



**Briefing: October 2020**

## Specialised neurology

**Nigel Edwards**

### **Introduction**

NHS England's Specialised Commissioning team lead a national programme aimed at improving specialised adult neuroscience services in England. The work programme seeks to support emerging regional teams as well as Integrated Care Systems in the NHS, through establishing 'what good looks like' for specialised neuroscience services for a local population – working closely with colleagues from other programmes such as Getting It Right First Time (GIRFT) and NHS RightCare to capture both provider and clinical insights and support local improvements.

There are two main workstreams to the programme: adult neurosurgery and specialised neurology services for adults.

### **Specialised neurology services for adults**

Much of the care that adults living with neurological conditions access is locally funded by CCGs (clinical commissioning groups) rather than specialised commissioning, so one of the aims of this work is to develop a clearer definition of specialised neurology, and improve access to specialised and specialist elements of care when required – delivering the right care at the right place and at the right time. For neurology, the programme explored three care pathways: multiple sclerosis, epilepsy and neuro auto-immune disease, with a view that learning from these three conditions will help build a future model for

specialised and specialist care that applies to most other neurology conditions, and help identify a definition of specialised neurology.

There are a number of opportunities to improve services and address a number of long-standing issues. The objectives of the current review are to:

- Improve time to diagnosis for complex neurology cases and access to specialised interventions
- Reduce inequalities in access to specialist care and input at key points in the pathway, removing the effects of a 'postcode lottery'
- Treat patients in the most appropriate care setting – delivering care as close to home as possible
- Address workforce issues through new workforce models, training and support, redistribute specialist resources to critical points in the pathway (such as diagnosis)
- Improve flow into, and out of, specialised services
- Improve capacity and demand management, by delivering the right care in the right setting
- Improve equity in access to clinical trials and support research.

## **Adult neurosurgery**

Adult neurosurgery is a specialised service, which means that it is funded nationally through specialised commissioning. Over the past year the national programme has worked with clinicians and patient groups to develop a view of 'what good looks like' for brain tumour, sub-arachnoid haemorrhage and pituitary surgery pathways, with the assumption that the principles from these three pathways are reflective of other elective, emergency and low volume pathways, respectively. Through these pathways, the programme aimed to identify the emerging model that would address issues of flow and access.

## **Scope**

The Nuffield Trust was asked by NHS England to bring together emerging thinking from NHS staff about how the delivery and commissioning models for specialist services could develop, by building on work undertaken by NHS England and NHS Improvement, synthesising new learning from national design events, and undertaking independent assessment of national and international models drawing on work done by Nuffield Trust to date.

This short report looks at specialised neurology.

Section A is based on a review of documents developed by NHS England and NHS Improvement, analysis of data and recent reports, and the outputs of two workshops with a cross-section of people involved in the area.

Section B is a forward-looking section that builds on previous work the Nuffield Trust has been involved in on commissioning models, a desk-based exercise undertaken by NHS England and NHS Improvement on national and international models, and additional exploratory conversations and desk-based work by the Nuffield Trust on other models not explored thus far.

## **Key messages**

This report was developed before the Covid-19 outbreak but the main substance of its findings remain largely unchanged. However, the closure of many services and delays in treatment as a result of lockdown, the shielding of some patients and the diversion of staff to other duties will have a lasting negative impact on waiting, which were already an issue prior to the pandemic due to increases in demand and constrained capacity. Enhanced infection prevention and control measures will constrain outpatient and diagnostic capacity. Since Covid-19 seems to be associated with some serious long-term effects, including neurological problems, the overall level of demand may increase further.

More positively, experience during the pandemic has demonstrated the potential of phone and video to provide outpatient and other care in some circumstances. This makes care more convenient for patients but may not necessarily be quicker.

There was broad support for a network approach and for the principles that should underpin it developed by the workshops. There are different options for how networks can be organised in terms of the relationship of the hub to its constituent parts, which will need to be tailored to local circumstances. A lead provider model has clear advantages in terms of governance and accountability, although it will not be possible to apply this everywhere. As with neurosurgery, the interface between inpatient services and rehabilitation requires attention, and imbalances between capacity and demand addressed to deal with problems with flow.

A new approach to the definition of specialised commissioning is proposed, which is defined by clinical input at critical points in the pathway where the expertise is essential to identify appropriate diagnostics or treatments for complex, refractory and rare cases. This represents a move away from a definition based on the place of care. Further work is required to refine this. This might use a model in which specialised top-up pays for specialised input, while non-specialised activity is paid via PBR or other payment methods. The current model of commissioning could be improved by decision-making being located closer to local systems. One option is for this to be led by the ICS/CCGs as these develop. National development of pathways and standards will still be important. Where possible, the whole pathway (or as much as practical) should sit with one commissioner.

These changes would mean that specialised commissioning would focus on a narrower range of services. Three different options for commissioning have been identified in this work and there is no reason why only one should be adopted – the models will work more or less well in different contexts. Further development of these concepts is needed over the next few months. As ICSs develop there will be opportunities to change the balance between specialised commissioning and responsibilities at the ICS/CCG level.

## **Service profile**

The definition of the speciality is not straightforward, as the area is complex and covers a number of conditions sometimes treated in other specialties. There is no clear definition for specialised neurology, and the current funding model reflects this so that NHSE pays for all activity that occurs in neurosciences centres. This creates some problems in creating coordinated pathways and networks of care, and divides responsibility for commissioning between national, regional and local commissioners.

These definitional problems may also be a serious obstacle to determining whether there is equitable funding, access or outcomes between different parts of the country. The analysis of differences in the usage of and spending on neurology services between areas is especially difficult, as is monitoring quality or creating standard practice.

There is significant unwarranted variation in patient experience and pathways through the system. This can cause delays to see a specialist and poorer outcomes for some patients who do not get specialist treatment. There are opportunities to provide advice and treatment more locally and to reduce the long distances that some patients have to travel.

