



Royal College
of Physicians



ASSOCIATION OF BRITISH NEUROLOGISTS

Local adult neurology services for the next decade

Report of a working party

June 2011

The Royal College of Physicians

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The Association of British Neurologists

The Association of British Neurologists was founded in 1932. Its aim is to improve the health and well-being of people with neurological disorders by advancing the knowledge and practice of neurology in the British Isles.

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Royal College of Physicians
11 St Andrews Place, London NW1 4LE

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Members of the Working Party

Dr David Bateman (chairman) consultant neurologist, Sunderland Royal Hospital

Dr Steve Pollock (vice chairman) consultant neurologist, Kent and Canterbury Hospital;
Southeast Coast SHA lead in acute care

Mrs Lucy Brazg chief executive, Neurological Alliance (on Working party until April 2009)

Dr Rodney Burnham RCP registrar until end 2009

Dr Patrick Cadigan RCP registrar from 2010

Dr Derek Calam Royal College of Physicians Patient and Carer Network

Professor Peter Crome consultant geriatrician; British Geriatrics Society representative

Dr Rhidian Dowdle consultant cardiologist, Royal Glamorgan Hospital; RCP Acute and General
(Internal) Medicine Committee representative

Dr Philip Dyer consultant endocrinologist, Birmingham Heartlands Hospital;
RCP Acute and General (Internal) Medicine Committee representative

Mr Joe Korner director of communications, The Stroke Association; Stroke Association representative

Professor Gregory Lip consultant cardiologist and professor of cardiovascular medicine,
City Hospital, Birmingham; British Cardiovascular Society representative

Dr G Llewelyn consultant neurologist, Royal Gwent Hospital, Newport; chairman, Services and
Standards Committee, Association of British Neurologists; Association of British Neurologists
representative

Dr Sunny George Philip consultant paediatric neurologist and honorary senior lecturer,
Birmingham Children's Hospital; observer, Royal College of Paediatrics and Child Health

Professor Leone Ridsdale professor of neurology and general practice, honorary consultant neurologist,
King's College London; Royal College of General Practitioners representative

Professor Graham Venables consultant neurologist, Royal Hallamshire Hospital, Sheffield;
president (2007–9), Association of British Neurologists; Association of British Neurologists
representative

Ms Tracy Scollin working party administrator

List of those who provided evidence

Ms Michaela Bartlett campaigns and policy officer, Epilepsy Action

Ms Ann Bond chief executive, Integrated Neurological Services

Dr Chris Clough consultant neurologist, King's College Hospital, London; neurology adviser, Department of Health

Ms Amanda Cole information analyst, Sue Ryder Care

Ms Alexandra Crampton policy and campaigns officer, Muscular Dystrophy Campaign

Dr Richard Davenport consultant neurologist, Western General Hospital, Edinburgh

Dr David Dick consultant neurologist, Norfolk and Norwich University Hospital, Norwich

Dr Edward Dunn consultant neurologist, Leeds General Infirmary; Acute and General (Internal) Medicine Committee, Royal College of Physicians

Ms Ava Easton development manager, Encephalitis Society

Dr Nick Fletcher consultant neurologist / clinical director (neurology), The Walton Centre, Liverpool

Dr Geraint Fuller consultant neurologist, Gloucestershire Royal NHS Trust; Neurology Specialty Advisory Committee, Royal College of Physicians

Ms Liz Garrod regional care development adviser (Hertfordshire and North London), Motor Neurone Disease Association

Mr Ben Graham psychologist, Headway East London

Mr Lew Gray secretary and **Ms Yvonne Kolesar** chair, Transverse Myelitis Society

Mr Paul Harper head of business management, Sue Ryder Care

Mr John Holt liaison officer, West Berkshire Neurological Alliance

Ms Barbara Howe specialist commissioner, Tower Hamlets PCT; director of specialised commissioning, London Specialised Commissioning Group

Dr Thomas Hughes consultant neurologist, University Hospital Wales, Cardiff

Mr Trevor Lawson head of communications, Brain Tumour UK

Ms Yvonne Lewis director of clinical services, Royal Hospital for Neuro-disability, London

Professor Gregory Lip consultant cardiologist and professor of cardiovascular medicine, City Hospital, Birmingham

Ms Andrea Liu consultant neuroradiologist, Cardiff and Vale NHS Trust

Mr Robert Meadowcroft director, policy and operations, Muscular Dystrophy Campaign

Dr Louis Merton clinical neurophysiologist, Queen Alexandra Hospital, Portsmouth; British Society for Clinical Neurophysiology

Ms Claire Moonan, health policy and campaigns manager, Parkinson's Disease Society

Nicola Russell director of services, MS Trust

Ms Farah Nazeer head of campaigning, Motor Neurone Disease Association

Ms Marie Oxtoby deputy chair, Greater Manchester Neurological Alliance

Dr Steve Pollock (vice chairman) consultant neurologist, Kent and Canterbury Hospital; Southeast Coast SHA lead in acute care

Professor Leone Ridsdale professor of neurology and general practice, honorary consultant neurologist, King's College London; Royal College of General Practitioners

Dr Mark Roberts consultant in neurological rehabilitation, Cumberland Infirmary

Dr Gregory Rogers clinical lead/GPwSI in epilepsy, Eastern and Coastal Kent PCT

Dr Anthony Rudd stroke physician, Guy's and St Thomas' Hospital

Mr Andrew Russell chief executive, Association of Spina Bifida and Hydrocephalus

Dr Martin J Sadler consultant neurologist, Derriford Hospital, Plymouth

Dr Martin Smith consultant in neuroscience and critical care, National Hospital for Neurology and Neurosurgery, UCL Hospitals NHS Foundation Trust

Ms Cath Stanley head of care services – England and Wales, Huntington's Disease Association

Ms Katie Tester information analyst, NHS Workforce Review Team

Dr Sue Thomas policy adviser, long-term conditions, Royal College of Nursing

Ms Margaret Topping MS specialist nurse, Hampshire Primary Care Trust

Ms Val Wells service development manager, The Dystonia Society, London

Dr Stephen Wilson consultant neurologist, East Elmbridge and Mid Surrey PCT and Epsom and St Helier NHS Trust

Executive summary

Neurological disorders are very common, accounting for about one in ten general practitioner consultations, around 10% of emergency medical admissions (excluding stroke) and disability for one in 50 of the UK population. They include many different conditions of varying severity, some very common and others exceedingly rare, from migraine to motor neuron disease.

Patients require access to different parts of the neurological care pathway at different stages of their illness (acute admission, outpatient care and long-term care). However, these are currently poorly planned and organised. Good management requires better integrated primary, secondary and tertiary resources to achieve a neurology network that is easily accessible, provides local care where appropriate and, when necessary, involves the regional neurosciences centre.

DGH services have suffered particularly due to a lack of local neurologists, with an unplanned increase in outpatient demand driven by waiting time targets, inadequate resources and poorly structured services networked across health providers.

Acute neurology services are of particular concern because they are rarely provided by neurologists, in contrast to those for stroke and other acute medical specialties, resulting in potential adverse outcomes.

Despite these concerns, the central recommendation of the 1996 RCP report, to appoint neurologists with appropriate infrastructure support in every DGH, has not been achieved and has been outpaced by spiralling demand. Neurology remains a shortage specialty, with appointments mainly to the regional neurosciences centres and an inequality of more than three to one in numbers of neurologists in different parts of the UK.

This new report makes three proposals:

- 1 an expansion and improvement of local services with a shift in emphasis from scheduled to emergency care
- 2 better organised care for patients with long-term neurological conditions, managed in part through an enhanced role for specialist nurses and general practitioners with a special interest in neurology
- 3 better local planning of services with increased clinical involvement within a commissioner/provider forum, creating a neurological network to improve clinical and financial outcomes.

Many of the practical recommendations are cost-neutral, and can simply be achieved through more efficient working and better use of existing resources. Over the next decade, they will require an increase in consultant UK neurologists from 600 to 880 (one per 70,000 population), most of the expanded workforce being based locally, and more equitably distributed. In turn, this will require expansion in the training grades.

