

# **The long term plan for the NHS: Getting it right for neurology patients**

## Introduction

The number of people living with neurological conditions in England is rising and will continue to increase. This is due in part to advances in neonatal healthcare meaning more children with neurological conditions survive beyond birth and into adulthood. More significant however is the impact of an ageing population. Advances in other disease areas, such as cancer, means that more people survive into old age and develop neurodegenerative conditions. This is highlighted most starkly by the latest neurology death data. Public Health England's 2018 Neurology Mortality reports show that number of deaths in England relating to neurological disorders rose by 39% over 13 years, while deaths in the general population fell by 6% over the same period.<sup>i</sup> The long term plan for the NHS provides an ideal opportunity to implement solutions to improve care for the increasing numbers of neurology patients and to prevent existing issues from becoming more challenging to resolve in future.

Mortality data also highlights that neurology is particularly adversely affected by health inequalities. Deaths of people with epilepsy<sup>1</sup> increased by 70% between 2001 and 2014, but mortality in the most deprived areas was nearly three times that in the least deprived. This data also shows that deaths associated with neurological conditions are 35% more likely to be premature.

Neurology consequently accounts for significant – and increasing - NHS activity and spending in England. From 2012/14 to 2015/16 there was a 14% increase in hospital admissions with a primary diagnosis of a neurological condition, and a 10% increase in emergency hospital admissions.<sup>ii</sup> For the neurological condition groups for which we have non-elective admission data<sup>2</sup>, inpatient non-elective spend was £522 million in 2016/2017. If all CCGs were to achieve the admission rates of their best demographically similar peers, a 10% saving (£50 million) could be achieved.<sup>iii</sup> . If this data was available for all neurological conditions, this figure would be far higher. Given the growing number of people with neurological conditions, this pattern of increased activity and spending is likely to accelerate, unless concrete action is taken to address this.

Yet, to date, neurology has not been proportionately prioritised on a national level. It lacks levers for improvement, being almost entirely unrepresented national and local accountability frameworks<sup>iv</sup>. As the Public Accounts Committee concluded in 2016, 'It is clear that neurological conditions are not a priority for the Department of Health and NHS England'.<sup>v</sup> Data about neurological services is patchy, which further hampers improvement.

Consequently, patient experience is comparatively worse than other disease areas. According to the NHS & CQC 2017 Adult Inpatient Survey, Patients with neurological conditions reported poorer experiences for confidence and trust, respect and dignity, respect for patient-centred values and overall experience of care.

In response to our 2016 patient experience survey, just 41% (n=2,132) of patients described the health services they received for their neurological condition as 'good' or 'excellent'.<sup>vi</sup> Furthermore, when asked the same question about services to meet their mental health needs, the percentage of patients rating services as 'good' or 'excellent' fell to just 19%.<sup>vii</sup> The 2013-14 NHS England survey of patients of GP practices found that people with long-term neurological conditions have the lowest health-related quality of life<sup>3</sup> of any long-term condition.<sup>viii</sup>

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<sup>1</sup> Epilepsy is the only neurological condition for which this data is available.

<sup>2</sup> Epilepsy, migraine and headache, multiple sclerosis and inflammatory disorders, Parkinsonism and other extrapyramidal disorders, peripheral nerve disorders, rare and other nervous system disorders, tumours of the nervous system

<sup>3</sup> Based on Eq5D scores

The lack of prioritisation of neurology coupled with rising prevalence means that neurology is impacting the wider NHS in terms of both patient outcomes and health service efficiency. Neurology patients in crisis are accessing A&E departments, increasing delayed discharge statistics, and dying prematurely when this could have been avoided.

We believe the long-term plan offers the opportunity to put in place concrete actions to improve care for neurology patients. Smart solutions, such as those that harness new models of care, the power of technology, and preventative approaches, are efficient and desirable. There is an opportunity for more innovative use of workforce, especially with regard to upskilling nurses and allied health professionals and investing in additional administrative support to unlock neurologist capacity. Better training and specialist advice for primary care can improve diagnosis and reduce inappropriate referral, freeing up secondary care capacity. The use of integrated personal commissioning and care planning can unlock more holistic care, improving patient outcomes and experience. This includes applying new digital models to facilitate improved take-up, and facilitating the use of guided self-management. In this document, the Neurological Alliance makes a series of proposals for how the long term plan could support improvement in neurology patient care. This document is structured in three parts – based on the structure of the working groups set up to lead development of the long term plan:

- 1. Prevention and neurology**
- 2. Integrated and personalised care for people with neurological conditions**
- 3. Neurology and the clinical priorities – with a focus on mental health**

In each section we set out the considerations for neurology patients and services, including detailed evidence about the issues and need for action. We then set out examples of interventions that will provide solutions and the benefits of these.

We hope this publication will be the start of a conversation with NHS England about how the long-term plan can support improvements that are urgently needed for neurology patients, but also how neurology could be a test bed for many of the new models of care and personalisation solutions the long-term plan will include.

## Our core asks and proposed actions

<b>1. Urgent national action to speed up diagnosis and prevent premature deaths and avoidable admissions associated with neurological conditions.</b>	
1a	Any regional-level future accountability frameworks e.g. for STPs should include mechanisms to better incentivise areas to seek to understand their local population of patients with neurological conditions and to commission services accordingly.
1b	Develop and pilot risk assessment tools for use in primary care for people with neurological conditions.
1c	Public Health England should be properly resourced to undertake further work to understand neurological conditions, including prevalence and incidence, and to better understand the increasing death rates for people with neurological conditions.
1d	Work with the Neurology Intelligence Collaborative to develop a properly resourced, national data plan for neurology focussing on development of data and intelligence that highlights where preventative action could make savings elsewhere in the system.
1e	NHS England to work with NNAG, and provide it with the resources needed, to provide national leadership around efforts to improve neurology.
1g	The long-term plan for the NHS must integrate with the forthcoming social care green paper proposals.
1h	Establish a successor to the NHS Vanguard Programme to continue progress on models of care on service transformation and roll out good practice evidenced through the first round of the Vanguards – such as consultant advice lines for GPs.
1i	Make trials more accessible to people with neurological conditions, including approaches which encourage health care professionals to engage with patients and carers about research opportunities, and new digital solutions which link interested patients up with trial opportunities e.g. through digital care plans.
1j	NHS England and NICE to work together to reduce the time delay in producing transparent health technology assessments, taking on best practice from international examples.
<b>2. NHS England should use neurology as a test bed for new initiatives relating to integrated personalised care for people with long term conditions, as it takes forward its work on new care models.</b>	
2a	NHS England to ensure that any future regional-level accountability frameworks include incentives for improvements in neurology.
2b	Neurology should be prioritised in a programme of work to co-design a suite of models for integrated MDTs working across primary and community care in partnership with the voluntary and community sector.
2c	Implementation of the recommendations in the Watcher Review on use of information technology in the NHS in order to support care planning.
2d	Develop a pilot to support STP areas to further develop the IPC approach for neurology.