There are currently 24 neuroscience centres and four neurology centres providing specialised services. These generated around 140,000 admissions (170,000 consultant episodes) in 2018/19 – of which 84% were elective, 56% of episodes were day cases and 15.5% were emergencies. Emergency patients consumed 71% of bed days. For inpatients, 75% were treated within the remit of specialised commissioning.

In 2018/19, the variation in admissions per 1,000 population was extensive with >35 CCGs having admissions per thousand population greater than the upper control limit, many of which had >10 admissions per thousand population. A similar number of CCG had admission below the lower control limit, although only one fell below four admissions per 1,000 population. The national average rate was 7.14 admissions per thousand population (Figure A).

Figure A: All neurology activity

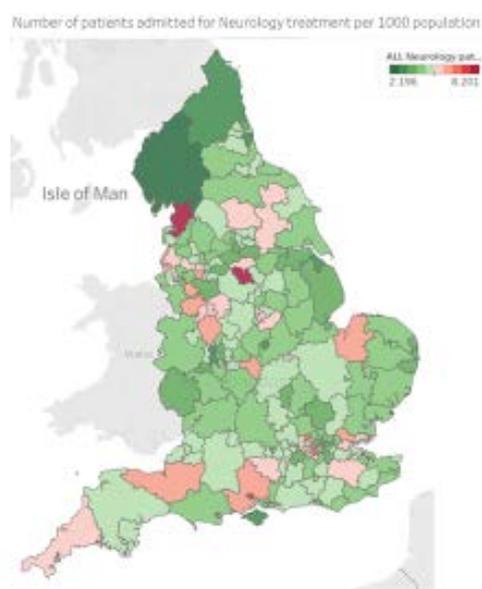
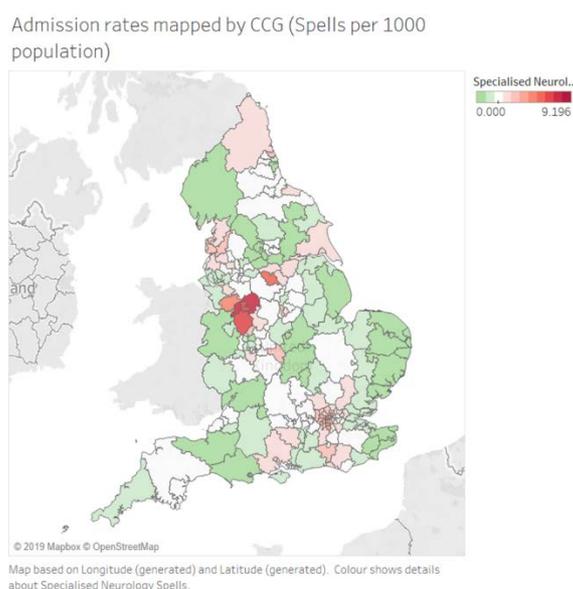


Figure B: Specialised Neurology activity



The activity per 1,000 population (Figure B) by CCG shows an even wider distribution for specialised activity. The national admission rate is 2.09 spells per 1,000 population (0.77 individuals per 1,000 population), with 53 CCGs (29%) having admission rates above the upper control limit and 63 CCGs (35%) having admission rates below the lower control limit. Only 65 CCGs (36%) fell within these boundaries (for a normal distribution this should be at 80-95% of CCGs). This is indicative of some of the definition problems faced by describing activity in this complex area.

There is a high level of variation in the use of admitted care between CCG areas. There is no obvious pattern and may only partially reflect differences in access, and be partly due to some of the issues about definition and attribution of some cases to neurology referred to above.

The episodes by main pathways for all admissions attribute to specialised commissioning are shown in the table below.

<b>Spells</b>			
<b>Pathway</b>	<b>2016/17</b>	<b>2017/18</b>	<b>2018/19</b>
Multiple sclerosis	39,637	37,987	39,306
Autoimmune disease	21,411	21,112	21,713
Headache	11,967	11,354	12,047
Motor neurone disease	7,318	7,341	7,128
Epilepsy	5,697	5,631	5,431
Stroke	9,605	2,926	3,148
Parkinson's Disease	4,158	4,317	4,841
Traumatic brain injury	316	267	297
Unallocated	26,806	26,006	26,783
<b>Grand total</b>	<b>126,915</b>	<b>116,941</b>	<b>120,694</b>

(Note the figures for stroke in 2016/17 include activity that has now been assigned to non-specialist activity in subsequent years)

