50% of patients with epilepsy and two years in 30% (Hart 1992). **The results of surveys have shown that about 20% of patients referred to epilepsy clinics with chronic epilepsy have been misdiagnosed, and the seizure prompting referral are not epileptic.**

All patients in whom a new diagnosis of epilepsy is made should be offered referral for specialist opinion. The purposes of referral are diagnostic confirmation, the establishment of aetiology and recommendations for investigations and initial treatment. There should be few exceptions to this policy."

In Wales GP's were noted to have a misdiagnosis rate of 50% for people with Parkinson's Disease.

Reference:Hobson P, Holden A, Meara J. Measuring the Impact of Parkinson's Disease with the PD Quality of Life Questionaire. Age Ageing 1999;28:341-6.

5. Staff shortages

5.1 The UK does not stand comparison with European Union (EU) or United States neurological staffing levels. When it comes to neurologists, the findings of the 2003 survey when compared to the 2000 survey reveal that there has been no improvement in the number of neurologists.

5.2 As the table below shows the NHS in England compares very badly with healthcare services in other European countries:

Country	Ratio of neurologists to population
Denmark	1: 21,186
Netherlands	1: 25,773

[1] CSAG Report: Services for Patients with Epilepsy 1999 – Chapter 7, point 7.7 and 7.8

Switzerland	1: 29,070
France	1: 38,462[12]
England (2003)	1: 206,493

5.3 To make a fair comparison between the 2000 and 2003 results only those Trusts who responded to both surveys were taken. This changes the figures because it excludes results from London in 2003, which had been the subject of a pilot survey in 2000. The English average in 2000 had been 1 neurologist for every 134,448 people. The adjusted 2003 figure is 1: 138,028. **It seems reasonable to conclude from this analysis that the chronic shortage of neurologists identified in 2000 remains unaddressed.**

5.4 The Association of British Neurologists in their Neurology Manpower Report 2003 recommend one neurologist per 80,000 population. This is simply forms the basic service, which at present they are struggling to provide. It would not provide enough staff for 24 hour cover, which would be the ideal. The ABN is on record as saying that[13]:*"There are too few neurologists in the United Kingdom to provide a comprehensive service to acutely ill patients".* This compares to the figure in this report which finds a rate of 1: 138,028.

5.5 Research published in the Emergency Medical Journal indicates 'major deficiencies' in post neurological care. This survey also found that to reach recommended staffing levels for neurological consultants there would have to be an increase of 70% in current numbers[14].

5.6 The survey also found wide regional differences in the numbers of consultants. Indeed, in London, South, Midlands & Eastern and England as an average, the number of neurologists is less than half the figure recommended by the ABN and Neurological Alliance figure.

5.7 If the ratio of neurologists to population is to approach the 1: 80,000 recommended the number of neurologists would have to more than double. However, the ABN recommended ratio is simply to cope with the current workload. This would see an increase of consultant neurologists to 845, from the current figure of 358[15]. To achieve 24 hour cover, the number of neurologists would need to be 1 per 43,000 population, or 1570. **This is not achievable in the foreseeable future because of a failure by Government to significantly expand the pool of specialist neurological registrars and from which consultants are appointed.**

5.8 In answer to Parliamentary Questions the Department of Health stated that the number of specialist neurological registrars has increased by just **three** between 1997 and 2001, from 159 to 162[16]. Over the same period the number of senior house officers (SHOs) within neurology fell by 19 between 1997 and 2001, from 141 to 122. This rose to 123 in 2002. The Department account for the fall as a 'reclassification of some specialties'[17]. **The fact that the pool of available doctors in training has not grown over the last few years is a real cause for concern.**

5.9 At present, there are 358 neurology consultants. The average length of training for a neurologist is six years. On the basis of the numbers currently in training, there will be fewer than 90 extra trained neurologists by 2006. With just 30 new neurologists coming on stream each year, and given retirements, there will on current trends be 550 more neurologists by 2010. **With no retirements, it would take until at least 2043 to hit the ABN's target. Taken together with the findings of the 2003 survey it reveals that the Department has failed to recognise the scale of the workforce planning task ahead of it if the NSF is to deliver.**

6. Funding

> *We have been struggling for the last 5 to 10 years to suggest to the trust, now enlarged, that there needs to be urgent expansion of the neurological consultant grades here*
>
> **Consultant Neurologist**
> **and Clinical Lead in Neurosciences**
> **At a Neurological Centre in South England.**

6.1 Trusts were asked whether they had applied for additional funding to enable them to appoint more consultants. While 79.5% of Trusts said that they had applied for additional funding less than half (47%) had been approved. The 2000 survey found that 51% of Trusts applied for funds with over half of these being approved.

6.2 The number of Trusts applying for additional funding for consultant posts varies across the country. The lowest number of applications approved was in London, this is despite the capital having the poorest ratio of neurologists to population.