2e	Explore the development of national and local incentives to ensure each patient has a named professional to help organise their care, perhaps under the auspices of integrated personal commissioning.
2f	Accelerate exploration of digital care plans, using neurology as a test bed for any pilots.
2g	While it undertakes work to mainstream the information standard, NHS Digital must engage with patient groups to ensure that opportunities to inform patients about the information they provide are taken, e.g. through continued signposting to patient organisations on NHS Choices.
2h	Develop a systematic national approach to supporting the development of self-management tools and peer support interventions, as well as support to promote and disseminate these tools to aid implementation.
2i	NHS England should work with Health Education England to produce a nationwide comprehensive workforce plan for neurology, to achieve a sustainable workforce able to meet existing and future levels of demand.
2j	Health Education England to review how neurology training routes could be refined to ensure better geographical spread.
2k	Include in the neurology workforce plan measures aimed to ensure that specialists are trained, supported and can develop their careers.
2l	Pilot the use of GPs with a special interest in epilepsy in several primary care network areas and analyse the impact on A&E attendances.
<b>3. The needs of neurology patients to be considered as part of action to address the clinical priorities in the long term plan, particularly in relation to mental health.</b>	
3a	Work with patient groups on plans to develop rehabilitation services for stroke and wider neurology patients through the mechanism of the long-term.
3b	Ensure that initiatives to reduce health inequalities experienced by people with learning disability and autism include a specific focus on common comorbidities, and also aim to tackle diagnostic overshadowing.
3c	NHS England should allocate some of the funding for mental health and long-term conditions to pump priming new services or demonstrator projects for neurology and mental health.
3d	Further develop training for therapists working within Improving Access to Psychological Therapies (IAPT) services to include information on how to support people with neurological conditions, including those with co-morbid neurodevelopmental disorders.

## 1. Prevention and Neurology

Historically neurology has not been linked to the prevention agenda, mainly because it is not currently possible to prevent the onset of many neurological conditions (with notable exceptions including lifestyle changes to prevent dementia and stroke, and public health messages around measures such as use of cycle helmets to prevent acquired brain injury). Given neurological conditions are long-term, they require lifelong management to prevent health crises that can lead to otherwise avoidable A&E attendances and emergency admissions – to the detriment of patient outcomes and NHS finances. Here we make the case for why neurological conditions should be included in NHS England’s work on prevention. In particular, we encourage NHS England to think holistically about prevention in its long term plan – beyond preventing onset of disease – as we set out below.

### 1.1. Preventing crisis and avoidable deaths

According to the 2018 GP survey, 19% of patients with a neurological condition had had an unplanned stay in hospital over the past year – this is twice the rate for all people with a long-term condition (9.8%). It is well documented that for people with ambulatory care sensitive conditions – such as epilepsy or ataxia or other long-term neurological conditions – an A&E attendance or emergency admission represents a failure elsewhere in the health system. For example, recent research by the Health Foundation revealed that 690,000 A&E attendances could be avoided if people were supported to better manage their long-term conditions<sup>ix</sup>. For people neurological conditions, A&E attendances and being admitted to hospital in an emergency represent an avoidable expense to the system, as well as being the last place an individual wants to be. For epilepsy – the only neurological condition for which emergency admission data is currently collected – there were 89,000 emergency admissions for adults and 36,000 emergency admissions for children. If all CCGs were to achieve the same numbers of their best 5 demographically similar peers, 6.5% (5,750) and 10% (3,675) of these admissions respectively could be avoided, according to NHS RightCare data.<sup>x</sup>

As with many other conditions, emergency admissions for neurological conditions are rising. From 2012/13 to 2015/16 there was a 10% increase in England in adult emergency hospital admissions with a neurological condition as the primary diagnosis on admission episode.<sup>xi</sup> Ten per cent of emergency admissions and attendances at A&E are for convulsions and seizures. From 2012-2013, that cost the NHS a massive £1.25 billion.<sup>xii</sup>

An issue of particular concern is that emergency admission rates differ hugely around the country. Adult emergency admissions for epilepsy<sup>4</sup> varies from 212 to 855 per 100,000 population across different CCGs.<sup>xiii</sup> It is clear that there is work to be done on prevention, particularly around tackling health inequalities and improving community care, in order to tackle emergency admissions in the worst areas.

The issues relating to emergency admissions of neurological patients are further compounded by postcode lotteries in terms of acute neurology services. The likelihood of a patient with a neurological problem being seen by a neurologist continues to vary dramatically depending on where they are admitted, with a handful of hospitals having no acute neurology service at all and others having access to a neurologist on three days or fewer a week. Moreover, 72% of district general hospitals do not have access to 24/7 MRI,<sup>xiv</sup> which is essential in detecting and monitoring acute neurological problems, such as traumatic brain injury. Indeed, on MRI the UK performs much worse than European neighbours: the UK has just 7.2 MRI units per million population, while Italy has 28.2 units per million and Germany has 33.6 per million.<sup>xv</sup>

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<sup>4</sup> the only neurological condition for which there are published figures.

Deaths associated with a neurological condition are 35% more likely to be premature.<sup>xvi</sup> While some of these deaths are unavoidable, many are preventable with better care. The data is not available across all neurological conditions but at least 42% of epilepsy deaths are known to be potentially avoidable. We also know there is a strong correlation between deaths associated with neurological conditions and deaths associated with falls.<sup>xvii</sup> Nearly 7% of deaths associated with a neurological condition had an underlying cause of death recorded as a fall. This accounted for 2,000 deaths in 2014.<sup>xviii</sup> As Public Health England states “a focus on epilepsy and falls related deaths could reduce avoidable mortality”. There is a close link here to ensuring appropriate care and support for frail elderly people, many of whom have a neurological condition.

Preventative interventions to reduce A&E attendances, unplanned admissions and avoidable death can be split into two parts – local solutions and national system architecture.

### **Local solutions**

Many local solutions are about providing integrated and personalised care for every neurology patient. This is discussed in detail in section 2 below. Here we discuss geographical variation in local access to services. We provide some examples of interventions that are currently provided in some parts of the country, proven to reduce A&E attendances, unplanned admissions and avoidable death.

Poor access to services is a factor which can lead directly to crisis situations arising. Evidence from Public Health England shows that access to neurology services varies significantly depending on geographical location. Only 37% of CCGs provide more than 80% of outpatient consultant appointments within the local CCG area. Local appointments are virtually non-existent across the East Midlands and North West regions. This results in people often having to travel long distances to access necessary care, or not receiving it all.

This is partly as a result of CCGs not prioritising neurology in the services they commission. This is perhaps unsurprising, given that just 21% (n=44) of CCGs that responded to the Neurological Alliance’s 2016 quality of commissioning audit had made an assessment of the number of people using neurological services in their area. CCG engagement with neurology is poor, compared to other condition groups, reflecting neurology’s low representation in the CCGOIS.