## Challenges and opportunities

### Growing activity

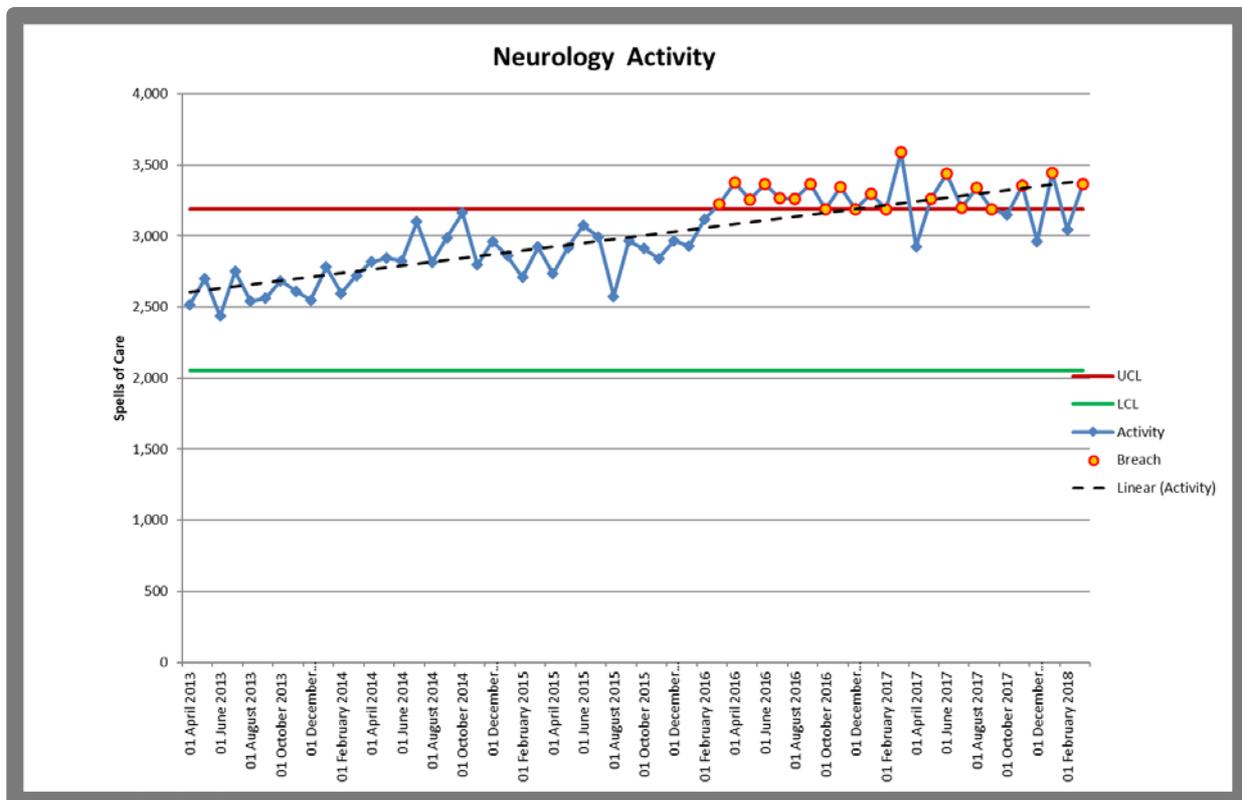
It should be noted that outpatient care represents the large majority of hospital activity, and particularly for epilepsy and headache.

The number of outpatient attendances has increased on average by 4% per annum since 2008/09, with the number of attendances in 2018/19 52% higher than in 2008/09, at an average of 121,677 attendances per month.

New appointments have seen an average annual rise of only 2%, with an average of 42,076 new appointments per month in 2018/19. Follow-up appointments have increased three times as fast at 6% per annum, at 79,214 appointments per month in 2018/19. The new-to-follow-up ratio has increased from 1:1.39 in 2008/09 to 1:1.88 in 2018/19.

Financial year	Appointment type				
	New	FUP	Not recorded	Total	FUP: New ratio
2008/09	401967	557661	21	959649	1.39
2009/10	415106	584012	26	999144	1.41
2010/11	436150	623127		1059277	1.43
2011/12	423558	636355	1	1059914	1.50
2012/13	424740	660878		1085618	1.56
2013/14	454667	730387		1185054	1.61
2014/15	477229	757002	38	1234269	1.59
2015/16	483631	813805	3857	1301293	1.68
2016/17	516213	882125	3848	1402186	1.71
2017/18	502223	904495	4506	1411224	1.80
2018/19	504916	950563	4650	1460129	1.88
<b>Grand total</b>	<b>5040400</b>	<b>8100410</b>	<b>16947</b>	<b>13157757</b>	

Neurology inpatient activity increased between 2013 and 2016, but stabilised thereafter.

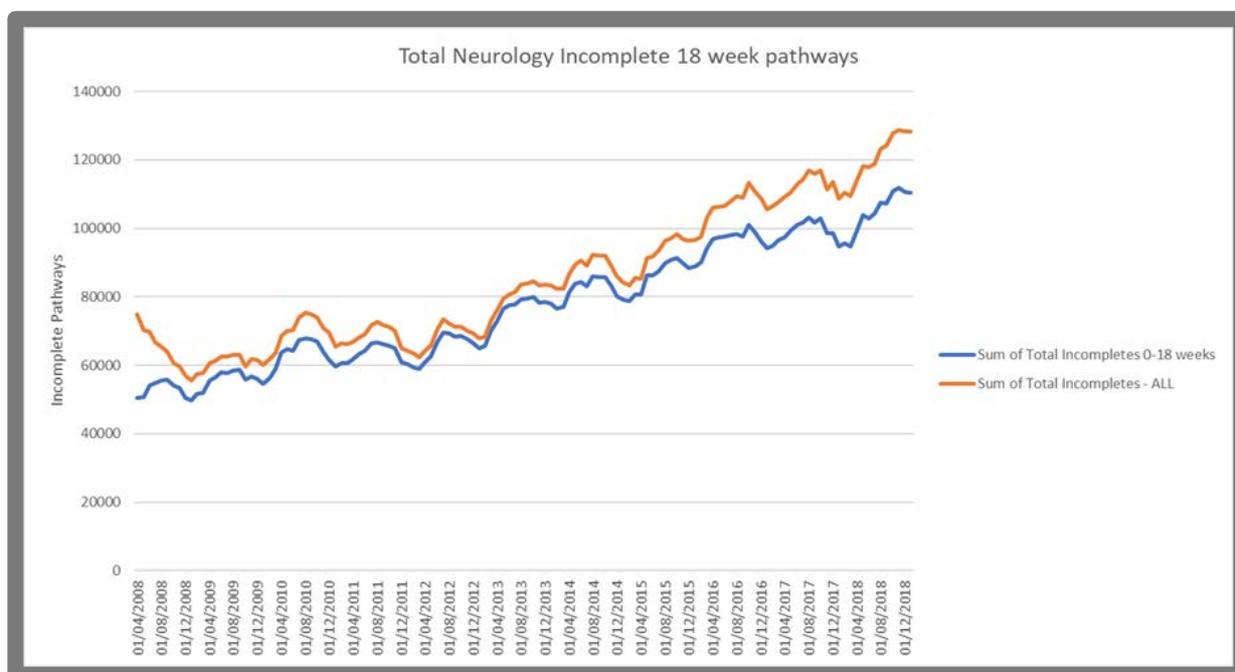


## Increased waiting

A combination of growing demand and reports of restrictions in capacity is resulting in increased waits. The number of patients on incomplete neurology pathways has nearly doubled since 2008, and the proportion of patients waiting more than 18 weeks has increased since 2015. There has been a 71% increase in patients not seen within this period over the last 10 years. Most patients waiting for neurology treatment will use an outpatient service. The majority of patients waiting for treatment for up to 18 weeks have not had a decision to admit.