Recommendations

Acute neurology services (unscheduled care)

- R1 Patients with neurological emergencies admitted to DGHs should receive the same standard of care as that provided by other specialties. They should ideally be admitted to hospitals providing an acute neurology service led by consultant neurologists.
- R2 This requires a major change in the way that local neurology services are provided with specific commissioning of neurology emergency care. There should be a change in emphasis from scheduled to unscheduled care, to allow the development of acute neurology services in the DGHs that provide inpatient services. This should be planned and agreed through a local neurosciences forum.
- R3 The DGH should have an acute neurology ward area, led by a consultant neurologist with specialist staff. Consideration should be given to locating this ward next to the acute stroke unit to allow for the sharing of specialist medical staff, nurses and allied health professionals.
- R4 The operational policy should include:
- daily consultant ward rounds
 - local neuroradiology linked to the regional neurosciences centre
 - local access to clinical neurophysiology
 - access to local ITU and neurorehabilitation
 - close operational links to the regional centre for rapid transfer and repatriation of appropriate patients, including surgically stable head injury and post-neurosurgical patients
 - the development of on-call rotas as resources permit.
- R5 Consultant neurologist management of emergency cases could be achieved immediately by modification of job plans to include ward liaison work, emergency outpatient clinics and daily ward rounds in admitting areas to prevent and shorten admissions.
- R6 This acute service requires an expansion in the DGH neurology workforce with job plans which include sessions for local unscheduled care. Consideration should be given to appointing neurologists solely to provide emergency care to ensure that this is achieved.

Neurology outpatient services (scheduled care)

- R7 Scheduled outpatient care should not only achieve national access targets, but should also be delivered close to the patient's home. Urgent advice should be easily available to reduce unnecessary admissions.
- R8 The present unrestricted referral system is a poor use of limited resources that need to be diverted to improve unscheduled care. Demand should be controlled by a local management strategy agreed by the clinicians using referral guidelines and audit to improve referrals.
- R9 Innovative methods should be explored such as email triage, email advice and telephone clinics. Greater use should be made of GPs, particularly for the management of headache and the follow-up

of some neurological conditions in remission. Consideration should be given to developing linked GPs across neighbouring practices to filter referrals arising in the practices, liaising with the local neurologist for training and support.

Long-term neurological conditions

- R10 The management of long-term neurological conditions requires joint planning with commissioners and primary and secondary care providers, along with local patient and voluntary sector input.
- R11 Clinical leads should be designated for the more common conditions, such as multiple sclerosis (MS), epilepsy and movement disorders, having responsibility for the development and provision of networked programmes spanning primary, secondary and tertiary care.
- R12 Initial diagnosis and treatment by neurologists in secondary care should be followed by community care consisting of access to a key worker and multidisciplinary community teams that are disease-specific for common neurological conditions, and led by professionals with specialist expertise, including nurse specialists, GPwSIs and professions allied to medicine. The community team should have close links with easy access to the appropriate DGH-based neurologist.
- R13 Specialist nurses play a particularly important role; these posts, both disease-specific and generic, should be expanded. Similarly, the role of GPwSIs within structured care pathways should be developed, particularly for chronic epilepsy, MS and Parkinson's disease (PD), whereby a local GPwSI leads each of these community services.
- R14 Commissioners should develop proper care pathways for the management of head injury, functional illness and the psychiatric complications of chronic neurological disease. They should also ensure neurological diagnostic input into local dementia services.

Relationship with the regional neurosciences centre

- R15 Commissioners should work closely with acute trusts, the regional neurosciences centre and RCP regional specialty advisers in neurology to ensure that new consultant neurologist posts have appropriate job plans with programmed activities for continuing professional development (CPD), audit, clinical governance, revalidation and, where appropriate, clinical sessions in the centre. This reflects the continuing importance of the regional neurosciences centre in the network of care, and acknowledges that, particularly while neurology remains a shortage specialty, it is important to ensure that new DGH-based neurology posts are attractive to potential applicants.
- R16 Until sufficient neurology sessions are available to provide on-call locally, the regional neurosciences centre should have responsibility for this component of provision within the DGH. Telemedicine to support the current telephone-based service should be explored.
- R17 DGH investigations with clinical neurophysiology tests (EEG and nerve conduction studies) and MRI/CT scanning should be available with regional neuroscience links through joint appointments, service level agreements and the use of telemedicine to ensure that local management of patients is properly supported.

Training

- R18 Current government policy does not support training expansion. However, a further increase in neurology training posts is necessary to provide staffing for a consultant-led DGH service. As neurology expands at a local level, exposure to DGH training for neurology trainees should be significantly increased from the current one out of five years.
- R19 Teaching neurology to medical students in a DGH setting should be encouraged in local neurologist job planning. DGH core medical training and acute medicine physician training should include rotation through neurology and include exposure to the acute inpatient service.

Workforce planning

- R20 The provision of a comprehensive DGH service requires at least one FTE consultant neurologist per 70,000 population, representing a total of around 880 posts at present UK population figures.
- R21 Although current government policy does not support training expansion, a further increase in neurology training posts is necessary to provide the staffing for a full consultant-led DGH service.

Commissioning and implementing services

- R22 There should be national and regional, as well as local, responsibility for implementing the report. A 10 year action plan should be agreed and monitored annually by the regional authority, which should assume responsibility for sustaining progressive development of local neurology services.
- R23 The development of the service model proposed requires the establishment of a local commissioner and provider group with strong clinical representation from neurology and primary care. DGH-based neurologists should recognise the critical importance of clinical championship in these groups, and this should be fully supported in job planning.
- R24 Working with regional commissioners and their equivalents in the other three countries of the UK, a plan should be made to progressively commission a comprehensive local neurology service over the next decade, based on a unit population of 500,000. Commissioning should be undertaken against nationally agreed service specifications and within an agreed quality assurance framework. It should particularly recognise the need for unscheduled as well as scheduled care, the importance of the regional neurosciences centre contribution, and the value of community teams for long-term conditions.
- R25 Evolution of services over a decade will require investment. However, a step-wise approach, in which initial improvements are achieved by controlling outpatient demand and improving the efficiency of unscheduled and networked long-term care, will lay the basis for planned future developments.
- R26 Commissioners for neurosciences and their equivalents in the other three countries of the UK should develop comprehensive local neurology services that recognise the importance of emergency and urgent as well as scheduled care, and the value of networked services for these and long-term conditions. Acute neurology services should be commissioned locally to ensure that appropriate facilities are established.

- R27 These plans should include strong clinical representation from the DGH neurologist(s) and should recognise the crucial importance of a regional component to the provision of a successful local service, and vice versa.
- R28 DGH-based neurologists should recognise the critical importance of clinical championship; this should be fully supported by the employing trusts through job plans.
- R29 Commissioning should be undertaken against nationally agreed service specifications and within an agreed quality assurance framework.

1 Introduction

In 1996 the Royal College of Physicians' (RCP) report *The district general hospital as a resource for the provision of neurological services*¹ recommended that neurologists with trainee support should be appointed to every district general hospital (DGH). The aim was to improve the care of neurological patients, enhance local education, and develop multidisciplinary links between hospitals and the surrounding community.

Three subsequent reports from the Association of British Neurologists (ABN)^{2,3,4} developed this theme, recommending that:

- there should be easy, timely and equitable access to outpatient neurology services regardless of geography
- all acutely ill neurology inpatients in the DGH should be managed by neurologists
- standards should be set for multidisciplinary working across social, primary, secondary and tertiary care to meet the requirements of the National Service Framework for long-term conditions⁵
- regional neurosciences centres should continue to play an integral part in patient care
- there should be a substantial increase in the consultant neurologist workforce to meet these recommendations.

Despite a shift in NHS policy that patients should increasingly be managed by specialists, a view endorsed by patients themselves,⁶ and that care should be commissioned and provided locally in line with the National Service Framework for long-term conditions in 2005 and the Darzi report in 2008,⁷ the recommendations of the RCP and the ABN have not been widely implemented.

Although there have been major government initiatives on waiting times, these have not helped develop a coherent strategy for neurological services fit for the 21st century. For instance, although Department of Health targets have had an impressive effect on reducing waiting times for new outpatient appointments, they have disadvantaged specific groups, including:

- patients with long-term conditions (because of reduced follow-up capacity in outpatient clinics)
- patients seen in waiting list initiative clinics (because of rushed initial consultations and then lack of proper continuity of follow-up care)
- acutely ill neurology patients admitted to DGHs, since only outpatient services have been commissioned to meet targets: thus someone with life-threatening status epilepticus may not be seen by a neurologist for some days, while a patient with a tension headache is rapidly seen in clinic
- referrals from other hospital-based clinicians displaced by target-driven primary care referrals, regardless of need.