There are no specific requirements relating to neurology for STPs. The introduction of longer-term strategic planning covering all commissioned services is potentially a step forward for neurology services, which have suffered from fragmentation and confusion over the division of commissioning responsibilities. But this promise is yet to be fulfilled: a 2016 audit of STPs found that STPs most commonly engaged with neurology by engaging with stroke/dementia, generally overlooking wider neurology. Their plans for neurology overall were found to be poor.<sup>xix</sup>

**Action 1a:** Any regional-level future accountability frameworks e.g. for STPs should include mechanisms to better incentivise areas to seek to understand their local population of patients with neurological conditions and to commission services accordingly.

Annual reviews of neurological patients by a specialist such as a nurse is a measure included in many of the NICE guidelines relating to neurological conditions. In practice these rarely happen. Again, data is only available for epilepsy, but the removal of the Quality Outcome Framework indicator for annual reviews of people with epilepsy has led to fewer annual reviews taking place. An annual review, even by a non-specialist such as GP, provides an opportunity to review care plans and treatment. Annual reviews can facilitate prevention by acting as a lever to pushing for intervention

if a need is identified and flagged as part of the process. This is particularly important for people with additional health needs, such as those who have a learning disability, who become pregnant, who have a comorbidity such as a mental health condition, or who are under the age of 18, especially those transitioning from paediatric to adult services or gaining independence. To maximise the opportunity for early intervention, risk assessment tools, which have already been developed for other conditions presenting in primary care, should be developed for people with neurological conditions. These could evaluate individual symptoms and signs and visually present combined risks, alerting GPs to “red flag” profiles. GPs would be better equipped to monitor, manage, and, where necessary, refer patients to community or secondary care teams, thus helping to prevent health crises and A&E attendances.

**Action 1b:** Develop and pilot risk assessment tools for use in primary care for people with neurological conditions.

The use of social prescribing and community-based support is a well-evidenced intervention that can simultaneously help improve patients’ health and reduce their take-up of services, as described in the case study in box 1. This has the added advantage of better addressing patients’ needs in a way that is not onerous on the already very stretched neurology workforce.

**Box 1: Case Study: Community-based support** Cumbria Headache Forum

Cumbria has critically low neurology staffing levels and limited funding for special nursing support. Due to the need to find expertise within a growing population of patients with headache, the Cumbria Headache Forum was established. The Forum runs as an open access, quarterly meeting with topics including self-management, relaxation techniques, mindfulness, stress management and diet. Headache experts are invited to contribute from both Cumbria and across the country and include GPs with Special Interest (GPwSI), Headache Specialist Nurses, psychologist, physiotherapist and dietary nurses, and is chaired a Consultant Neurologist with expertise in headache management. The Forum facilitates headache management in the community and provides support to patients who feel isolated and unable to cope alone with their condition. The forum requires very little investment, with a cost of around £3 per patient per session.

A 2018 audit showed that:

- 87.5% learned new information about headache or migraine which has helped them to better understand the condition.
- 71% have taken more active role in management since attending the forum
- 100% participants would recommend CHF to family or friend who suffers from headache or migraine to attend the forum

It is expected that the forum is contributing to improved outcomes in patient care, experience and quality of life, and that this is translating into reduced admission rate and A&E attendance.

***System architecture solutions***

All the major health service improvement programmes over the last decade have been underpinned by rich, nationally collected data, intelligence and metrics. While there has been limited investment in neurology data over the last five years, this was starting from such a low baseline that we still lack

even basic knowledge about neurological conditions such as accurate prevalence and incidence statistics, as well as more detailed knowledge about service performance and patient outcomes.

**Action 1c:** Public Health England should be properly resourced to undertake further work to understand neurological conditions, including prevalence and incidence, and to better understand the increasing death rates for people with neurological conditions.

While Right Care provides an effective mechanism to work with local and regional decision makers, a lack of data has hampered work to design pathways. Getting it Right First Time neurology data is welcome but focusses on a small proportion of (inpatient) neurology activity in the health service. The Neurology Intelligence Network that was established just five years ago has had its resources cut to such an extent that very little new data production is possible. For rarer neurological conditions, data is almost non-existent.

**Action 1d:** Work with the neurology intelligence collaborative to develop a properly resourced, national data plan for neurology focussing on development of data and intelligence that highlights where preventative action could make savings elsewhere in the system.

In recent years national resources for improvement in neurology have been reduced. The National Clinical Director (NCD) post was axed in 2016 efforts to streamline NCDs as part of the Five Year Forward Review. While the National Neuro Advisory Group (NNAG) initiative has been attempting to fill the vacuum, to provide strategic oversight and coordination of the improvements needed in neurology, it is being run on minimal resources. Two years in, this group is starting to bring about much needed change, however it is currently subsidised by the charity sector. A longer-term, more sustainable solution to support NNAG is needed for it to succeed.

**Action 1e:** NHS England to work with NNAG, and provide it with the resources needed, to provide national leadership around efforts to improve neurology.

Neurology also continues to lack levers for improvement, being almost entirely unrepresented national and local accountability frameworks. Mechanisms to drive neurology improvements, including improved accountability measures particularly on any future regional-level accountability frameworks, and properly resourced national leadership, should therefore be brought forward as a priority (See action 1a).

Last but not least, the national social care system architecture is a critical part of the solution to preventing crisis in neurological patients. A report on the care home vanguards revealed that admissions reduced when health care professionals working with care homes on a regular, ongoing basis were linked in with other NHS services as part of a wider network of expertise.<sup>xx</sup>

**Action 1f:** The long-term plan for the NHS must integrate with the forthcoming social care green paper proposals.

## 3.2 Preventing disease progression

As well as preventing crisis and avoidable death, neurology has another important prevention aspect – preventing disease progression. This is achieved by ensuring timely and appropriate referral, diagnosis and treatment. There is of course a link to preventing crisis and avoidable death, as many patients who present at A&E with neurological symptoms will not yet have had a confirmed diagnosis or started on treatment.

### *Improving GP knowledge*

Neurological conditions are often complex to diagnose. This is due to the nature of diseases of the brain and spine, whereby a wide variety of symptoms can manifest in different ways in different patients. With many neurological conditions, diagnosis must be made by a specialist, necessitating referral from a GP.

Whether making diagnoses themselves, or referring on, GPs must be able to recognise symptoms. But, being generalists, GPs may struggle to recognise the symptoms of neurological conditions. The relative rarity of many neurological conditions means GPs will often only see a case once or twice in their career. Our 2016 neurology and primary care report<sup>xxi</sup> found that fewer than half of GPs surveyed<sup>5</sup> felt confident in their ability to make an initial assessment and referral for people presenting with signs and symptoms of multiple sclerosis – one of the more well-known neurological conditions. For rare conditions this will be much lower.

The large majority of GPs in England (84%, n=701) feel that they could benefit from further training on identifying and managing people presenting with neurological conditions. This can lead to situations in which GPs refer inappropriately, overloading secondary care. But more often, GPs may not refer quickly enough. Our 2016 Patient Experience Survey<sup>xxii</sup> found that 42.5% of patients surveyed<sup>6</sup> saw their GP five or more times before seeing a neurological specialist.