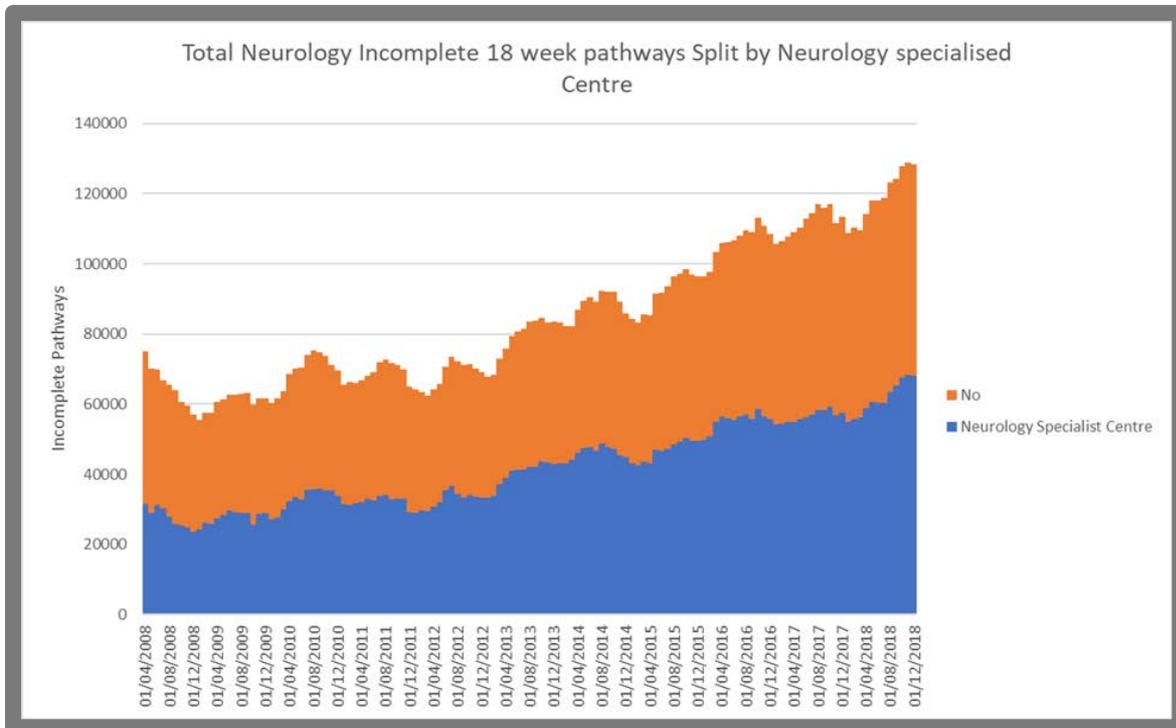
The Neurological Alliance [survey](#) also showed that people with neurological conditions experienced significant waits for referral and access to specialists. 39% of people saw their GP five times or more before being referred to a specialist; 55% experienced delays in accessing health care; and 29% had to wait more than 12 months to see a neurologist despite needing to.

Around half of neurology patients on incomplete 18-week pathways<sup>1</sup> are treated in specialised centres. Patients with rare conditions are having to wait longer to see a specialist.

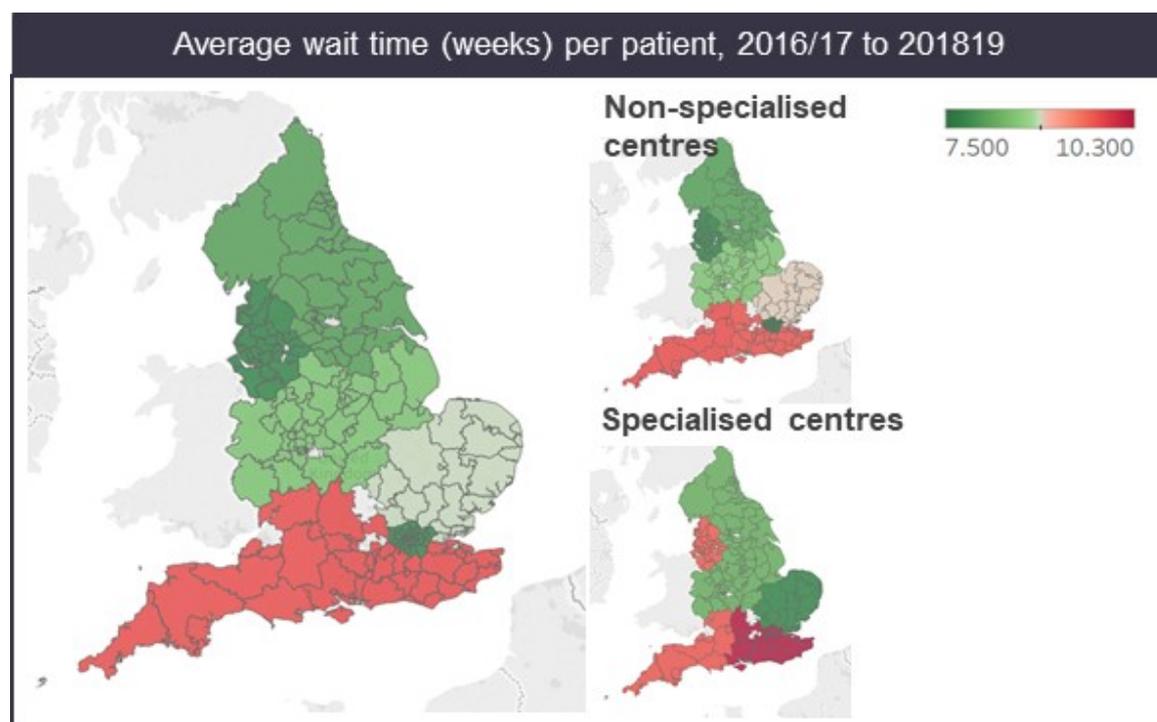


<sup>1</sup> This is the approved measure for waiting times and represents patients that been assessed but are waiting for definitive treatment

The problem of growing waits affects all neurology and, as shown below, the proportion of specialised to non-specialised commissioned neurology patients waiting for extended periods has not altered markedly.