Although by 2006 the number of UK neurology consultants had risen from one full-time equivalent (FTE) per 200,000 population in 1996⁸ to one per 115,000,⁹ mostly in response to outpatient pressures, this still remains less than a third of the European average.¹⁰

Worse, only 86 out of the 285 consultant neurologist appointments in the last decade¹¹ have been *directly* to a DGH, making improvements in the management of acute inpatient and neurological long-term conditions all but impossible. Most neurologists, even newly appointed, are still regional neurosciences centre-based and can only provide a *visiting* outpatient and ward consultation service to DGHs.

This 'hub and spoke' model was sensible when there were fewer neurologists with less access to investigation, but it is now out of date. It should be progressively replaced by a regional network, in which neurological resources in primary, secondary and tertiary sectors, appropriate to the differing needs of patients, are linked together by structured, equitable and shared clinical pathways.

There have been major advances in neurology over the past 15 years, enabling quicker diagnosis, less need for admission and better evidence-based management, with more effective treatments for epilepsy, Parkinson's disease, multiple sclerosis and migraine, all of which can be delivered close to home. Locally delivered care, especially for patients with long-term conditions, might be improved by increased involvement of general practitioners with a special interest (GPwSI), as well as specialist nurses.

Although availability of some investigative facilities in DGHs (such as MRI) has improved, others (such as clinical neurophysiology) have not, and local inpatient neurology beds are rarely provided, despite the steady loss of regional centre beds. This makes it very difficult for neurologists to look after acutely ill patients directly and, by default, these are usually managed by other specialties with advice from a visiting neurologist, or by telephone consultation with the regional neurosciences centre.

To complicate matters, the structure of DGH acute medical services has fundamentally changed. The general physician is now being supported by the acute medicine physician (these posts expanded by 23% in 2008),¹¹ with patients being triaged – quite rightly – to appropriate specialist care as soon as possible, either as an inpatient or outpatient. But, without neurologists *based* in the DGH, there is no appropriate triage route for neurology patients who are *admitted* other than to a physician not trained in neurology. Many unnecessary admissions result from lack of specialist neurology input at the front door. Thus ABN-approved standards for the DGH management of acute neurological emergencies are rarely implemented:

*Acutely ill adult patients with neurological disorders, who do not require immediate intervention, should be seen by a neurologist within 24–48 hours. If the patient is critically ill then they should be seen immediately. All such patients should be under the care of a neurologist.*²

Unsurprisingly, the failure to implement this standard leads to problems, for example:

- ‘very few neurological in-patients were even seen by a neurologist’¹² and, for epilepsy at least, diagnostic errors by non-neurologists are common¹³
- fewer than half of individuals surviving acute encephalitis saw a neurologist within 24 hours of admission; one third had to wait more than three days; 36% were under the care of a doctor other than a neurologist; while only one quarter were managed in a specialist ward on the first day in hospital; and 50% were never transferred to a neurology ward.¹⁴

These problems are exacerbated by inequitable access to neurologists across the UK. In 2006 the population served by one FTE consultant varied threefold:¹⁵

London	one per 51,395
England overall	one per 117,526
Scotland	one per 113,181
Wales	one per 164,296
Northern Ireland	one per 160,875

Furthermore, any increase in consultant neurologists has been hampered by insufficient training posts to provide the necessary expansion. In the three years to 2009 almost 50% of prospective consultant appointments were not made, either due to lack of applicants or trust cancellation of the post, probably for the same reason.¹⁶

Evidence, both published^{17,18,19} and presented by neurology charities (see online-only appendices uploaded alongside the electronic version of this report) to the Working Party, emphasises the ways in which the needs of patients with acute and chronic conditions are not being met by current service provision, due largely to an inadequate specialist workforce outside the regional neurosciences centres.

Given these continuing concerns about the standard of care for neurological patients in the DGH, the RCP and the ABN commissioned this new report with the intention of making further recommendations for neurology services in the DGH and community for the next 10 years.

The provision of DGH paediatric neurological care is not considered, since this is now the responsibility of the Royal College of Paediatrics and Child Health. Similarly, rehabilitation is the remit of the British Society of Rehabilitation Medicine.

The Working Party committee members included potential stakeholders, with representation from acute medicine physicians, geriatricians, cardiologists, neurorehabilitationists, neurologists, general practitioners, patient representatives, the Neurological Alliance and The Stroke Association.

This report is intended for a wide audience: all those involved in planning or delivering the care of patients with neurological disorders, including commissioners, purchasers, general practitioners, allied health professionals, specialist nurses, DGH physicians, neurophysiologists, neuroradiologists and general radiologists, neurologists, the neurological charities and patients.

The recommendations are included at the end of each section of this report and are brought together on pages viii–xi.

2 Definitions and the frequency of neurological disorders

- 2.1 Neurological disorders affect the brain, spinal cord, peripheral nerves and muscles. They include a wide range of diseases, from the common (eg migraine), to the rare but diagnostically and therapeutically challenging (eg myasthenia gravis), the latter category making up a substantial and difficult proportion of the neurologist's caseload.
- 2.2 Neurological diagnosis is generally regarded as 'difficult' and doctors can easily be confused by the many patients with symptoms unexplained by identifiable organic disease (functional problems), which constitute up to one fifth of new neurology outpatients.²⁰
- 2.3 Despite considerable advances in investigations, diagnosis still relies almost entirely on history and examination, both of which require training, practice and experience to interpret and perfect. Moreover, this skill dictates the most cost-effective investigation strategy, and the relevance of any MRI abnormalities found (a significant proportion of which are, with increasing sensitivity of imaging, incidental).
- 2.4 Neurological diseases include:
- intermittent disorders, such as epilepsy, migraine and other headache problems
 - progressive long-term conditions, such as PD, MS and dementia
 - life-threatening acute conditions, such as stroke, meningitis, encephalitis, status epilepticus, acute inflammatory neuropathies, traumatic brain injury and subarachnoid haemorrhage.
- 2.5 They are very common. In the UK:
- neurology symptoms account for about one in 10 general practitioner consultations²¹
 - 0.6–1% of the population is diagnosed with a neurological condition every year^{21,22} and one in six people has a neurological condition that makes a significant impact on their lives²²
 - two percent of the UK population are disabled by a neurological condition²¹
 - the lifetime prevalence of both MS and PD is two per 1,000 population, and double that for active epilepsy²²
 - the lifetime prevalence of headache is over 90%, and for young women it is the most common symptom reported in the community.²³