### *Waiting times for specialist care*

Waiting times between presenting in primary care and seeing a specialist can delay diagnosis and vary significantly: although 40% (n=2,096) of patients reporting that they needed to see a

### **Box 2: Neurological conditions and prevention**

#### **Primary prevention**

Preventing neurological conditions from occurring in first place. Examples include:

- preventing brain injuries for example through use of helmets, cycle lanes, and pool safety
- preventing peripheral neuropathy through diabetes control
- life style changes to prevent stroke and dementia

#### **Secondary Prevention**

Detecting neurological conditions as soon as possible, treating them to slow or halt progress.

Examples include diagnosing people with MS early and starting them on a course of disease modifying drugs and screening for mental health, emotional and cognitive issues.

#### **Tertiary prevention**

Improving quality of life for people affected by neurological conditions through actions to reduce symptoms, limit disability, and maximise function. Getting this right will also contribute for improved life expectancy for people living with neurological conditions.

Examples include neurorehabilitation and disease management programmes (including self-management).

<sup>5</sup> 1,001 regionally representative GPs from across the UK (England, n=831) were surveyed

<sup>6</sup> n=2,652

neurological specialist had this appointment within three months of their first GP visit, 23% (n=1,204) of patients waited more than 12 months<sup>xxiii</sup>.

Sometimes a longer wait in primary care will reflect an appropriate need for some ongoing monitoring and assessment of symptoms at that level. However, evidence suggests significant concern among GPs about unnecessary waits, with 85% (n=708) of GPs in England are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral for patients to see a consultant neurologist.

Box 3 highlights the benefits of using a consultant advice line to enable GPs to seek a second opinion to reduce unnecessary referrals and speed up appropriate referrals. This intervention was developed through the NHS Vanguard Programme.

**Action 1g:** Establish a successor to the NHS Vanguard Programme to continue progress on models of care on service transformation and roll out good practice evidenced through the first round of the Vanguards – such as consultant advice lines for GPs.

### **Box 3: The Walton Centre's Consultant Advice Line**

#### **Overview**

The drive towards neurology care being delivered outside of hospital settings requires a degree of specialisation within the primary care workforce who review patients with increasingly complex conditions and health needs. The CAL provides GPs with specialist neurology consultant advice and guidance to support management of their patients with neurological symptoms/conditions within primary care, and it is available to GPs in any area. The service has shown to have reduced secondary care referral rates in the surrounding CCG areas.

#### **Aims**

- Reduce the number of patients being referred to hospital outpatients inappropriately
- Improve quality through driving up standards and reducing unwarranted variation in outcomes and spend
- Enable effective working of professionals across tertiary, secondary and primary care
- Support the strategic direction of the GP Forward View (2016) to improve GP access to consultant advice on the management of neurological symptoms/conditions and potential referral onto secondary care and neurology specialists in tertiary care

#### **Outcomes and benefits**

- Between April to December 2017, 43% (189) of total calls (443) to the CAL received advice and guidance only, thereby potentially avoiding an outpatient's or specialist's appointment.
- This equates to a saving of £37,303 across the 9 CCGs in the Walton Centre catchment (assuming an OPFA cost of £224 for 40% (76) of calls and an OPFUP cost of £183.00 for 60% (113) of calls based on current utilisation)
- The introduction of the CAL reduced referral rates. Where GPs asked for and subsequently received specialist advice and guidance, only 33% of patients went on to be referred to secondary care.
- Nationally there are very large variations in the number of patients being referred to hospital outpatients, suggesting that for some referrals, patients could be managed differently. The GP Forward View sets out the need for better integration of primary and secondary care, and improved GP access to consultant advice on potential referrals. The CAL Service is one way the NHS can practically deliver this new way of working.
- Patients are seen by the right services first time and treated quicker

## ***Investment in research and development***

While our emphasis so far has been on ensuring timely referral and diagnosis in order to access treatment, the sad reality is that for many neurological conditions there are few or no available treatments. We still don't know enough about the causes, prevalence and prevention of neurological conditions, symptoms, and mortality. In 2013/14, just 5% of NIHR research spending was on neurological conditions.

More research is vital. It will improve outcomes and quality of life for people with neurological conditions and injuries. Research leads to better understanding of conditions, their causes and symptoms, and enables the development of new treatments and care for people with neurological conditions and injuries. This can be seen in the range of new disease-modifying therapies for multiple sclerosis, and the control of associated complications following spinal injuries that lead to improvements quality of life, such as activity-based rehabilitation. It is therefore essential that research into neurological conditions is able to take place in a supportive regulated environment with appropriate funding levels.

The majority of patients would be interested in taking part in research if offered. Yet, 59% (n=3,461) of respondents to a Neurological Alliance survey noted that they have not been offered an opportunity to take part in a clinical or research study but would be interested to do so if an opportunity arose.<sup>xxiv</sup> So is also vital that opportunities for people living with neurological conditions to take part in research projects are communicated effectively by health care professionals. Clinicians, specialist nurses and allied health professionals, therefore, need to be aware of trials around the UK and have the time to engage with research activities. Furthermore, they need to be able to explain the potential benefits of participation in a study to patients.

**Action 1h:** Make trials more accessible to people with neurological conditions, including approaches which encourage health care professionals to engage with patients and carers about research opportunities, and new digital solutions which link interested patients up with trial opportunities e.g. through digital care plans.

## ***Access to treatments***

As well as the need for more investment in developing new treatments, we also have specific concerns around the time taken to bring new innovations from a research setting into clinical practice in the NHS, particularly in relation to treatments for rare neurological diseases. Patients only have access to medicines once reimbursement decisions are implemented by national health systems. In international comparisons, England falls behind European counterparts in the speed and breadth of reimbursement of rare disease medicines: from 2001 to 2016 just 47 per cent of such medicines licensed by the European Medicines Agency were reimbursed for routine use in England compared to 81 per cent in France and 93 per cent in Germany.<sup>xxv</sup> And it took an average of 27.6 months until reimbursement was made in the English system, compared to an average of 20 months. It is essential that NHS England and NICE work to reduce the time delay in producing transparent health technology assessments, particularly highly specialised technologies, to ensure that patients can quickly access life-saving and life-enhancing treatments.

**Action 1i:** NHS England and NICE to work together to reduce the time delay in producing transparent health technology assessments, taking on best practice from international examples.

## 2. Integrated and personalised care for people with neurological conditions

A consistent theme across all Neurological Alliance work over the last ten years is a call for more integrated and personalised care. Neurological conditions are by their nature complex and require care and support from a range of professionals as well as less formal networks like family carers, making integration of care even more important. Similarly, many neurology patients access social care services, so integration across both health and social care, including across funding boundaries, is central to maximise patient experience and outcomes.

