



**THE  
NEUROLOGICAL  
ALLIANCE**

# NEURO PATIENCE

Still waiting for improvements  
in treatment and care

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# Forewords



The title of this report was written with intended irony. Neurological *patients* – or people with neurological conditions, as we would usually refer

to the one in six people in England we work on behalf of – are running out of patience. As we explore in this report, people with neurological conditions are quite literally waiting, often with worrying, painful neurological symptoms that are preventing them from living their day-to-day life. They are waiting for a referral to a specialist, waiting for an appointment with a neurologist, waiting for new treatments to be developed and waiting to get the financial and social care support they need. They are also waiting – along with The Neurological Alliance and our members – for change.

People with neurological conditions do not have time to be patient. This was brought into sharp focus during the promotion of the National Neurology Patient Experience Survey, on which this report is based. I emailed everyone who, upon completing the last survey, had asked The Neurological Alliance to contact them again when we next ran the survey. I received countless replies from family members saying the person who completed the survey last time had died. I thought a lot about these family members and how difficult it must have been to write those emails. They were certainly difficult emails to read; we have not been able to bring about change fast enough for a lot of people.

This is our third biennial survey and the results suggest that little has changed over the six

years since our first survey. Neurological patient experience remains at a shockingly low level across all of the main metrics we ask people about. Yet, where this survey differs from previous iterations is that we have strengthened the methodology, resulting in over 10,000 responses being received. The experience of 10,000 people cannot be ignored. The responses reveal significant regional variation, representing a postcode lottery which must be addressed. And the differences in the level of person-centred care experienced by people with neurological conditions compared to people with cancer are inequitable and unjust.

*‘The Neurological Alliance is waiting, somewhat impatiently, for people with neurological conditions to be prioritised by the health system, recognised by the benefits regime and given access to appropriate social care.’*

The Neurological Alliance is waiting, somewhat impatiently, for people with neurological conditions to be prioritised by the health system, recognised by the benefits regime and given access to appropriate social care. This report sets out what we want to happen to ensure that people with neurological conditions do not have to wait much longer for care and support that is accessible, personalised and holistic.

**Sarah Vibert**  
Chief Executive  
The Neurological Alliance

# Forewords



Excellent care for people with neurological conditions requires an integrated approach to funding, planning and delivering services. At the level of an individual patient, this means

GPs, neurologists, allied health professionals, mental health professionals, nurses, social workers and others working together support an individual to optimise healthcare outcomes and maximise independence. At system level, this means primary, secondary and specialised care working in partnership to provide a seamless pathway for patients. Integration also requires different commissioning bodies, care settings and NHS organisations to work collaboratively.

*‘Neurology is the ideal candidate for demonstrating how integrated care can work.’*

All too often however, as the latest research from The Neurological Alliance demonstrates, the system struggles to provide integrated care for people with neurological conditions. We see from the survey results the issues that exist in relation to appropriately triaging patients who are referred by GPs to neurologists and a lack of information sharing between different parts of the system. We also see the low levels of mental health support, and even poorer experiences of social care.

Neurology is the ideal candidate for demonstrating how integrated care can work.

In this respect the new regional Integrated Care Systems (ICSs) that will develop out of the Sustainability and Transformation Partnerships (STPs) present a huge opportunity for neurological service improvement. I cannot think of another clinical specialty where delivering the triple integration of primary and specialist care, physical and mental health services, and health with social care is more relevant – or more pressing. But the promise of an integrated system will only be delivered for people with neurological conditions if those leading ICSs are willing to embrace the neuro challenge. In my role as Chair of the National Neuro Advisory Group (NNAG), I am keen to see neurology as a priority for the ICSs.

Data is clearly important to support local areas to prioritise. In this respect it is helpful to see the neurology patient experience data presented at STP/ICS level. This not only shows the areas which require improvement but also what is possible in terms of the best performing. Coupled with the forthcoming Getting it Right First Time neurology data and workforce research by the Association of British Neurologists, the National Neurology Patient Experience Survey data provides strong evidence about what needs to happen to deliver good, integrated care for everyone with a neurological condition. We are in the process of defining ‘what does good look like’ as whole pathways for a full range of neurological and neurosurgical conditions. This will include tighter definitions of specialist multi-disciplinary teams, clinics and regional networks. I look forward to working with The Neurological Alliance and NNAG to make this happen.