3 Acute neurology services (emergency care)

- 3.1 In 1987 Morrow and Patterson²⁴ found that nervous system disorders account for 20% of DGH acute medical admissions, of which half are strokes. Since then not much has changed. Evidence, both published and presented to the working party from Leeds, Plymouth and Norwich, confirmed that up to a quarter of medical admissions are 'neurological', a third to a half of which are stroke, with the rest comprising other neurological emergencies, predominantly seizures and headache.^{25,26}
- 3.2 A recent study²⁵ of 1,197 DGH medical emergencies demonstrated that, at 15% (181), neurological disorders are the third most common reason for presentation after cardiology (359) and respiratory medicine (248), and considerably more common than the next specialty, gastroenterology (121). Stroke (33%), seizures (25%) and headache (20%) were the most common presenting neurological problems. Despite having a regional neurosciences centre actually located within the particular DGH studied, only a third of these admissions were seen by neurologists or neurosurgeons, and only half of those admitted were under the neurological services.
- 3.3 Even with protocols for direct admission of stroke and daily neurovascular clinics, a 2009 study in Edinburgh²⁶ still found that 9% of acute medical admissions were neurological. Only 8% of these cases were referred for a neurological opinion, although about 40% of those not referred might have benefited from specialist advice or management.
- 3.4 Very few DGHs have on-site neurologists with the local resources to manage these acute patients. Although complex cases are sometimes transferred, inadequate numbers of regional neurosciences centre beds and problems recognising these as neurological conditions cause significant delays.
- 3.5 Neurological emergencies are therefore usually managed by DGH physicians or ITU staff with or without advice by telephone from the centre, or during infrequent visits from centre-based neurologists. Worse, they are cared for in wards without specialist neurology nursing or junior staff, an approach consistent neither with best clinical practice nor with current Department of Health policy.
- 3.6 This contrasts strikingly with the care provided to patients with acute stroke and disorders affecting other systems, which is becoming increasingly specialist based. The development of the acute medical unit with rapid triage to appropriate specialist care will exacerbate this disparity.
- 3.7 There can be no justification whatsoever for the suboptimal care provided to so many acutely ill neurology patients, in contrast to the expertise available to other emergency admissions. Equity at the very least demands that neurology patients be seen by a neurologist, able to take over their care where appropriate, within 24 hours of admission.
- 3.8 Evidence about better models of acute neurological care was therefore taken by the Working Party. There are units, for example in Plymouth and Norwich, which manage most neurological emergencies, sometimes including acute stroke. To succeed, they need sufficient consultant neurology staff to provide daily input and they require around one FTE neurologist per 75,000 if a full outpatient service is also to be maintained. They also need dedicated beds, specialist junior doctors and nursing staff, clinical neurophysiology and access to 24-hour, seven-days-per-week imaging. However, inpatient neurosurgery is not a prerequisite, provided there are close links to an appropriate unit.
- 3.9 The nature of the input and work patterns of the consultants significantly affect quality of care and length of stay. The introduction of an attending system in Plymouth improved care and nearly halved the bed requirements, while also improving care for short-stay patients.²⁷
- 3.10 Audit of inpatient consultation has demonstrated diagnostic and management value.²⁸ Liaison neurology develops this approach and has been shown to increase the number of neurology

admissions seen from 10% to 50%, with the proportion attended by a neurologist within 24 hours being increased to three quarters, all with a halving of median length of stay without increased use of CT or allied health professional resources.²⁹ A similar improvement in care and length of stay was achieved by the Leeds service, which was particularly helpful with functional symptoms, spinal cord syndromes, alcohol withdrawal fits confused with epilepsy, stroke, syncope and migrainous aura. This improvement was maintained even in the absence of the liaison neurologist on holiday, reflecting experiential training of the other physicians.

- 3.11 UK neurologists are seldom involved in the care of acute stroke and transient ischaemic attack (TIA), which is mostly undertaken by geriatricians. However, evidence from the British Association of Stroke Physicians suggests that best stroke care is delivered by collaboration between all relevant specialists. More DGH neurologists would increase the potential for shared inpatient resources and rotas for the management of acute stroke and TIA mimics, as well as other acute neurology.
- 3.12 Such a collaborative approach of shared working with DGH physicians, particularly geriatricians, extends beyond stroke. The management of some neurological disease forms a large part of geriatric care workload and this will continue for the foreseeable future. Indeed this is appropriate given that geriatricians have a better understanding than neurologists of older people with multiple morbidities. The extent of their role in the management of neurological disease will depend on local circumstances, in particular the availability of neurologists but, crucially, must be underpinned by adequate training, shared protocols and commitment to the same standards of care and clinical governance.
- 3.13 A similar shared working approach applies to the important contribution that many other specialties make to DGH neurology. Cardiology, for instance, contributes to the management of syncope and autonomic dysfunction, as well as blood pressure and arrhythmia management. Local access to cardiovascular investigations, including 24 hour rhythm monitoring, and transthoracic and transoesophageal echocardiography is mandatory for diagnosis in cerebrovascular disease.
- 3.14 Finally, the management of acute head injury in the DGH requires much improvement. At present patients are managed on general or orthopaedic wards, with little planning for early rehabilitation. Evidence was presented to the Working Party showing that co-location of the DGH neurological rehabilitation unit with the stroke unit provides substantial benefits, as does close working with the local DGH neurologist. Head injuries were managed on this unit bringing, amongst other benefits, earlier transfer from regional neurosurgery beds.

Recommendations

- 3.15 Patients with neurological emergencies admitted to DGHs should receive the same standard of care as that provided by other specialties. They should ideally be admitted to hospitals offering an acute neurology service led by consultant neurologists. [R1]
- 3.16 This requires a major change in the way that local neurology services are provided with specific commissioning of neurology emergency care. There should be a change in emphasis from scheduled to unscheduled care to allow the development of acute neurology services in the DGHs that provide inpatient services. This should be planned and agreed through a local neurosciences forum. [R2]
- 3.17 The DGH should have an acute neurology ward area, led by a consultant neurologist with specialist staff. Consideration should be given to locating this ward next to the acute stroke unit to allow for the sharing of specialist medical staff, nurses and allied health professionals. [R3]

3.18 The operational policy should include:

- daily consultant ward rounds
- local neuroradiology linked to the regional neurosciences centre
- local access to clinical neurophysiology
- access to local ITU and neurorehabilitation
- close operational links to the regional centre for rapid transfer and repatriation of appropriate patients, including surgically stable head injury and post-neurosurgical patients
- the development of on-call rotas as resources permit. [R4]

3.19 Consultant neurologist management of emergency cases could be achieved immediately by modification of job plans to include ward liaison work, emergency outpatient clinics and daily ward rounds in admitting areas to prevent and shorten admissions. [R5]

3.20 This acute service requires an expansion in the DGH neurology workforce with job plans which include sessions for local unscheduled care. Consideration should be given to appointing neurologists solely to provide emergency care to ensure that this is achieved. [R6]

4 Neurology outpatient services (scheduled care)

- 4.1 Neurology clinic activity expanded by 40% from 2003 to 2007, in contrast to geriatric (30%) and general internal medicine (GIM) (5%).³⁰ This increase was not anticipated. In England this has been complicated by ‘choose and book’, which offers a deceptively simple solution to making appointments, but fails to recognise the immense value of triage by consultant neurologists, along with advice and direct communication between GP and consultant.
- 4.2 While targets have reduced unacceptable waits for new appointments, the increase in outpatient activity has outpaced consultant supply, disadvantaging the provision of acute inpatient and long-term care, and often achieved only by ad hoc waiting list initiatives with – unsurprisingly – temporary benefit on the waiting time.
- 4.3 A recent King’s Fund study has suggested that ‘not all referrals are necessary in clinical terms and a substantial element of referral activity is discretionary and avoidable.’³¹ This was apparent to the Working Party, who were clear that innovative referral management strategies are required, agreed between the commissioner, primary care and provider, and supported by audit, consultant feedback and peer review. Otherwise, it will be difficult to introduce or finance, for instance, the effective use of referral guidelines or identification of, and remedial action for, high referring practices.
- 4.4 This development would encourage the introduction of referral guidelines and possibly the identification of link GPs within a single practice or a group of practices as mutual channels for improved access, education and better targeted referrals.
- 4.5 Two examples of the benefits of such a collaborative approach are email triage of referrals,³² which replaced patient attendance in 45–60% of referrals, speeding decisions, saving 40% of consultant time and producing high GP satisfaction with a very salutary effect on referral quality; and also NeuroMail,³³ an email advisory service to GPs which has been very successful.
- 4.6 Community outpatient activity can take different forms. For example, provision of neurology clinics in GP surgeries has been piloted from three centres,³⁴ demonstrating the benefit to patients and GPs through better interfacing between primary and secondary care. The increased travel time for the neurologist has to be part of the job plan. Community clinics can only work in certain circumstances, but may become part of the portfolio of clinic services needed to improve access and encourage education and training in primary care.
- 4.7 With the required skills, and practising within a neurology network that provides appropriate governance, GPwSIs and specialist nurses have the potential to improve care and reduce follow-up requirements by consultant neurologists. For example, although 97% of patients with headache are managed in primary care, they still account for 10–20% of neurology outpatient referrals.²³ But, if GPs were to increase headache referrals by even 1%, this would double the demand for new headache appointments.²³ A GPwSI intermediate care headache service might manage these patients more economically and with better patient satisfaction,³⁵ freeing up consultant neurology outpatient capacity.