There are also significant regional variations in waiting times.



## **Rising costs**

There are a number of factors driving increased costs in neurology. The complexity of patients is growing, which tends to be associated with longer lengths of stay, particularly as there is a lot of potential for a block in flow in a pathway, with many patients experiencing an extended stay (averaging approximately 21 days delayed transfers of care spent in a neuroscience centre before transfer).

New drugs and treatments offer the prospect of improved outcomes in a number of pathways but are also likely to drive high costs (see Part B: Commissioning).

## **Opportunities for efficiency and improved flow**

In common with neurosurgery, there are opportunities to improve patient care and improve the efficiency of bed utilisation through removing the obstacles to the flow of patients from neuroscience centres (NSCs) to other services.

In elective care, work is already in hand to improve the models of delivery in a number of areas. Referral is being improved by developing standardised referral pathways and structured templates, increasing the use of advice and guidance services, and providing more opportunities for shared learning between specialists and referrers.

Similar transformation work is underway to improve shared decision-making and self-management support for headache and migraine, and to change the outpatient model through developments such as community migraine and MDT clinics

Work by GIRFT has identified a number of areas of variation that may indicate opportunities for improvements in efficiency. These include:

- Substantial variation in spending on neurology in different regions, from £5.10 to £17.40 per head. The variation does not reflect differences in the rates of admission of patients with neurological conditions, but in the way services are organised to look after these inpatients.
- Marked variation in terms of both drugs being used and in the spend per head. This reflects different treatment strategies, rather than misused, and so might provide information on how standardisation could improve care.
- Variations in staffing, admissions, outpatient use and input to the care of other inpatients, which suggest there is both under- and overuse of specialist neurology, along with opportunities for optimising this.

The GIRFT programme will be investigating these variations further to identify those that cannot be accounted for by differences in local context.

The RightCare progressive neurological conditions [toolkit](#) provides many case studies of ways in which specialist resource is being better utilised – see examples of GP advice line, MND GP red flag tool and multiple examples of effective MDT working in Parkinson's disease.

There are a number of issues with neurophysiology (EEG & EMG). As well as a lack of specialists, poor and very variable referrals result in many unnecessary requests particularly from non-neurologists. These services are often provided by or supplemented by private providers that have no incentive to reduce demand.

### **The NHS Long Term Plan**

The NHS Long Term Plan does not consider these specialties directly but does have a number of important implications for them. Firstly, the development of larger Integrated Care Systems covering large populations offers the opportunity to support more effective methods of provision across providers or, where they are required, the development of networks. It also could lead to more effective local commissioning of some specialist services than has been possible for the much smaller CCGs. The second implication is that an improved focus on population health, and the ambition to reduce variation in care, could help deal with some of the issues about disjointed pathways and the results of the lack of rehabilitation on patient outcomes and flow. The third opportunity comes from the development of digital systems that will help to support digital/virtual outpatients and consultations, e-referral and improve image transfer and some of the other obstacles to cross system working that currently exist.

Improving mental health services, and better integrating these with wider services is a central tenant of the LTP. At least half of people with a mental health condition also have at least one long-term physical illness, and many have multiple and complex needs that current systems struggle to meet. The need for people to have their mental, cognitive and emotional health properly looked after is particularly important given that neurological conditions relate to the brain and nervous system. Sometimes it is not clear whether a particular symptom is mental (psychological) or physical (organic) in origin. Many recommendations within the NHS LTP, particularly the expansion in the Improving Access to Psychological Therapies (IAPT) programme for people with long-term physical conditions, could therefore help to improve support for people living with a neurological

condition. See [https://www.neural.org.uk/resource\\_library/mental-health-consensus-statement](https://www.neural.org.uk/resource_library/mental-health-consensus-statement)

## Developing the model

### Principles for the model

The aim is to create a model that can make the most of the power of a national system and regional networks, realising the benefits of a well-functioning community of practice that links these together. Participants in the workshop process and other stakeholders identified the principles that should underpin the model. The key ones are:

- The model should be designed around the patient with equity of access. While unarguable, neither of these principles are necessarily what underpin some current models
- It should ensure clinical excellence and care in the right setting, and be close to home where possible
- There is oversight at network and system level
- Have the right skills in the right place
- The model needs to be well organised, collaborative, with strong governance and effective information flows
- Utilise opportunities to improve care coordination, efficiency and effectiveness through use of enhanced data and technology
- There should be appropriate support for carers, as many report they have experienced negative and long-lasting health impact
- The model needs to be adapted to urban, semi-rural and rural locations.

The main components of this model are as follows.

### Service configuration

A great deal of neurology advice, diagnosis and care can be delivered in local providers, and it is important for other services (in particular emergency medicine) to have rapid access to high-quality neurology opinion and advice. However, England has lower levels of neurological staffing than most other developed countries (many of which are themselves experiencing shortages).<sup>i</sup>

EU average: 1/15,000 USA: 1/19,000 UK: 1/84,000 (but with London 1/37,000, South Wales 1/91,000)
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This means that it is not currently practical to have self-contained neurology services in every local hospital. While the benefits from centralisation found in neurosurgery are less pronounced in neurology, creating a critical mass of expertise for the management of rare and complex conditions is important and beneficial.

The future model will therefore need to be based on a network with a division of responsibilities between the centre and outposted units – usually in general acute hospitals. Versions of this have been in operation for a long time in a number of places, but there is more to do to formalise these, to ensure that full advantage is taken of advances in technology (both for local diagnosis, information transfer and telemedicine), and to standardise elements of pathways to improve quality and reduce unwarranted variation.