**Professor Adrian Williams**  
Co-Chair  
National Neuro Advisory Group

# Summary of findings

This report, based on the experiences of more than 10,000 individuals, has three key messages. Care and support for people with neurological conditions must be:

- **Accessible**, the speed of access to specialists must improve overall and should not vary depending on where you live.
- **Personalised** and tailored to the needs of each individual.
- **Holistic**, addressing people's mental health, social care needs, and their financial security.

## Accessible



**39%**

of respondents saw their GP five or more times before being told they needed to see a neurologist\*



**29%**

of respondents who needed to see a neurologist waited more than 12 months



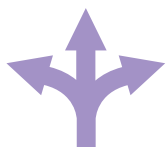
**55%**

of respondents said they have experienced delays in accessing healthcare



**38%**

of respondents do not have access to a specialist nurse but would like this support



**30%**

of respondents have not been referred or signposted to mental health support but would like this\*\*



**34%**

of respondents do not believe they see a specialist often enough to meet their needs

\* Of those who said they saw a GP

\*\* Of those who said they have mental health needs

# Summary of findings

## Personalised



### PROVISION OF INFORMATION

**43%**

of respondents were not given written information when they were told they had a neurological condition



### COMMUNICATION

**23%**

of respondents were not given an explanation of their diagnosis, that they understood, when they were first told they had a neurological condition



### SHARED DECISION MAKING

**30%**

of respondents do not feel involved in making choices about their healthcare



### CARE PLANNING

**10%**

of respondents have been offered a care plan



### COORDINATED

**28%**

of respondents disagree that information about their treatment and condition is effectively passed between the different people who care for them

## Holistic care

% of respondents reporting their needs are not being met at all, in relation to:

**40%**



Mental health

**43%**



Financial

**38%**



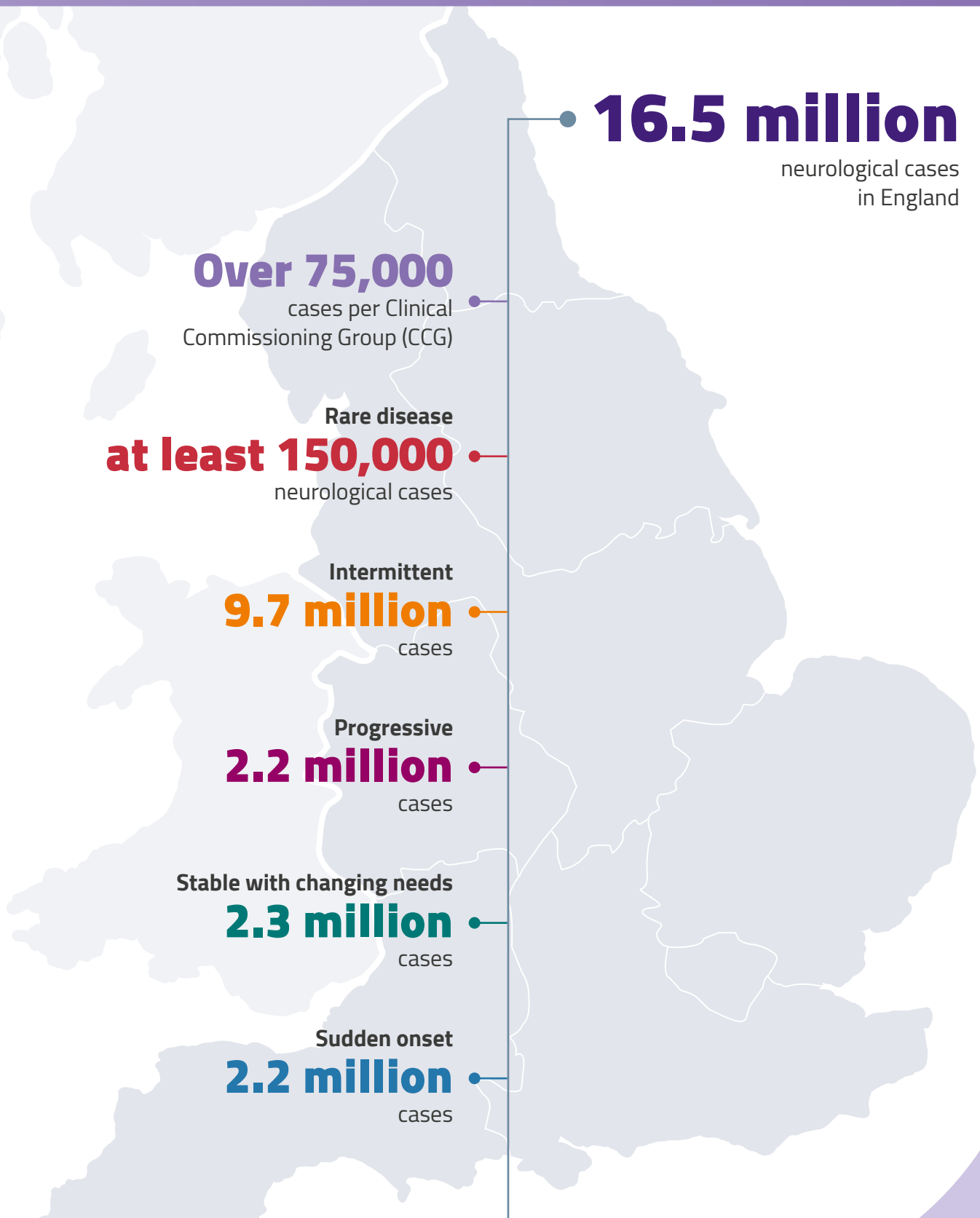
Social care

**26%**



Healthcare

# Section 1: Policy context



Figures based on estimations of condition prevalence using the references detailed in the accompanying data table overleaf. Where only UK prevalence figures were available a calculation has been made based on the Office for National Statistics estimation of UK and England populations, 'Overview of the UK population, November 2018'.

# Section 1: Policy context

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 of these conditions are still not well understood. Neurological conditions are very wide ranging. There are over 600 types of neurological condition, of which some are very common, and others are comparatively rare. The latest prevalence estimates suggest there are over 16 million neurological cases in England, equating to at least one in six people having a neurological condition.

The National Neurology Patient Experience Survey is the only pan-neurological survey exploring the views of people across the spectrum of neurological conditions in England. Through gathering data on a wide range of topics – from diagnosis and information, to hospital care, support for mental wellbeing, and access to social care, welfare and employment – we present a comprehensive picture of people’s experiences of living with a neurological condition in 2018/19. In the absence of nationally collected neurological patient outcomes measures, or social care data that is segregated by condition, this approach provides intelligence about how well health and care services in England are performing in relation to people with neurological conditions. Moreover, the data brings the experiences of 10,000 people with neurological conditions to the fore, highlighting the need for greater prioritisation of neurology by the health and care system.

## **The need for pan-neurological improvement in the NHS**

Where neurology is included as an NHS priority, it almost always in relation to individual neurological conditions, rather than neurology as a whole. This is due in part to the wide

range of conditions that fall under the neurological banner and the different care pathways involved. The Long Term Plan for

*There is a growing evidence base to suggest that neurology as a whole needs to be a focus for improvement efforts in the NHS.*

the NHS is typical of this approach: a number of specific, more common, neurological conditions (stroke and dementia in particular, also cerebral palsy) are singled out, yet many neurological conditions are entirely absent from the Plan,<sup>i</sup> and neurology as a whole is overlooked. Similarly, the NHS accountability mechanisms have no pan-neurological improvement measures. For example, the CCG Outcome Indicator Set includes measures relating to only two neurological conditions: stroke and epilepsy. While improvement efforts are welcome for individual conditions, there is a growing evidence base to suggest that neurology as a whole needs to be a focus for improvement efforts in the NHS.



# Section 1: Policy context

- The number of people living with neurological conditions in England is rising and will continue to increase, due in large part to our ageing population.<sup>ii</sup>
- The 2013–14 NHS England survey of patients of GP practices found that people with neurological conditions report the lowest health-related quality of life of any long term condition.<sup>iii</sup>
- The NHS & CQC 2017 Adult Inpatient Survey, found that people with neurological conditions poorer experiences for confidence and trust, respect and dignity, respect for patient-centred values and overall experience of care than those from other disease groups.<sup>iv</sup>
- There is an increasing trend in deaths associated with neurological conditions: 39% increase in neurological deaths compared to 6% decrease in all-cause deaths since 2001. Deaths associated with a neurological condition are 35% more likely to be premature.<sup>v</sup>
- Neurology accounts for significant – and increasing – NHS activity and spending in England.
  - From 2012/14 to 2015/16 there was a 14% increase in all hospital admissions with a primary diagnosis of a neurological condition, and a 10% increase in emergency hospital admissions.<sup>vi</sup>
  - Neurological conditions (including stroke and dementia) accounted for 12,736,365 bed days in 2016/17.<sup>vii</sup>

- According to the 2018 GP survey, 19% of patients with a neurological condition had had an unplanned stay in hospital over the past year, twice the rate for all people with a long-term condition (9.8%).<sup>viii</sup>

It was on the basis of evidence about poor quality of life, health inequalities, and premature mortality, as well as increasing prevalence, NHS activity and spend in relation to people with neurological conditions that the Public Accounts Committee (PAC) concluded in 2016 that 'it is clear that neurological conditions are not a priority for the Department of Health and NHS England, and we are concerned that the progress that has been made may not be sustained.'<sup>ix</sup> Data presented in this report and the accompanying technical report adds significantly to the case for change.