Recommendations

- 4.8 Scheduled outpatient care should not only achieve national access targets, but should also be delivered close to the patient’s home. Urgent advice should be easily available to reduce unnecessary admissions. [R7]
- 4.9 The present unrestricted referral system is a poor use of limited resources that need to be diverted to improve unscheduled care. Demand should be controlled by a local management strategy agreed by the clinicians using referral guidelines and audit to improve referrals. [R8]

- 4.10 Innovative methods should be explored such as email triage, email advice and telephone clinics. Greater use should be made of GPs, particularly for the management of headache and the follow-up of some neurological conditions in remission. Consideration should be given to developing linked GPs across neighbouring practices to filter referrals arising in the practice, liaising with the local neurologist for training and support. [R9]

5 Long-term neurological conditions

- 5.1 Care for patients with long-term neurological conditions has traditionally been based in DGH or regional neurosciences centre outpatient clinics, generally consultant delivered and, more recently, with specialist nurse input. Shortage of specialists and lack of multidisciplinary working has resulted in patchy support for these patients, for example:
- Epilepsy Action³⁶ reported that in England (2008) 50% of trusts do not have a consultant with special expertise or interest in epilepsy; and 60% of trusts have no epilepsy nurse
 - the sentinel audit into epilepsy deaths³⁷ noted that a number of those who died had not seen a neurologist in the preceding year despite still having seizures
 - the Parkinson's Disease Society¹⁸ showed that, despite NICE guidance, 15% of patients have never been seen in hospital by a specialist; 30% diagnosed within the last year have not been given clear information about the diagnosis; 25% of all patients with PD have never seen a PD nurse; the majority have not received multidisciplinary team assessment or treatment; and a third of patients admitted to hospital did not feel that the staff knew anything about PD.
- 5.2 Evidence from other charities (see online-only appendices uploaded alongside the electronic version of this report) and published work^{19,38} revealed a lack of strategic planning and of local facilities, poor and unequal access to care, failure to implement NICE guidelines, and the wish, expressed by all charities, for patients to be treated by professionals in multidisciplinary networked teams that include, where appropriate, specialist nurses and GPwSIs.
- 5.3 In its response to the National Service Framework for long-term conditions, the ABN⁴ recommended integrated care pathways, with networks of care having a lead clinician, multidisciplinary teams, key workers and a single point of contact for patients.
- 5.4 Most patients with straightforward stable neurological disorders do not need continuing care at a hospital. What they do need, however, is the reassurance that they are being cared for within a network of care that encourages shared best practice, good communication and easy access to the service when and where necessary.
- 5.5 The Working Party examined different ways of improving care in the light of the Darzi principle of care closer to home, noting evidence from innovative practices, including the contributions of the 'teams without walls' approach³⁹ and the Action On Neurology programme.³³ It was impressed by the evidence that team management⁴⁰ of patients with long-term neurological conditions is cost effective, particularly by avoiding unnecessary admissions through early intervention and support.
- 5.6 There is great variety between different models of good practice reflecting local variation but, as with scheduled care, the good examples highlight the benefits of a planned and collaborative approach between primary and secondary care, and the engagement of the local neurologist.
- 5.7 Recurring themes are the single point of contact, the need for a caseload register (essential for planning), regular review, self or relative/carer referral, fast re-access to specialist advice, signposting of services and a means to confer rather than refer. Such programmes can be entirely NHS-based, such as NeuroPact in St Helier,³³ or use joint working between the statutory and voluntary sectors, such as the Integrated Neurological Services and the West Berkshire Neurological Alliance.
- 5.8 The GPwSI role as part of a network of neurological services has considerable potential. As well as reducing pressure on hospital clinics and improving access for those who cannot drive or travel, this might bring an extra dimension of care for long-term neurological conditions. GPwSIs have a good understanding of psychosocial, family and employment issues, with links to social and other local services, and are able to create opportunities for joint clinics, education and improved specialist access.

- 5.9 For instance, in epilepsy, GPwSIs improve care for breakthrough seizures, diagnosis review, adverse effects of medication, poor seizure control and – importantly – they provide services for those such as substance users and people with mental health problems who tend to avoid secondary care.
- 5.10 However, GPwSIs cannot function in isolation. As the Action On Neurology programmes³³ show, they require the equal collaboration of local commissioners, GPs and the neurologist. Follow-up of the four projects involving GPwSIs demonstrated that the only successful one was underpinned by such coordinated planning.
- 5.11 Since the 1996 RCP report, the specialist nurse role has evolved in line with NICE and ABN recommendations. The creation of DGH neurology beds will help develop a career pathway for neurological nursing in both secondary and primary care.
- 5.12 Most specialist nurses are disease-specific, though there are generic nurses, such as the one sponsored by the West Berkshire Neurological Alliance. They improve significantly the quality of care at lower cost, mainly by preventing unnecessary admissions, through advice, information, support, counselling and – with appropriate safeguards – adjustments in medication. Consultant neurologist time spent training the nurses and cooperative working is more than offset by the reduction in consultant neurologist outpatient demand, freeing capacity for complex cases.
- 5.13 The Parkinson's Disease Society provided evidence that a PD nurse can reduce consultant neurologist outpatient time by 40%, assuming responsibility for monitoring and adjusting medication, and reducing (re)admission rates by 50%.⁴¹ The total cost saving would be in the region of £6 million in England alone.⁴² Much the same applies to specialist nurses in epilepsy and MS.⁴³
- 5.14 The 1996 RCP report¹ recognised that 'proper provision of neurological services will necessitate major expansion of resources for rehabilitation'. This has not happened, and most rehabilitation services are still only provided regionally. However, recognition that early rehabilitation before patients are medically stable may speed recovery means that neurorehabilitation should start in secondary care. DGH neurorehabilitation should therefore be developed as part of a local neurology service spanning primary and secondary care.
- 5.15 This requires considerable expansion in DGH-based consultant neurorehabilitationists, but would open the way to collaborative working in the post acute management of stroke and chronic neurological conditions. For instance, the neurological rehabilitation unit could be co-located with the stroke unit, with better community links as part of a coordinated network of care for patients. This would provide flexibility to cope with seasonal fluctuation in stroke admission rates, along with earlier transfer of patients from the regional neurosciences centre and on to community care. It would also be an invaluable teaching and training resource. Evidence given to the Working Party showed the considerable benefits of this arrangement.
- 5.16 Unlike the European model, psychiatry and neurology in the UK have developed as separate disciplines, with psychiatry often based in separate hospitals. This has resulted in a lack of a cooperative approach, disadvantaging several groups of patients. Up to one third of new outpatients in neurology clinics have functional rather than recognisable physical disorders,²⁰ and recurrent 'neurological' admissions for non-organic disorders, particularly non-epileptic attack disorder, are common. Patients with functional disorders may have a much higher chance of distress and disability than those with neurological disease; and they often use considerable resources through multiple admissions and outpatient appointments. Also, patients with chronic neurological disorders often develop psychiatric or psychological complications. Neurologists are well trained in the diagnosis but not management of these patients, for whom there is rarely appropriate access to liaison psychiatry. Proper care pathways need to be developed for these

patients. The DGH-based neurologist would be well placed to take on clinical leadership for the trust in developing better models of care with psychiatrists.

- 5.17 The Dementia Strategy⁴⁴ makes clear that implementation should be the responsibility of psychiatry. Its second objective requires good quality early diagnosis and intervention for all, and proposes a specific service for their delivery. UK neurological research has considerably advanced the understanding and diagnosis of many types of dementia, particularly in younger patients where the differential diagnosis is wide and sometimes complex. However, the value of neurological involvement with dementia services, particularly in diagnosis, is often overlooked, perhaps because of the high prevalence of dementia in older people and the small number of neurologists at present. Nonetheless, dementia services should include access to neurology, which is more likely to be achieved with more DGH-based neurology consultants.
- 5.18 Better arrangements are needed for the transfer of children with chronic neurological disorders from paediatric to adult neurology services, for example those with epilepsy or muscular dystrophy. These are best developed locally, but in consultation with the regional neuromuscular and epilepsy services.