Yet our research shows that neurological services are characterised by disjointed care pathways, with patients being left to join up the dots<sup>xxvi</sup>. This is compounded by a lack of coordination of care or access to care and support planning. Furthermore, all too often, when patients with neurological conditions are hospitalised their normal medication gets missed, which results in their having to stay far longer than they should have for the reason for which they were admitted. We therefore welcome a renewed focus on this by NHS England and are calling for the long term plan to pilot new approaches with the neurology patient group.

Achieving integrated and personalised care requires different aspects of the NHS to come together seamlessly with the patient at the centre. In this section we discuss three main strands of potential activity that could support the delivery of more integrated and personalised care for people with neurological conditions: commissioning solutions, professional practice solutions and workforce solutions.

### **Box 4: Case Study: integrated personalised care for people with MS on disease modifying drugs**

The MS service in Leeds has a part-time band 4 coordinator dedicated to managing the administration of DMDs and coordinating care for approximately 350 people with MS. The coordinator is responsible for liaising with consultant neurologists, pharmacists and home delivery services to ensure the timely renewal of DMD prescriptions, and for operating a helpline for people with MS with non-clinical DMD queries that receives between 10 and 20 calls per week. The coordinator is also responsible for managing clinic lists for people with MS in order to best utilise clinic capacity, and producing patient pathways for new DMDs based on pharmaceutical guidelines. The main benefits of the DMD coordinator role are:

- People with MS on DMDs have a direct point of contact for non-clinical issues and an advocate to deal with problems involving home delivery companies and monitoring appointments.
- Non-clinical yet complex administration tasks are relieved from clinical staff.
- Individuals on DMDs are effectively tracked - the DMD coordinator maintains a database detailing monitoring events and alerts that are followed up if missed, ensuring that monitoring is effective and timely.

<https://support.mstrust.org.uk/file/MSFV-DMD-report-10-5-17-2.pdf>

## 2.1. Commissioning solutions

### *Integrated care pathways*

Care pathways in neurology are often fragmented, characterised by services that do not work well together. One key solution to ensure better integration is therefore to map patient pathways. Where they are found to be falling short, those engaged in planning services can take action to rectify this. We have welcomed the work NHS RightCare has been undertaking work to produce frameworks for optimal care in various neurological conditions. However, such frameworks will only be effective if they are implemented by regional and local decision makers. Those working to integrate care across regional populations must be incentivised to optimise care pathways, employing intelligent solutions as seen in the case study below (box 5). Moreover, data is key (see action 1d), as there needs to be understanding by those planning and paying for services that investing in optimising care pathways will result in both savings and better patient outcomes downstream.

**Action 2a:** NHS England to ensure that any future regional-level accountability frameworks include incentives for improvements in neurology.

### *Multi-disciplinary team working*

At present, secondary care too often tends to be organised around acute care, investigations and consultant care, rather than multidisciplinary integrated care. Too often patients do not have access

**Box 5: Case Study: Multi-Disciplinary Team working** Community neuro-rehabilitation service, CSH Surrey Surrey.

This community neuro-rehabilitation multidisciplinary team works closely with the MS specialist nurse, and consists of a physiotherapist, occupational therapist, speech and language therapist and a dietitian. This team also works closely with other local services, such as palliative care. This is a team which provides local, coordinated, efficient, effective and holistic care to people living with MS in the Surrey area.

- The team work closely with internal and external local services, such as wheelchair services, continence specialists, consultant neurologists and social services.
- They also communicate closely with local district general hospitals, tertiary services, orthotics services and palliative care. Joint home visits between these services occur as required.
- The MS nurse is able to visit people with MS in specialist neurological rehabilitation units within the community hospital for intensive rehabilitation and disability management.
- The MDT meets weekly to discuss the service, and patients that would benefit from seeing different members of the team. Additionally, close communication is maintained throughout the week.
- The MDT also work together to run very well attended newly diagnosed days in collaboration with First Community Health Care that covers East Surrey.
- The service also provides a 'one stop helpline' (telephone and email) for everyone living with MS.

Benefits of working in this way

- Ensures everyone with MS in the CSH Surrey area receive the care they require from the relevant expert professionals
- Referrals to other services and relevant health professionals are streamlined
- People are seen by neuro-specialists with an expert and wide-ranging knowledge of MS
- Releases capacity of MS neurologist and neuro rehab consultant

to a full range of health professionals, or experience care that is not integrated. Over half of neurology patients (56%, n=2,714) feel that their health and care professionals work well together at least some of the time, while one in five (20%) feel this 'never' happens. This can contribute to unnecessary admissions, re-admissions and poor care, with parallel costs.

We know that for people with neurological conditions, access to a well-coordinated multi-disciplinary team is key to the provision of good care and maximising patient outcomes. We advocate well-coordinated multidisciplinary team working, provided where possible via a multispecialty provider in a community care setting. An example of this is provided in box 5. An essential pre-requisite to effective MDT working is having patient data that each member of the team is able to access. An example of digitised care plans, to which each team member can contribute, is provided in box 7.

**Action 2b:** Neurology should be prioritised in a programme of work to co-design a suite of models for integrated MDTs working across primary and community care in partnership with the voluntary and community sector.

**Action 2c:** Implementation of the recommendations in the Watcher Review on use of information technology in the NHS in order to support care planning.

### ***Integrated personalised commissioning***

NHS England strategy team recently explored the potential of integrated personal commissioning (IPC) (an approach centred around more holistic and personalised planning) for people with neurodisability and concluded that it could play a very helpful role. According to NHS England's findings there are a number of potential advantages to an IPC approach:

- Improved system navigation and management
- Rapid access to support (e.g. for fluctuations)
- Personal budgets to improve the way services fit into people's lives (e.g. can pay for own gym membership)
- Aligning service offer around risk stratification (e.g. home adaptations and equipment as standard offer for patients who fit agreed profile)

Together with the National Neuro Advisory Group, we are commencing a project on care planning to tackle identified barriers to its wider use. This will include identifying exemplar areas that currently embody good practice in care planning and use of referral letters for patients with neurological conditions, working to identify features of planning and referral that are working well and the processes and approaches behind this, and identifying and transferrable learning on good care planning in neurology that can inform similar approaches in other areas.

Given the IPC work being undertaken by NHS England, and the care planning work being undertaken by NNAG, we believe that neurology is well placed to be used as a test bed for new approaches to integrated care and hope to collaborate with NHS England to achieve this.

**Action 2d:** Develop a pilot to support STP areas to further develop the IPC approach for neurology.

## 2.2 Professional practice solutions

### *Care and support planning*

It is now well understood that effective care planning and coordination is an essential aspect of care for people living with a long term health condition.<sup>xxvii</sup> The need for care planning has been included in many NHS England plans and strategies over the last decade, but we know the number of patients who are offered a care plan remains low. The Neurological Alliance's data shows only 15% of neurology patients currently have care plans, with 82% of neurology patients saying they have never been offered a care plan<sup>xxviii</sup>. For the long term plan, it is essential that measures are put in place to make care planning a reality for patients.