### **Diagnostics and specialist interventions**

Imaging and other diagnostic equipment may often be available at local hospitals. However, patients may need to go to a tertiary centre where complex investigations are required and if there is diagnostic uncertainty, or where a one-stop work-up might be desirable.

Our workshop participants did not reach a consensus view on whether all complex investigations needed to be done at a tertiary centre. This may reflect the wide variety of these tests, and the variability of capacity and capability across networks that makes a blanket judgement on this issue difficult. Networks will need to develop a set of standards for diagnostics and determine which providers in the network have the ability to deliver them, and work with those that do not to increase their capacity. Commissioners will need to support this by building this capacity through contracts.

Workshop participants thought there was a case for some highly specialised treatments being restricted to tertiary centres, although (following the pattern of earlier innovations) this may change over time. These include:

- Stem cell therapy and complex rehabilitation e.g. for spasticity/pain in MS
- Brain biopsy
- Surgical resection or brain stimulation for epilepsy
- High cost drugs and devices
- MRI guided ultrasound for movement disorders
- DBS and Duodopa in Parkinson's Disease.

## Clinics

For specialist clinics, only a small number of activities fall unequivocally into the category of needing to be delivered in the tertiary centre. There was overwhelming consensus that specialist clinics do not need to be restricted to tertiary centres, and can be delivered locally if the provider is part of a network with appropriate governance, standards and quality measures. As with diagnostics, the decision depends on practical considerations such as the expertise and equipment that is available locally. One determinant of this is the way that multidisciplinary teams and clinics will operate.

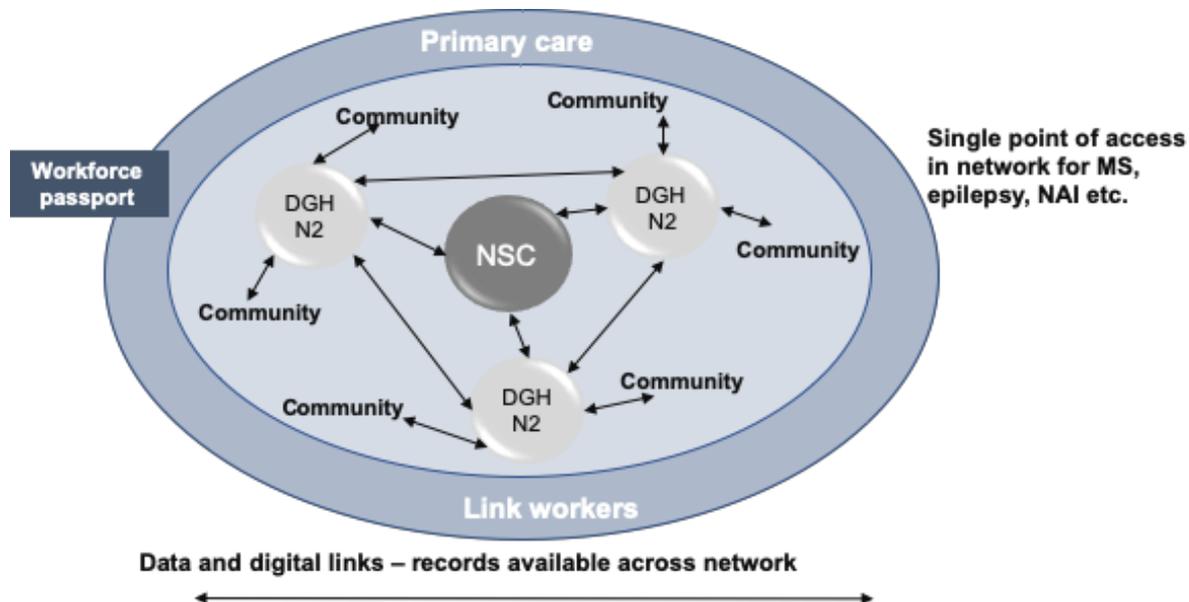
There is work to do to develop the concept of the MDT clinic – workshop participants identified the following characteristics.

### **MDT clinic**

- The patient is present (probably physically but could be virtual) and receives MDT input directly, i.e. is seen by multiple professionals at the same time ('one-stop shop')
- MDT clinics should be responsive, and advice and care provision should be given
- Final clinical decisions are made with the patient present
- Can be locally delivered.

MDTs are expensive and have a significant opportunity cost. They will need to be well managed and delivered cost effectively. Further work and thought are required to develop this approach.

## Network working



A number of different permutations of networks were discussed, but there was a broad consensus that a model such as that illustrated below is the most appropriate.

Workshop participants stressed a number of principles about the design and operation of a successful network. These included:

- The need to adapt the model design to fit the local circumstances in particular, not to impose a particular version
- Multidisciplinary governance including shared clinical governance and standards
- Ensuring that the skills of staff can be fully deployed to work to the 'top of their licence', and that they can work on multiple sites across the network
- Shared data and information across the network.

The network will have the following characteristics: <sup>ii</sup>

- It can take a population view to ensure equity across the system
- Be the centre for all inpatients, interventional radiology and mechanical thrombectomy
- Provide neurophysiology and complex neuroradiology with routine diagnostics, including CT and MRI done locally and where necessarily reviewed by the centre
- Provide outpatient services in local hospitals
- Oversee / provide neurorehabilitation
- Manage referrals are managed centrally to support better compliance with pathways and standard triage across the network. This could include the provision of a GP advice line
- Networks may hold consultant contracts or have shared contracts with local providers – both models can be made to work. The key is to have flexibility to cover leave and relationships that allow for easy access to advice and referral

- Shared clinical governance and audit across the network.

There may be a trade-off between central control of the network and the ability of the centre to achieve patient flow to secondary care services. Other networked models in which local services are provided via a service level agreement operate well in some locations. Services need to evolve over time recognising local circumstances.