Recommendations

- 5.19 The management of long-term neurological conditions requires joint planning with commissioners and primary and secondary care providers, along with local patient and voluntary sector input. [R10]
- 5.20 Clinical leads should be designated for the more common conditions, such as MS, epilepsy and movement disorders, having responsibility for the development and provision of networked programmes spanning primary, secondary and tertiary care. [R11]
- 5.21 Initial diagnosis and treatment by neurologists in secondary care should be followed by community care consisting of access to a key worker and multidisciplinary community teams that are disease-specific for common neurological conditions, and led by professionals with specialist expertise, including nurse specialists, GPwSIs and professions allied to medicine. The community team should have close links with easy access to the appropriate DGH-based neurologist. [R12]
- 5.22 Specialist nurses play a particularly important role; these posts, both disease-specific and generic should be expanded. Similarly, the role of GPwSIs within structured care pathways should be developed, particularly for chronic epilepsy, MS and PD, whereby a local GPwSI leads each of these community services. [R13]
- 5.23 Commissioners should develop proper care pathways for the management of head injury, functional illness and the psychiatric complications of chronic neurological disease. They should also ensure neurological diagnostic input into local dementia services. [R14]

6 Relationship with the regional neurosciences centre

- 6.1 Regional neurosciences centres provide diagnostic and management expertise in complex and rare neurological disorders. They have the beds, though often too few, for the investigation and treatment of these patients, as well as access to specialised neurocritical care and neurosurgery. They also tend to have sophisticated services unavailable in DGHs, eg complex clinical neurophysiology, specialist neuroradiology, neuropsychology and neuropathology. They play an integral part in the care of many patients at varying times during their illness.
- 6.2 By providing clinical governance, audit, CPD, appraisal, research, teaching medical students and training young neurologists, these centres are a fundamental and essential part of any regional neurology network. This network is crucial to the future development of local DGH services, also permitting the growth of practice- and population-based research.
- 6.3 DGH-based consultant neurologist appointments must be part of this broader regional network, with easy access to the regional neurosciences centre's clinical and educational facilities. Such access also provides scope for all neurologists, centre- or DGH-based, to offer subspecialty services of wider regional value, linked to local long-term condition services.
- 6.4 The precise model will vary, with DGH-based consultants playing different roles in the regional neurosciences centre, for example, providing sub-specialist clinics, on-call, teaching, research or management, possibly with their DGH role back filled by centre-based clinical academic neurologists, but the collaborative network principle is the same.
- 6.5 Few DGHs provide even basic EEG or nerve conduction studies. Most clinical neurophysiology work is based in the regional neurosciences centre. Given the shortage of clinical neurophysiologists, this problem is unlikely to be resolved quickly. However, DGH services could be improved by appointing neurophysiology technicians to undertake EEGs and simple peripheral nerve tests, with remote reporting if required. Furthermore, neurologists with subspecialty training in epilepsy, peripheral nerve or muscle disease could, with training, technical support and planned time, provide some local input to their own clinical neurophysiology service (and so patients would not have to travel to the regional centre).
- 6.6 It is still important that the governance of such services remains with the regional centre, where clinical neurophysiologists would continue to undertake more complex investigations, and also provide training and mentoring across the whole regional neurology network.
- 6.7 MRI and carotid duplex scanning are now available in most DGHs. A local neurology service requires the appointment of radiologists with appropriate training in non-interventional neuroimaging, supported by image-linked access and video conferencing to the regional neuroradiology service. This must be formalised through service level agreements, shared funding of appointments, and protected time. A regular DGH multidisciplinary radiology meeting with remote regional neurosciences centre links is feasible and should be part of any DGH neurology service. This is fundamental to the safe and secure operation of DGH neurology. DGH general radiologists cannot be expected to report difficult neuroradiology; misinterpretation can be disastrous. Complex and interventional neuroimaging will continue to be based in the regional centre.

Recommendations

- 6.8 Commissioners should work closely with acute trusts, the regional neurosciences centre and RCP regional specialty advisers in neurology to ensure that new consultant neurologist posts have appropriate job plans with programmed activities for CPD, audit, clinical governance, revalidation

and, where appropriate, clinical sessions in the centre. This reflects the continuing importance of the regional neurosciences centre in the network of care, and acknowledges that, particularly while neurology remains a shortage specialty, it is important to ensure that new DGH-based neurology posts are attractive to potential applicants. [R15]

- 6.9 Until sufficient neurology sessions are available to provide on-call locally, the regional neurosciences centre should have responsibility for this component of provision within the DGH. Telemedicine to support the current telephone-based service should be explored. [R16]
- 6.10 DGH investigations with clinical neurophysiology tests (EEG and nerve conduction studies) and MRI/CT scanning should be available with regional neuroscience links through joint appointments, service level agreements and the use of telemedicine to ensure that local management of patients is properly supported. [R17]

7 Training

- 7.1 Medical students lack competence and confidence in neurology, even sometimes amounting to ‘neurophobia’.⁴⁵ This is not surprising, since some get less than three weeks of neurology exposure. Where students get more, they have as much confidence in their neurology knowledge and skills as with other specialties. Given the ubiquitous nature of neurological disorders, increased educational opportunities for undergraduates are essential and a proper DGH neurology service would easily provide the necessary exposure to common conditions.
- 7.2 ‘Neurophobia’ extends to core medical trainees, who rarely have any formal neurological training in DGH or participation in centre-based rotations. They have little contact with junior or senior neurologists. This lack of familiarity and exposure may account for the current recruitment difficulties into neurology training grades.
- 7.3 The development of DGH neurology, particularly involving increased involvement with inpatient management, would address this through attachment to neurology teams, joint working with stroke units, and exposure to neurology trainees and multidisciplinary working. It is likely that the same experiential improvement noted by the Leeds liaison service would apply to junior staff.
- 7.4 Neurology trainees value attachments in the DGH, which bring experience of acute unselected common neurological emergencies, including stroke, and the care of associated comorbidities. This provides valuable experience in management without immediate access to regional neurosciences centre facilities, better contact with other trainees (to mutual benefit) and exposure to the wider aspects of neurology outside hospital, including specialist nurses, GPs and multidisciplinary teams. Currently SpR training should include one year in a DGH; the development of DGH-based neurology would provide the potential for more DGH neurology training as the number of local neurology trainers increases.
- 7.5 The Working Party received evidence that both trainee and specialist workforce planning will be devolved locally in the future. While this is being undertaken, the Working Party recommends that some central control be retained to ensure that there is sufficient expansion of the training grades to meet the requirements of a DGH-based, as well as centre-based, service in the immediate future. In particular there should be more trainees in regions, where there is a shortage of consultant neurologists.

Recommendations

- 7.6 Current government policy does not support training expansion. However a further increase in neurology training posts is necessary to provide staffing for a consultant-led DGH service. As neurology expands at a local level, exposure to DGH training for neurology trainees should be significantly increased from the current one out of five years. [R18]
- 7.7 Teaching neurology to medical students in a DGH setting should be encouraged in local neurologist job planning. DGH core medical training and acute medicine physician training should include rotation through neurology and include exposure to the acute inpatient service. [R19]

8 Workforce planning

- 8.1 It is axiomatic that people with neurological conditions should be managed by professionals with appropriate neurological expertise.
- 8.2 While the ABN calculations suggest that an outpatient diagnostic service in the UK requires one FTE consultant neurologist per 100,000 population,² more are required to provide DGH inpatient care for neurology patients, including on-call, contribution to acute stroke care, training of junior staff, GPwSIs and specialist nurses, teaching medical students and the development of new services.
- 8.3 Evidence presented to the Working Party indicated that, in the Netherlands – with a broadly similar health system to the UK, but where neurologists look after stroke, back problems and head injury – there is one FTE consultant neurologist per 26,000 (and one geriatrician per 80,000).
- 8.4 In 2002, based on European practice, the ABN recommended² that one FTE neurologist per 43,000 would provide a comprehensive DGH neurology service, including local on-call. To meet this target would require increasing neurology consultants to about 1,000 FTEs, a process, which according to evidence presented by the Workforce Review Team, would not, at the current rate of expansion, be achieved until well after 2025.
- 8.5 The Working Party recognised that this figure of one per 43,000 included elements of psychiatry, stroke, neurophysiology and neurorehabilitation, which are more integrated into European neurology. Since in the UK, there is considerable overlap between the roles of geriatrician, stroke physician, neurorehabilitationist and neurologist, this figure needs to be revised.
- 8.6 Comprehensive DGH neurology services will be team based, and their development inevitably and rightly will reflect the resources already available to care properly for neurology patients. More neurologists need to be appointed to the DGH to provide the necessary services described in this document, particularly acute neurology, but expansion will be determined by a bottom-up, rather than a top-down, commissioning process, reflecting local needs.
- 8.7 No figure can therefore be prescribed, but the Working Party was struck that two units providing a comprehensive service reported being under some strain with one FTE per 75–80,000, and that an increase to one per 70,000 is appropriate for the service model described by the Working Party.