6.3 **While more neurology departments are seeking to expand, the success rate has fallen.**

7. The National Service Framework

7.1 The National Service Framework on Long-Term Conditions was announced in February 2001 by then Secretary of State for Health, Alan Milburn MP. In June 2002 former Minister of State for Health, Jacqui Smith, confirmed that the NSF would have a particular focus on the needs of people with neurological conditions and brain and spinal injury, and also address some of the common issues faced by people living with long-term conditions. In addition to this, the Minister also announced that it would have an emphasis on those of working age.

7.2 The External Reference Group (ERG) for the Long-term Conditions NSF was appointed in autumn 2002 to take forward detailed development of the NSF. The NSF is due to be published in 2004, with implementation to take place in 2005, over a ten-year period.

7.3 Whilst the NSF on Long Term Conditions has been welcomed by groups representing those suffering from neurological conditions, there have been a number of concerns. **In particular the focus on working-age adults, this leaves a gap as neurological conditions are not addressed by the Children or Older People NSFs. This could lead to a lack of co-ordination at the transition points between paediatric and adult services, and adult and geriatric services.** There is also some concern that the NSF will not be published in full in 2004. Almost 2 years passed

between February 2001 announcement of the NSF and the first meeting of the External Reference Group in December 2002.

7.4 The Long Term Medical Condition NSF is to be one of the new generation of NSFs written post implementation of *Shifting the Balance of Power*. As a result the document will not contain milestones or targets. While we would welcome the Government's acceptance that they cannot control everything from Whitehall, there is a risk that the NSF will not have *any* traction on local NHS priorities because many of the conditions it addresses are relatively low prevalence when considered in isolation. **If the NSF is to deliver it must have clear mechanisms in place to monitor how Strategic Health Authorities are using their Local Delivery Plans to put in place the right mix of local and specialist services.**

8. Conclusions

8.1 Neurological conditions result from damage caused by illness or accident to the brain, spinal column or nerves. They have many causes, many of which are not yet known, and they affect young and old, rich and poor, men and women and people from all cultures and ethnicities. Some neurological conditions, such as epilepsy, are lifelong and people can experience their onset at any time of life; some, such as cerebral palsy, are present from birth; some, such as muscular dystrophy, commonly appear in early childhood; and some, such as Alzheimer's disease and Parkinson's disease, affect mainly older people. Certain conditions have a sudden onset owing to accident or illness, such as head injury, stroke or cancers of the brain and spine. Neurodegenerative conditions, such as multiple sclerosis and motor neurone disease, can affect people at any age and often cause a slow deterioration of a person's quality of life and ability to live independently.

8.2 Neurological conditions are poorly understood. Public awareness is low, even of relatively common conditions such as epilepsy. Many rare conditions are largely unheard of and poorly understood, even by non-specialist health professionals. That can lead to problems with the quality of initial diagnosis and the care pathways down which people are directed.

8.3 The reason that access to services is so patchy is quite simple: there is a lack of capacity, with not enough neurologists to meet demand.

8.4 Three years after I conducted my first survey progress has been disappointingly slow. The NSF must deliver better care for all patients with neurological conditions, not just those of working age. This cannot happen unless the Government prioritises the recruitment of the staff to deliver it.

References

[1] "Neuro Numbers" The Neurological Alliance, 2003, p1. The figure quoted includes those who suffer from migraines and tension headaches.
[2] "Levelling Up" – The Neurological Alliance, 2002, p9.
[3] House of Commons Official Report, 6 Mar 2001 : Column 22WH
[4] "Neurology in the United Kingdom – 2000 and Beyond", 1997, p3. The Association of British Neurologists.
[5] The NHS Plan Command Paper 4818, 2000: 12.20
[6] The NHS Plan Command Paper 4818, 2000: 12.13
[7] The House of Commons Official Report, 4th July 2003, column ref 490W.
[8] Acute Neurological Emergencies in Adults (2002), The Association of British Neurologists, p18.
[9] The Scope for Reduction of Death and Disability Caused by Neurological Disorders, The British Brain and Spine Foundation, July 1998.
[10] The Alzheimer's Society http://www.alzheimers.org.uk/How_is_dementia_diagnosed/Diagnosis_process/info_diagnosis.htm
[11] The Myelin Project Survey 1999 – Report Ref: M&F/006a Munro & Forster – August 1999.
[12] Acute Neurological Emergencies in Adults (2002). The Association of British Neurologists, p8.
[13] Acute Neurological Emergencies in Adults, 2002:2, The Association of British Neurologists.
[14] Emergency Medical Journal, September 2001
[15] Acute Neurological Emergencies in Adults, 2002:2, The Association of British Neurologists.
[16] House of Commons Official Report, 4th July 2003, column reference 541W.
[17] House of Commons Official Report, 16th July 2003