One of the key mechanisms to deliver care and support planning is having a named care coordinator. Care coordinators support patients through decision making, and can act as a problem solver to get things done quickly. Their importance is outlined in the case study in box 6.

We know that another of the obstacles to making care and support planning a reality for patients with neurological conditions is the perception – by professionals - that it as a burdensome, time-consuming process. Technological solutions, such as in the case study in box 7, may help to overcome such obstacles. Where solutions to improve care planning are in place, they should be upscaled as appropriate.

**Action 2e:** Explore the development of national and local incentives to ensure each patient has a named professional to help organise their care, perhaps under the auspices of integrated personal commissioning.

**Action 2f:** Accelerate exploration of digital care plans, using neurology as a test bed for any pilots.

### **Box 6: Case Study: Care Coordination**

MND Association Care Centre and Network Programme

The NICE Guideline for MND notes the importance of a multi-disciplinary team approach in the management of the condition, with well-coordinated care. It does not however make any recommendation about how or who should coordinate that care. The MND Association through its 'care centre and network' programme makes some funding available to regional centres of excellence for the funding of a clinical care coordination role, so that care can be seamless between the speciality neurological team at the services, and between provision in the community, whether through a dedicated multi-disciplinary team or through hospice and palliative care services.

**Box 7: Case Study: Innovative solutions to improved use of care planning** Neuro LTC: Online Integrated Care Plan, University Hospital Southampton NHS Foundation Trust, in partnership with Solent NHS Trust.

This project is investigating the use of patient-held, personalised, online care plans for patients living with long-term neurological conditions, as a means to improving communication and integration across various care settings, improving patient care and increasing self-management capabilities.

The project uses the Trust's existing patient online service (My Medical Record – myMR) as a platform to allow health care professionals and patients to create, access and manage individual care plans for patients living with long-term neurological conditions. The platform interfaces with hospital and community systems to automatically upload relevant documents. Patients are encouraged to add personal information, preferences and complete health surveys online to improve communication and planning between multi-disciplinary care teams and patients. Moreover, the record is accessible to the patient, who can select which health professionals have access to their record.

By empowering patients to have a central role in their care plan, and creating a single space for sharing information, the project expects to see an increase self-management capability, and improve integration of health care across settings.

### **Information, self-management and peer support**

In parallel to a lack of care and support planning, patients have told us that they often are not given information at the time of diagnosis. Information is critical to not only understanding and coming to terms with an often life changing diagnosis, but also to support self-management, to enable people to take personal responsibility to prevent their health from further deteriorating, as far as possible.

Of central importance is the provision of written information following diagnosis. This should be in a letter written to the patient by the consultant, in which they explain the diagnosis and signpost the patient to further relevant information and sources of support, to support them at the time of diagnosis, as well as in the future. Third sector organisations provide a wealth of information on such topics and it is vital more is done to sign post patients to such sources of support.

**Action 2g:** While it undertakes work to mainstream the information standard, NHS Digital must engage with patient groups to ensure that opportunities to inform patients about the information they provide are taken, e.g. through continued signposting to patient organisations on NHS Choices.

Peer support programmes, delivered in groups, can help to instil hope and provide informal education about the condition. Research has shown that such programmes can contribute to improved wellbeing and enhance confidence in self-care, self-efficacy, and levels of activation.<sup>xxix</sup> In addition to the advantages to the patient, peer support is less costly compared to a professionally led prevention and promotion activity, and the voluntary sector is well placed to provide and contribute to the cost of trained volunteer facilitators.

Increasingly, supported self-management is becoming a digital offer, which is important as it caters to the needs of people living with mobility issues and other symptoms (e.g. fatigue, pain), which may make it difficult to travel to face-to-face interventions. It also enables people to monitor their symptoms on an ongoing basis, prompting them to seek help as required. This can be seen in the case study in box 8.

#### **Box 8: Case Study: Epilepsy Self Monitor (EpSMon) – An NHS Innovation Accelerator**

EpSMon is a free epilepsy risk management and prevention tool, enabling patients to self-monitor via a digital app. It can be used as a self-management tool by providing risk assessments to patients and encouraging early intervention for people with rising risk. EpSMon informs of changes to risk factors by patients monitoring their seizures and well-being, and encourages seeking medical help if required. EpSMon is a digital version of a SUDEP (Sudden Unexpected Death in Epilepsy) and Seizure Safety Checklist, developed and available for professionals who register with SUDEP Action for annual updates from a UK-wide development group of experts.

A preventative tool such as EpSMon can have a significant impact on the personal and financial costs of epilepsy through reduction in deaths and decrease in A&E appointments, thereby reducing the £1.5 billion in costs associated with epilepsy within the UK every year.

- Adopted as a solution via a training package for emergency services, and also promoted by Royal College of GPs' e-learning
- HSJ Awards 'Patient Safety' category finalist, BMJ Awards 'Highly Commended', Health Business Awards 2016 winner
- Evaluated as part of a 2017 NIHR Cochrane Review of epilepsy technologies

**Action 2h:** Develop a systematic national approach to supporting the development of self-management tools and peer support interventions, as well as support to promote and disseminate these tools to aid implementation.

## 2.3. Workforce solutions

Central to achieving integrated and personalised care for patients with neurological conditions is ensuring that the neurology workforce is equipped to deliver this. Given that the implementation of improved integrated personalised care will help people with neurological conditions to stay as well as possible, tackling workforce problems will also support preventative measure, discussed in chapter 1.

### ***Neurology workforce plan***

We believe a comprehensive neurology workforce plan is needed to pull together a number of measures to better support the neurology patient group. We use the term ‘neurology workforce’ to include the ‘neurosciences’ workforce, but also those working in areas such as mental health, rehabilitation, social care and community care. This should include proposals about how to resolve these issues over the shorter term, including innovative use of resources and the creation of stop-gap solutions. It should also explore what constitutes a sustainable level of staffing, and how to get there, with corresponding measures to increase the neurology workforce over the longer term.

This plan would provide solutions to the critically low neurology staffing levels currently seen in some areas of the country, including shortages of neurointerventional radiologists, consultant neurologists and specialist nurses, and help to stem the rising tide of people with neurological conditions experiencing crises which result in use of emergency services. It would and provide innovative solutions to these problems, and in so doing, address the need for better coordinated multi-disciplinary team working to deliver personalised care centred around the patient,

**Action 2i:** NHS England should work with Health Education England to produce a nationwide comprehensive workforce plan for neurology, to achieve a sustainable workforce able to meet existing and future levels of demand.

### ***Innovative solutions to workforce issues***

Patients not having access to a full range of health professionals is partly a result of neurology services not being adequately staffed. The system is overstretched, with demand exceeding capacity year-on-year. The neurology workforce in place is not sustainable to meet existing patient needs, let alone the projected increase in the number of neurology patients, if current trends continue. Our workforce compares poorly internationally. For example, for every neurologist in the UK, France has five and Italy has eight. Consequently, the numbers of neurologists are at critical levels in many parts of the country, leading to bottlenecks in the timely provision of care. Similarly, there is a shortage of specialist nursing posts, with existing specialist nurses having unsustainably high caseloads which exceed recommended levels.<sup>xxx</sup> Moreover, for people with rarer neurological conditions, access to specialist neuro nursing is often not available.