### **Network governance**

The experience of creating a mandated network from existing services – i.e. between separate organisations – is often found to be challenging.<sup>iii</sup> For managers, it involves investing in a lot of work developing and managing relationships externally. For clinicians it can cut across how they manage the care of their patients.<sup>iv</sup>

The literature on network governance distinguishes between shared governance and centralised governance.<sup>v</sup> Shared governance models are non-hierarchical, usually do not have a statutory form, and are hosted by a member organisation. They require relatively high levels of inter-organisational trust and some shared goals between the participants.

The literature on this suggests that where there are high levels of coordination costs (due to large numbers of participants in the network), lower levels of inter-organisational trust, and/or where one provider has a central position in the flow of patients, information and resources that lead organisation models of networks tend to be preferred and are more effective.

There are two main types of lead organisation models:

- 1) where one organisation is established, and its entire purpose is running the network (e.g. VISA the credit card clearing system) or
- 2) a lead contractor model in which one network member takes the role of administering the network – this is effectively the position occupied by the Walton Centre.

For neurosciences, the extent to which senior managers will be able to spend the time or consider participating in the governance of the network may generally be more limited than it is for cancer. However, where there is a network run by a neuroscience centre, it would be appropriate for there to be some form of oversight board or other consultative arrangements – ensuring that the voice of the constituent parts of the network and commissioners gets heard in its operations and strategy, and avoiding the problem of the

NSC dominating the governance. The model developed for the Operational Delivery Networks could offer a useful template for this.

The networks will also require:

- Metrics that capture issues of flow, pathway compliance, assurance that the patients reached the correct specialist rapidly, performance of low volume care and clinical outcomes.
- Patient engagement: experience from cancer networks suggests that data on patient experience and direct mechanisms for patient engagement are both important.
- Mechanisms to allow staff to work across the network (e.g. passport arrangements).
- Data-sharing agreements between providers.

### **Transfers within networks**

Whatever model is adopted, the development of a repatriation agreement similar to ones used in trauma networks would be useful for both neurosurgery and neurology. This sets out standards for time within which a transfer needs to take place (48 hours), the provision of support to the process, the obligations placed on receiving and referring hospitals, and the requirements for information exchange and informing relatives. It also specifies the escalation machinery and mechanisms for resolution of issues where clinicians do not agree.

## **Part B**

### **Commissioning**

NHS England will, depending on legislation, continue to be responsible for specialised commissioning. However, there are opportunities to develop and improve how commissioning is done, and in particular to deal with some of the issues of the interfaces between specialised neurology, other neurology and primary care, rehabilitation and other local services.

The future of commissioning for all services is likely to change as more integrated care providers develop. In many parts of the country, there are moves to align CCGs to Integrated Care System boundaries. Although some larger or less geographically coherent ICSs may retain more than one CCG, it is likely that commissioning within these will still be coordinated, particularly for more complex areas or providers that span different CCGs. A complicating factor is that most neuroscience centres are serving more than one ICS,

which will create some complexity if some or all neurology commissioning is devolved to the ICS or CCG level.

The different functions that commissioners of neurology are required to do include (in a simplified form) are:

- Needs assessment and gap analysis
- Specification of pathways and promoting integration of care
- Shaping the provider system including strategic choices e.g. location of services
- Payment and activity and financial management
- Quality assurance.

As ICSs, ICPs and neurology networks develop, there are opportunities to change where these functions are located in ways that better align risk, expertise and the strategy for improving population health.

**Defining specialised neurology** – Before describing the commissioning system, it will be important to have a shared understanding of the definition of specialised neurology. Workshop participants suggested the following, which has been expanded on in subsequent work:

“Where there are more specific skills, expertise” and “where enhanced investigation, interpretation and intervention can be provided leading to a better experience or outcome for the patient”.

“Specialised care isn’t a procedure, device, or even usually a drug. It is clinical input at critical points in the pathway where the expertise is essential to identify appropriate diagnostics or treatments for complex, refractory and rare cases.”

This moves away from the current approach that focuses on the place of delivery. There is consensus about this definition of specialised neurology and about those components that best fit at a local level. There remains a degree of uncertainty about the territory between these areas, and this may be contingent on the capabilities of local services or the capacity of tertiary centres. There is a need for further work to clarify this, but it is likely that this area will continue to be debated.

An issue that remains is that individual patients will have needs that fit this definition for some aspects of their care but not for others, and may move in and out of these categories over time. This means that the points where specialise neurology pathways have interfaces with other parts of local systems will still create some challenges. Rather than

commissioners trying to design how these operate, it is more practical to ensure that the centre and its network develop easy-to-navigate interfaces with local providers, including standardised electronic referral, telephone advice and guidance for hospital clinicians, and GPs and specialist advice such as specialist nurses. Commissioning can then support these arrangements by the design of funding mechanisms (see below).

This would allow a model in which only the specialised part of services would be supported by a top-up, and other activity would be paid for by the payment by results (PBR) tariff or other agreed payment methods.

**Needs assessment and gap analysis** – this fits well at CCG/ICS level with the ICS, local government working with providers. The Joint Strategic Needs Assessments developed by local authorities may indicate opportunities for neurology and associated disciplines to support wider health improvement efforts, and assist in developing interventions to help return people with disabilities to work.

**Specification of pathways/integration** – the development of national pathways with input from the NSCs is an efficient way of standardising care and reducing variation. This is a role that NHSE/I nationally seem best placed to broker. Some of these may need to be adapted locally to fit, and this could be done at region or ICS level, but it could make more sense for this to be done on their behalf by a provider network with the national team/region and the ICS providing scrutiny.

**Shaping the provider system** – decisions about the location of services and in particular about the centralisation, devolution or capacity of elements of the system are an important role for the ICS as a strategic commissioner. However, in doing this they will need to involve other ICSs and national and regional interests, due to the interdependencies with neurology and with other hospital and tertiary services.

**Payment and activity and financial management** – there are a number of options available, both in where financial risks are managed and the currencies used for payment. Some of these can be blended depending on the type of service being commissioned.