Recommendations

- 8.8 The provision of a comprehensive DGH service requires at least one FTE consultant neurologist per 70,000 population, representing a total of around 880 posts at present UK population figures. [R20]
- 8.9 Although current government policy does not support training expansion, a further increase in neurology training posts is necessary to provide the staffing for a full consultant-led DGH service. [R21]

9 Commissioning and implementing services

- 9.1 Neurology patients often require care across different health providers, as well as significant social care. One of the principal recommendations of the National Service Framework for long-term conditions is to achieve joint commissioning between health and social care.
- 9.2 However, examples of successful engagement are hard to find and the Working Party was concerned that the isolated commissioning of single parts of the care pathway will lead to fragmentation, be clinically unsustainable and represent poor value for money.
- 9.3 This problem is compounded because neuroscience commissioning can be complex, reflecting the spectrum from long-term management of common conditions (such as PD) in the community, to single site national programmes for much rarer diseases (for example, mitochondrial disorders). Moreover, traditional regional centre-based service design has disadvantaged local provision. The Working Party welcomes the devolution of policy making,⁴⁶ which should provide a basis for the planning of local services, which could then be developed by clinicians in both primary and secondary care.
- 9.4 Neurologists, either DGH- or regional neurosciences centre-based, must provide clinical leadership and advice to local and specialty commissioners for the development of services, organised as a network of care comprising the regional centre, associated DGHs and community services, allowing patients easy access at any point in the network appropriate to their needs at the time, and with the facility to move around the network as clinically necessary. This needs to be supported by better contact between neurologists and commissioning authorities and by acute trusts in job planning to allow time for this.
- 9.5 This report describes a comprehensive model for neurology services in the DGH and in the community, networked with the regional neurosciences centre. To establish this service fully will require the expansion of consultant neurology posts from the current FTE of one per 115,000 to one per 70,000, representing an increase from the current numbers (c600) to around 880 FTEs. Based on present rates of expansion (extrapolation of the presented Workforce Review Team English data), this will not be achieved until well after the next decade.
- 9.6 However, a faster expansion of DGH-based neurologist posts would not only address the current inequality of services, but provide much better care in the community, prevent unnecessary admissions and clinic attendances, shorten length of stay, and reduce hospital outpatient follow-up, all of which are likely to prove more cost effective than the current haphazard approach.
- 9.7 We recognise that, even without the likely financial restrictions, this model will take time to establish, not least because of the lag in expanding the training grades through to completion, but that is all the more reason to develop a strategy and start implementing this now.
- 9.8 It is inevitable that the development of a local neurology service, fit for purpose, will require financial support over the next decade, but it is clear that much can be done initially without major investment.
- 9.9 Central to the implementation of this report is the creation of local neurology service commissioning groups with adequate clinical representation from primary and secondary care, to ensure pragmatic clinical pathways and resourcing priorities. The contribution of locally based neurologists and primary care physicians is essential to this process, as is the development of links to regional commissioning boards and deaneries.
- 9.10 Membership of this commissioning group should include:
 - the commissioner for long-term conditions/neurosciences

- the medical director or equivalent of the local primary care trust(s)/GP consortia
 - local GP champions for neurological disease
 - the local DGH neurologist(s)
 - the DGH neurology business manager
 - clinical nurse specialists
 - allied health professional representative
 - consultant in neurological rehabilitation
 - link to regional planning board
 - charity representative(s).
- 9.11 This group should plan and, over a decade, provide integrated services based on this report for a population of around 500,000 (see appendix), a unit size that will ensure economies of scale sufficient to provide properly supported neurology inpatient and investigation facilities. DGHs covering smaller populations may have to combine in order to provide a shared neurology service and avoid the professional disadvantages of the isolated neurologist.
- 9.12 As a first step, this group should examine the provision of scheduled care and design a service with agreed activity. This should be matched by the provision of more innovative access to specialist neurological advice and the development of networked primary care programmes, starting with headache.
- 9.13 Resources freed by this approach should be used to increase the emphasis on unscheduled care, initially with the development of liaison work, and acute neurology care pathways involving all acute DGH physicians. There are clear benefits from closer working with the acute stroke team and urgent neurovascular clinics.
- 9.14 Care of long-term conditions should become increasingly community-based, with community teams including specialist nurses, and GPwSI and allied health professionals.
- 9.15 Nationally there should be awareness of problems caused by restrictions on training and lack of strategic planning, and a determination not to lose sight of these until it is clear that they can be handled regionally.
- 9.16 At a regional and deanery level, key stakeholders with strong clinical input should develop a networked regional strategy based on these recommendations, including workforce and training predictions.
- 9.17 These plans should be submitted to the regional or local health board for approval and supervision with timelines for action.
- 9.18 While there will be little money available in the immediate future for the development of new posts, evidence to the Working Party stressed that some of these recommendations should be self-funding through increased efficiency, while considerably improving care. We cannot afford not to implement them.

Recommendations

- 9.19 There should be national and regional, as well as local, responsibility for implementing the report. A 10 year action plan should be agreed and monitored annually by the regional authority,

which should assume responsibility for sustaining progressive development of local neurology services. [R22]

- 9.20 The development of the service model proposed requires the establishment of a local commissioner and provider group with strong clinical representation from neurology and primary care. DGH-based neurologists should recognise the critical importance of clinical championship in these groups, and this should be fully supported in job planning. [R23]
- 9.21 Working with regional commissioners and their equivalents in the other three countries of the UK, a plan should be made to commission progressively a comprehensive local neurology service over the next decade, based on a unit population of 500,000. Commissioning should be undertaken against nationally agreed service specifications and within an agreed quality assurance framework. It should particularly recognise the need for unscheduled as well as scheduled care, the importance of the regional neurosciences centre contribution, and the value of community teams for long-term conditions. [R24]
- 9.22 Evolution of services over a decade will require investment. However, a step-wise approach, in which initial improvements are achieved by controlling outpatient demand and improving the efficiency of unscheduled and networked long-term care, will lay the basis for planned future developments. [R25]
- 9.23 Commissioners for neurosciences and their equivalents in the other three countries of the UK should develop comprehensive local neurology services that recognise the importance of emergency and urgent as well as scheduled care, and the value of networked services for these and long-term conditions. Acute neurology services should be commissioned locally to ensure that appropriate facilities are established. [R26]
- 9.24 These plans should include strong clinical representation from the DGH neurologist(s) and should recognise the crucial importance of a regional component to the provision of a successful local service, and vice versa. [R27]
- 9.25 DGH-based neurologists should recognise the critical importance of clinical championship; this should be fully supported by the employing trusts through job plans. [R28]
- 9.26 Commissioning should be undertaken against nationally agreed service specifications and within an agreed quality assurance framework. [R29]

Appendix

Commissioning recommendations for local neurology services for a population of 500,000

Introduction

This appendix provides outline commissioning guidance for neurological conditions to clinical advisers, GP consortia, regional boards of the National Specialist Commissioning Framework and national agencies. Evidence is taken from previous ABN reports, PD and MS nurse societies' recommendations, and the experience of several DGH-based neuroscience units. The recommendations have been developed around a population of 500,000, a size that will support the development of neurology inpatient and outpatient services, as well as local coexisting long-term care programmes. It does not include commissioning guidance for neurological rehabilitation, which has recently been made in two separate documents, to which commissioners are referred.^{47,48}

Although neurological symptoms and conditions are common in all communities, current provision of neurological services has largely been based around existing neurology specialist centres. The new report recognises the frequency of neurological symptoms and illnesses, and the consequent disability in the community, and suggests a radical shift towards more locally provided expertise and services.

An essential prerequisite of the commissioning process is the early identification and involvement of clinical leads from primary, secondary and tertiary providers, who are jointly responsible for the development and running of the networked service.