**Box 9: Case Study: Invest (in existing team resources) to save** Senior band 8 MS nurse consultant, MS service in Sunderland.

Following extensive training for her prescriber qualification, the nurse consultant is able to distribute repeat prescriptions for disease modifying drugs (DMDs) without input from a consultant neurologist. Once DMDs have been prescribed, the consultant is no longer involved in the repeat prescriptions. The role also allows her to inform GPs of what to prescribe and she is able to order MRI scans where necessary. Patients can access their treatments quickly through the hospital's E-prescription service, and through outpatient prescriptions. She also prescribes medicines for symptom management, from pain to continence, steroids for relapses, and antibiotics and drugs for spasticity. She is able to consult the neurologist for advice as needed. All her prescriptions are also double checked by the hospital pharmacist.

Benefits of working in this way:

- More efficient DMD care pathway for people on treatment – faster access to DMDs and SPoA
- Fewer neurologist appointments, and reduced pressure on neurologists
- Closer relationship between MS nurse service and the local GP networks
- Improved GP understanding of DMDs, prescriptions and potentially of MS in general
- Safer prescribing (as MS nurses often have a more in-depth understanding of individuals, their symptoms, lifestyles, and of the likelihood of the degree of adherence to drug monitoring regimes)

There are several ways to tackle the current issues around access to neurology specialists, which are particularly acute in some parts of the country. Clearly increasing the overall number of neurologists and specialist nurses is a desirable. But this is a long-term and expensive solution. More innovative use of existing resources should therefore be undertaken where possible. This includes the traditional secondary care outpatient and Consultant Neurologist-led functions being undertaken in different ways.

One solution for neurologists involves changing their training routes, whereby they split their training across different hospitals to enable better geographic spread is one option.

**Action 2j:** Health Education England to review how neurology training routes could be refined to ensure better geographical spread.

More efficient use of neurologist time would also reduce waiting times – for example through using non-clinical support staff and specialist nurses, freeing up their ability to take on new primary care referrals. This would tackle the waiting times discussed in chapter 1. See box 1 for a case study examples of where this is working well. Similarly, introducing more administrative support for specialist nursing teams could help free up their capacity and deliver a better service for their patients.

Role substitution or replacement with other skilled team members is also a viable option. This includes GPs with a special interest, or the increased use of other clinical decision makers including nurse specialists and allied health professionals.

Similarly, small additions to existing team staffing resource can reap dividends in terms of freeing up specialists' time. Examples include investing in training to upgrade existing nurse posts to prescribing

roles, as per the case study above (box 9) and ensuring adequate administrative and technology support for the team.

Primary Care Networks are another potential solution to enable care to be delivered for patients with suspected neurological conditions at a scale that is large enough to allow a degree of GP specialisation across a local population. Furthermore, the use of GPs with a special interest in specific neurological conditions can provide an intermediate tier of care having the benefit of reducing demand on secondary care .

**Action 2k:** Include in the neurology workforce plan measures aimed to ensure that specialists are trained, supported and can develop their careers.

**Action 2l:** Pilot the use of GPs with a special interest in epilepsy in several primary care network areas and analyse the impact on A&E attendances.

Follow-up patients may be highly suited to more innovative solutions than the traditional model of sporadic face-to-face consultations. Examples include guided self-management, and where appropriate the provision of mutual advice through peer support groups. This would result in a significant release on capacity. In addition to freeing up capacity in the system, such solutions can help to better meet the needs of patients who say they want access to expertise closer to home.

### 3. Neurology and the clinical priorities

Each of the clinical priorities identified for the long term plan has an important neurological aspect, reflecting the wide-ranging nature of the neurological conditions umbrella. In this section we explore these relationships and set out the case for including neurology in actions to address the clinical priorities that will be included in the plan. We also provide detailed analysis about the specific considerations for neurology and mental health, and women and children with neurological conditions.

#### Cancer

There are a number of types of cancer that are considered neurological. However, as highlighted to us by brain tumour charities, and more publicly by Dame Tessa Jowell before her death from glioblastoma, brain cancers have not been a priority within the wider cancer agenda. They too often get overlooked or lost amongst the more prevalent diseases, both for research funding and for care and treatment initiatives. This means that there are limited, if any, treatment options for these diseases which would increase chance of survival and quality of life. Cancers of the brain must not be overlooked for research funding in order to increase survival and improve quality of life.

#### Cardiovascular

In the past, stroke has generally been treated as a circulatory system disease, and categorised under cardiovascular and respiratory diseases, both in England and more widely. This was of classifying stroke led to delay in resource allocation and training of medical, radiological, and nursing staff who know how to deal with brain diseases.<sup>xxxii</sup> But under the latest International Classification of Diseases (ICD-11), from 2017 stroke has officially been classified as a neurological condition, in line with a wider move to transfer all cerebrovascular diseases to the section of diseases of the nervous system.

There is the potential for improvements in stroke care to benefit the care of a wider group of patients with neurological conditions, if a coordinated approach is taken to improvement and stroke is not treated in isolation from the wider neurological banner. This is particularly true for rehabilitation and we would welcome the opportunity to continue to work with NHS England to develop rehabilitation services for stroke and wider neurology patients through the mechanism of the long term plan.

**Action 3a:** Work with patient groups on plans to develop rehabilitation services for stroke and wider neurology patients through the mechanism of the long-term.

#### Learning disability and autism

Learning disability and autism are common co-morbidities for other neurological conditions. For example, between 11 and 39% of autistic children and adults have epilepsy, in contrast to 1% of the general population<sup>xxxiii</sup>. The Learning from Deaths report (LeDeR) from Bristol University has highlighted evidence of sustained and profound health inequalities for people with a learning disability, autism or both, and recently covered epilepsy as an additional surveillance topic. We also know that diagnostic overshadowing is common between autism and other neurological conditions. For example, an individual may be diagnosed with epilepsy, but co-morbid conditions such as autism or a mental health condition may be overlooked. We welcome the inclusion of learning disability and autism as clinical priorities yet urge NHS England to consider the needs of people with neurological conditions alongside this work given the strong link.

**Action 3b:** Ensure that initiatives to reduce health inequalities experienced by people with learning disability and autism include a specific focus on common comorbidities, and also aim to tackle diagnostic overshadowing.

## Mental Health

We estimate that more than 50% of patients with neurological conditions will have emotional, cognitive and mental health needs.<sup>xxxiii</sup> Furthermore, GP survey data shows that people with neurological conditions have the highest co-morbidity with mental health conditions out of all long-term conditions. Despite these prevalence figures, to date there has been little consideration about how parity of esteem applies to people with neurological conditions.