Approach	Comment
Capitation – a budget based on the cost per year for providing all specialist neurology to a population.	Requires a single organisation to take responsibility for the whole network – still has some difficulties in boundary issues and where neurology patients are treated in other specialties.

Year of care budgets for patients with long-term conditions, with activity-based payment for other cases.	Complex to calculate and administer, and it is not clear if the benefit from this would be worth the significant complexity created.
Activity-based funding for all activity.	Difficult to control and creates incentives that may get in the way of integrated care and redesigned pathways.
Block contracts with volume targets made with different providers in the network.	Easier to control but similar issues about creating barriers to change.

In all cases, there is a strong argument for high cost drugs to be dealt with via a separate funding stream attached to particular programmes or patients.

International experience suggests that complex contracting mechanisms based on activity payments are difficult to operate. In the Netherlands, for example, a standard DRG payment is used, but the costs of complexity and specialisation are recognised by a subsidy to tertiary providers. This too has a number of unsatisfactory elements as it may over-reward specialist providers and prevent other providers from participating in the network of care.

**Quality assurance** – this remains a key task for a commissioner, but can be done at a relatively large scale and it does not seem to be sensible to do this more than once per network. ICSs could agree that one will take on quality monitoring on behalf of all the ICSs in a region.

There is not an obviously correct single answer to the question of how functions should be allocated, and pragmatic solutions based on local circumstances will be needed.

One solution is a model in which regions and ICSs jointly task the neuroscience network provider with responsibility for working with local providers to manage the commissioning budget for the main pathways, and some other aspects of specialist care on their behalf. In this model, commissioning responsibilities would be shared. The region/ICS would be responsible for holding the providers to account for improving population health outcomes, for service quality and working effectively with the local providers – particularly for those pathways with a strong link to primary care. The provider network would be responsible for pathway and service design, internal quality assurance and resource allocation within the network.

A key question is how to ensure a CCG voice in a model where specialised neurology is provided by the type of capitated network described here. This will be important for quality assurance and to ensure that local needs are recognised – particularly in services where there is a significant crossover between specialised and local services, such as headache or PD. It will also help to reduce the amount of travel that patients need to undertake by ensuring that more care is provided locally.

The alternative is commissioning at CCG level. Workshop delegates were not very supportive of a large-scale devolution of neurology commissioning to CCGs. They were concerned that this would increase the level of variation between areas and potentially further fragment the pathways of care. However, this did not take into account that in future the ICS and CCG will generally be conterminous, and that the decision-making approach required in these models is one based on a high level of clinical involvement and the active participation of the providers.

There is an example where an ICS has successfully worked to develop locally commissioned elements of neurology working with the tertiary centre, which has allowed a much more devolved and local service to be developed. In this case, there does need to be funding of specialist high cost drugs available to local providers. Over time, as ICSs develop their capability more, elements of the higher volume and less complex elements of care could be commissioned at ICS/CCG level.

A third approach is for specialised commissioning to only pay for the workforce and clinical time in rare, complex or refractory cases, and for the remaining work commissioned at CCG/ICS. There may be residual issues about the higher costs of maintaining a critical mass of expertise, research and other non-activity related costs that will need to be addressed – this is the thinking behind the provision of provider-level subsidy in the Dutch model.

In all cases, there may be arguments for keeping a separate funding stream for drugs, but allocating budgets to incentivise efficiency and compliance with pathways. In both models, it does continue to make sense to develop pathways nationally. In doing this, it will be important that the pathways reflect what is possible rather than being aspirational or gold plated.

## Future developments

Neurology has been developing rapidly over the last few years, and this is likely to continue. Some of this will increase costs, but all of it is likely to have an impact on patients, their carers and staff. Key areas identified by workshop participants included:

- The implications of informatics, big data, genomics and other diagnostic information, and the application of AI as an aid to diagnosis and treatment
- The development of a range of immunotherapies in many conditions, genetic therapies requiring frequent intrathecal delivery, and an increase in expensive treatments for rare disorders (e.g. individualised therapies such as antisense treatments)
- The growth of stimulation-based therapy – responsive neurostimulation for drug resistant epilepsy
- New devices, including wearables, hand-held MRI
- New predictive tests for degenerative disorders, with potential treatments prior to manifestation.

There will continue to be less need for travel to specialised neurology centres as technology allows people to be diagnosed and treated closer to home.

## Summary of recommendations

A number of clear conclusions emerged from the workshops and the additional analysis presented above.

- There was broad support for a network approach following the generic model proposed at the workshop (with modifications) and for the principles that underpin it. There are, however, different versions of the network in terms of the relationship of the hub to its constituent parts, which will need to be tailored to local circumstances.
- A lead provider model has clear advantages in terms of governance and accountability, although it will not be possible to apply this everywhere.
- Pathways – there is support for the development of pathways for more common conditions at national level, although there is some further work to do for some of these.
- As with neurosurgery, the interface between inpatient services and rehabilitation requires attention, and imbalances between capacity and demand addressed to deal with problems with flow.
- The current model of commissioning could be improved by decision-making being located closer to local systems. One option is for this to be led by the ICS/CCGs as these develop. National development of pathways and standards will still be important. Where possible, the whole pathway (or as much as practical) should sit with one commissioner. The new definition of specialised commissioning allows for more local decision-making and a model in which specialised top-up is used to pay for specialised input, while non-specialised activity is paid via PBR, has some merit and should be developed and tested.
- Three different options for commissioning have been identified in this work and there is no reason why only one should be adopted – the models will work more or less well in different contexts. Further development of these concepts is needed over the next few months. There may be other options that can be explored as ICSs develop and there are developments in commissioning in other specialised areas.





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59 New Cavendish Street

London W1G 7LP

Telephone: 020 7631 8450

[www.nuffieldtrust.org.uk](http://www.nuffieldtrust.org.uk)

Email: [info@nuffieldtrust.org.uk](mailto:info@nuffieldtrust.org.uk)

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