There is likely to be no single solution, as geography, location of hospitals and resources, and pre-existing working patterns in primary, secondary and tertiary care will affect the provision of services. For example, most tertiary neurological services also need to provide secondary care services and to liaise with primary care in order to serve the needs of its local population. How the commissioning within a population is apportioned between local, regional and national agencies will vary; the boundaries between them are less important than their proper interaction. Currently, the 37 UK centres have an average catchment population of 1.67 million, suggesting that for each centre, commissioning support should be drawn from at least three 500,000 population units.

1 Scheduled care

Number of new outpatient appointments annually

The neurologist's role when seeing new patients is to establish a diagnosis and make management plans using community teams (where available) to follow patients up and re-refer when appropriate. Across England the current average number of new appointments in neurology is 9.5 (standard deviation of 3) per 1,000 resident population over the age of 15. There is currently wide local variation, a consequence in part of the variation in availability of consultant neurologists.⁹ Moreover, the number of new appointments has risen by 11% in the past year, an incremental rise that has been sustained nationally for four years.⁴⁹ However, the experience of four secondary neurological units, along with the national figures, suggests that a good approximation of current demand would be around 4,000 new patient appointments *per 500,000* population per year.

Number of follow-up appointments annually

In England in 2008–9 the number of follow-up appointments in each PCT varied considerably, with a mean of 19.4 (sd8.4) per thousand of population.⁹ The overall ratio of old to new appointments was 1.46.⁹ Between 5,000–9,000 follow-up appointments will be required for a population of 500,000.

The wide range partly reflects need for consultant follow-up of complex cases, but more the lack of organised community follow-up. As more community programmes with nurse specialist and GPwSI support are established, the numbers of consultant follow-up appointments should fall in line with commissioning intentions that scarce consultant resources should focus more on diagnosis, advice and management planning.

Types of clinic

General neurology clinics

These provide an unselected local service with easily accessible urgent appointments. Spiralling demand needs commissioning management through agreed guidelines, the innovative use of IT and a reduction in routine consultant follow-up for long-term care. Resources saved should be redeployed to increase rapid access urgent clinics as part of an admission reduction policy.

Local specialised clinics

These should be provided in epilepsy, MS and movement disorders as part of long-term care programmes (see below). There should also be an intermediate headache service provided by GPwSI in the community with supervision by, and referral to, secondary care for complex cases.

The increasing numbers of patients with functional disorders seen in scheduled neurology clinics requires formalised access to a psychology and liaison psychiatry service. There should be neurological involvement in the development of a dementia service, particularly for diagnostically difficult and young patients.

Locally delivered regional specialist clinics

There should be regular visiting multidisciplinary clinics for neuromuscular disease⁵⁰ neurogenetics, neurosurgery and neuropaediatrics, provided by specialists based in the regional centre.

Regional clinics

A minority of services, for instance for rare diseases, or those dependent on multidisciplinary working with neurosurgeons, neuroradiologists or neuropathologists, will be delivered within the regional centre.

2 Emergency care

Acute neurology

A planned approach to the management of local acute neurology would reduce admissions, improve management and hasten discharge. Given the current shortage of neurologists, this may need to be undertaken initially as a planned collaboration with other clinicians, particularly stroke, other acute physicians and geriatricians.

As a minimum this requires two neurology consultant programmed activities daily in each admitting hospital to manage acute neurological emergencies, including daily clinical decision unit ward rounds, inpatient supervision, emergency clinics to avoid admission and other referrals arising in the hospital.

One option for many hospitals would be to consider appointing a liaison neurologist in preference to an elderly care physician or acute care physician, as at least 10% of acute cases are neurological. These posts may be self-funding, preventing admissions, reducing medical error and shortening lengths of stay through better targeted investigation and intervention.

Where smaller sized DGHs occur in close proximity, one hospital should specialise in acute neurology, and appropriate cases from the neighbouring hospitals should be rapidly transferred to this unit. Daily ward liaison sessions by neurologists are necessary at the other hospitals to see the emergencies and to ensure the right patients are transferred promptly for further acute neurological care and investigation. This model will achieve most efficient use of resources with local provision of acute care and best outcomes. Also, in more sparsely populated areas of the country where the DGH population is smaller, more neurologists could be appointed in preference to stroke physicians to allow a greater presence or combine with the stroke teams to provide daily acute neurological care. Telemedicine should be considered in some areas (eg Cumbria).

Neurological participation in TIA clinics should be strongly encouraged, since up to half the cases seen are neurological rather than neurovascular. This *de facto* existence of unscheduled urgent neurology clinics should be recognised and developed.⁵¹

Local neurology beds

Between 10–15 dedicated neurology beds (excluding stroke care) are necessary to deal with local inpatient neurology care. The number of beds should be calculated to include post neurosurgical repatriation and head injury, and a programmed investigation unit for lumbar puncture and intravenous therapy. Where possible, these beds should be co-located with acute stroke units, because of the overlap of nursing, medical and diagnostic expertise, and rota demands. Time should be identified for daily consultant ward rounds, including neurology liaison with the acute stroke unit.

Junior neurology staffing and rotas

It is unlikely that sufficient junior neurologists will be available to fully staff local neurology beds, and every attempt should be made to capitalise on the overlap between acute stroke and neurology by maximising the integration of resources. A similar pragmatic approach should be employed with specialist training opportunities for geriatrician SpRs and acute medicine trainees.

One FT2–3 from the core medical rotation per six beds is required, preferably as part of a joint stroke/neurology post, together with two to three neurology/acute medicine/geriatrician SpRs to cope with ward work and to contribute to outpatient capacity and on-call.

The requirements of the European Working Time Directive (EWTD) makes it unlikely that sufficient FT2–3 staff would be available to provide a stand-alone rota. The neurology on call will need to be subsumed into the general hospital rota. This means that a robust SpR rota of no less than one in five, including prospective cover, is necessary, supported by a consultant neurologist on call. It is also unlikely that six neurology SpRs will be available for this size of service, and the shortfall will need to be made up with senior ST3s acting up, stroke and neurorehabilitation SpRs, and trust grade doctors. Cover from SpRs from non-neurological disciplines is less attractive as it weakens specialist support. However, pragmatic solutions, such as a period of specialist stroke/neurology training for geriatrician SpRs and acute medicine trainees, would provide an interim approach, if underpinned by proper governance.

Consultant neurology on-call

Six to 10 consultants are required to run a local, on-call service, which could include a contribution to the stroke thrombolysis service.

On-call support services

This would require CT and MRI out of hours. It is unlikely that a 24/7 EEG service would be financially viable, though hybrid models in adjacent units might be possible for the management of status epilepticus. ITU availability is required at a local level.

3 Long-term conditions

These include epilepsy, MS, movement disorders, head injury and 'rare conditions' with overlapping long-term needs, including motor neuron disease, neuromuscular disease and the consequences of single incident brain injury (neurosurgery, head injury and encephalitis). Support for the neurological complications of dementia should also be considered.

Most of the care for this group of patients should take place in the community. These patients are best managed by specialist nurses and GPwSIs linked into networked programmes of care with easy access to secondary/tertiary specialist care, as well as generic community and social resources. Identified linked neurologists should be part of these teams, providing advice on difficult cases, support, education and rapid access to secondary care.

No figures yet exist for GPwSI, but for specialist nurses the figures are:

- three MS nurses⁵² (MS Trust recommendation)
- three PD nurses⁵³
- nine epilepsy nurses⁵⁴
- one specialist nurse each for single incident brain injury and 'rare conditions'.

Community-based neurorehabilitation team

The make-up of this is difficult to specify, because there are a variety of different models, including intermediate care and charitably-supported teams. However, all should have clinical leadership, preferably a GPwSI with links to secondary care. The core should comprise physiotherapy, occupational therapy, speech therapy and clinical psychology. They can be easily developed from community stroke teams, which are really no different, being a dedicated team for static brain injury.

4 Investigations

There should be access to necessary regional specialist services, such as interventional radiology, PET scanning, complex neurophysiology, which should be defined through service level agreements.

Local investigations

This should include sufficient CT/MRI, nuclear scanning, basic neurophysiology, nerve conduction studies and EEG, including telemetry, for a population of 500,000. Service level agreements should be in place for reporting of MRI scans by neuroradiology, in conjunction with local named general radiologists dedicated to neurology.

Neurology consultant numbers

To deliver a comprehensive DGH neurology service requires 7 FTE consultants.

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