Mental health needs associated with neurological conditions can impact considerably on patient outcomes, especially where timely and appropriate diagnosis and interventions are not available. A co-morbid mental health condition can often lead to reduced ability to self-manage a physical condition, manifesting itself in poorer adherence to treatment plans and lower attendance at medical appointments. This contributes to more acute episodes, poorer clinical outcomes and higher mortality rates. A lack of early detection, treatment and intervention for emotional, cognitive and

**Box 10: Case Study: Consideration of cognitive, emotional and mental health needs embedded within neurology service pathways.** The Children’s Headache Clinic GOSH

The children’s headache service at Great Ormond Street Hospital sees over 100 new patients a year. Referrals, once received from paediatricians and neurologists, are vetted by the multi-disciplinary team. Structured questionnaires including headache diaries, RCAD (Revised Childhood Anxiety and Depression Scale), PeDS QL (a measure of quality of life), PedMIDAS (Paediatric Migraine Disability Scale) and Current Concern Questionnaire are sent out. Information on school attendance and social participation is also requested. Information about what to expect in clinic is also given along with pointers to useful resources. It is made clear that an MDT approach involving psychology is offered.

The psychologist offers individual sessions for children with mental health needs. There is a rolling Headache Group for children facilitated by the psychologist which forms part of the Headache Service. The Nurse Specialist and Psychologist also facilitate teleconferences with local teams including paediatrician, psychologist, welfare officers, SENCO, School Teachers to discuss care and way forward. Service audits found that in 3 out of 10 children anxiety/depression co exists with the headache problem. Of these only 1 out of 3 was this picked up and addressed by the referring clinician. In addition, the service has diagnosed young people with High Functioning Autism during the management/screening process – this enabled providing the most appropriate psychological care model.

Following a focus group of parents about the service, the following feedback was reported: ‘The team takes a dual pronged approach with both the medical and psychology aspects being equally important. The psychology input was no longer about finding a psychological cause for the headache, but rather recognising the contributing factors and the impact of headache and supporting with dealing with this. This approach allowed young people to be more honest about their feelings, enabling fuller exploration and strategies to help. Having someone to call between appointments was missing from local services. Families expressed feeling isolated and alone between the six month appointments locally, but at GOSH have an easily accessible link for

mental health needs associated with neurological conditions not only lowers health outcomes, it can reduce quality of life and increase disability. In children it can often be a factor in lower educational attainment. Patients report that the combination of a neurological condition and mental health condition can bring them to crisis point. In some cases, not recognising and treating a co-morbid mental health condition can lead to inpatient admissions.

There is often a complex interplay between neurological conditions and co-morbid mental health conditions. As neurological conditions relate to the brain and nervous systems there is an increased complexity in the interaction between physical needs and broader emotional, cognitive and mental health needs. It can be difficult to unpick where the neurological condition ends and where a mental health condition begins or how the two interplay with each other. Providing accurate diagnosis and effective treatment for emotional, cognitive or mental health needs in this context can be challenging.

Current services are characterised by disjointed pathways, poorly coordinated care and variation across the country. Our work indicates gaps in the availability of, and access to, specialist neuropsychological and neuropsychiatric support within multidisciplinary teams. This is particularly notable within community-based services. Availability of psychological support in general can also be an issue and we found that those with neurological conditions are often not able to access mental health services as their condition is seen as organic. For those who are accepted by mental health services, they often find that these services are not appropriately tailored to meet their specific needs. Signposting to information or other self-management resources to support emotional, cognitive and mental health needs is often poor.

Specially designed services that bring together neurology and mental health are required to achieve the best outcomes for patients. With effective psychological triage within the neuroscience pathway, it can be determined which individuals would be suitable for mainstream mental health services and which individuals need specialist psychological interventions to meet the needs of their condition.

**Action 3c:** NHS England should allocate some of the funding for mental health and long-term conditions to pump priming new services or demonstrator projects for neurology and mental health.

Mainstream services, such as IAPT long term conditions services, must be equipped to serve the neurology patient population, providing personalised care that meets their needs. Primary care mental health staff must be upskilled so as to be able to recognise their patients' needs, and service models must allow them to tailor treatments as appropriate e.g. offering face to face or individual sessions where communication or cognitive difficulties would make telephone sessions or group sessions inappropriate.

**Action 3d:** Further develop training for therapists working within Improving Access to Psychological Therapies (IAPT) services to include information on how to support people with neurological conditions, including those with co-morbid neurodevelopmental disorders.

Secondary and tertiary mental health services must similarly be equipped to support neurology patients' mental health needs. This includes the provision of care pathways between mental health and neurology services, and mental services having adequate input from suitably qualified staff, such as neuropsychologists and neuropsychiatrists. The forthcoming neuropsychiatry and neuropsychology service specification is very welcome, but its manner of implementation will be critical to making the difference needed for neurology patients.

**Box 11: Case Study: Self-management for mental health** Epilepsy and You run by Epilepsy Action

Epilepsy and You is an online, structured self-management programme for adults with epilepsy in the UK. It can be accessed from a computer, tablet or smartphone and takes around two hours a week, over eight weeks, at any time to suit the learner. The course is full of information, tools, personal stories and activities. These include goal-setting, action planning, keeping a gratitude journal and contacting other people with epilepsy. Learners are supported to:

- Think about the different ways that epilepsy affects them, both physically, mentally and emotionally
- Learn skills for dealing with issues that arise from living with epilepsy, and take action to use them
- Be more involved in managing and making decisions about their own treatment
- Improve confidence and self-efficacy

Independent evaluation of Epilepsy and You by Coventry University showed that the programme provides 'meaningful benefit and value to people with epilepsy'. In particular, participants reported increased knowledge, skills and confidence (activation) to manage their epilepsy, maintained at least three months after completion. Also, participants reported significant value through reducing their level of social isolation. Feedback on Epilepsy and You clearly demonstrate the benefits in relieving anxiety, and meeting other emotional needs of people with epilepsy.

Information and self-management can also play an important role in meeting mental health needs, as seen in the example given in box 11 above. Patient organisations have a lot of resources available in this regard. Cognitive, emotional and mental health needs of neurology patients should be considered at the time of diagnosis, with screening included in ongoing care. A good example of this is given in the case study in box 10 on the previous page.

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### **About the Neurological Alliance**

The Neurological Alliance is the only collective voice for 80 organisations working together to make life better for millions of people in England with a neurological condition. We work with our member organisations to campaign nationally and locally to ensure better services and outcomes for all those with a neurological condition.

### **About neurological conditions**

Neurological conditions are disorders of the brain, spinal cord or nerves. They can have a range of causes including genetic factors, traumatic injury, and infection. The causes of some neurological conditions are still not well understood. There are a large number of diverse neurological conditions. Some are very common, such as dementia, stroke, epilepsy, and migraine, while some are comparatively rare. In between is a wide range of conditions such as Parkinson's disease, multiple sclerosis, and traumatic brain injury. According to the latest estimates, the total number of neurological cases in England has now reached 12.5 million, or an average of 59,000 cases per CCG.

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