## NHS improvement initiatives in neurology

Since 2016, when the PAC published the findings of its inquiry into neurological services, there has been a marked change in momentum. There are now a wide range of improvement initiatives in the NHS which take neurology as a focus. However, we note the statement of the 2016 PAC report that 'changes have not yet led to demonstrable improvements in services and outcomes for patients'. Unfortunately, this still seems to be the case. This report highlights that people's experiences of neurological care have not changed between 2016, when we last undertook our patient experience survey, and today. It is imperative that the promise of neurological improvement initiatives is realised on the ground, as soon as possible. It is also essential that the various different initiatives are well coordinated with one another, in order to reach their potential.

# Section 1: Policy context

## Neurology improvement initiatives in England, 2019

- The **Getting It Right First Time** neurology and neurosurgery programmes are looking at improving the quality of care within neurology services by reducing unwarranted variations between hospitals.
- **NHS RightCare** is a national NHS England programme aiming to ensure people access the right care, in the right place at the right time. It aims to tackle variation across the country in terms of the type of care patients receive.
  - In 2016 RightCare published **neurology focus packs**, tailored to each Clinical Commissioning Group (CCG), to help them to focus on delivering the biggest improvements in health outcomes and value of services for people living with neurological conditions.
  - RightCare is producing three **neurological pathways** – for Headache and Migraine, Progressive Neurological Conditions, and epilepsy, due to be published in 2019, providing a set of resources to support local health economies to concentrate their improvement efforts.
- **NHS England's Neuroscience Transformation Programme**, focussing initially on three neurological disease areas, is seeking to simultaneously reduce expenditure and improve patient care within its specialised commissioning remit.
- **NHS England's Elective Care Transformation Programme** includes a strand on neurology in its wave five best practice solutions work, supporting frontline teams to run rapid testing of innovative approaches to transform outpatient services.
- The **National Neuro Advisory Group**, espoused by NHS England and co-chaired by The Neurological Alliance, bring all system leaders together to improve outcomes for people living with neurological conditions.
  - The **Neurology Intelligence Collaborative** is an initiative of the National Neuro Advisory Group, to provide a forum for sharing, aligning and developing neurosciences data and intelligence. It is undertaking a project which aims to improve outpatient coding for neurology. The Neurological Alliance provides its secretariat.

The **Neurology Intelligence Network**, sponsored by Public Health England in partnership with NHS England, provides publicly available sources of neurological data and interpretation.

# Section 1: Policy context

*It is imperative that the promise of neurological improvement initiatives is realised on the ground, as soon as possible.*

At present, the National Neuro Advisory Group (NNAG), co-chaired by those who gave forewords to this report, provides the leadership and coordination function within the national neurology policy sphere. Introduced following the removal of the neurology National Clinical Director role in 2016, the NNAG has made significant inroads in ensuring alignment across all current national neuroscience initiatives; trouble-shooting emerging issues and problems in neuroscience service delivery that fall out of the scope of the Neurosciences Clinical Reference Group; and developing and coordinating a national programme of service improvement. The achievements of the NNAG to date are listed in its 2019 Impact Report.<sup>x</sup> All this work is delivered with very little resource, relying chiefly on charity funding as well as the time and goodwill of participants involved.

## **Local decision making and integration**

A challenge for NNAG, as for the NHS at large, is to ensure the translation of national improvement initiatives into change for people with neurological conditions. In an era where top-down national policy making is no longer the main mode of operating in the health arena, there is increased emphasis on the role of regional NHS England teams and local health economies. The Long Term Plan for the NHS lays out how Integrated Care Systems (ICSs) will be in place everywhere by April 2021 'bringing together local organisations in a pragmatic and practical way to deliver the 'triple integration' of

primary and specialist care, physical and mental health services, and health with social care.'<sup>xi</sup> ICSs will develop from the 42 Sustainability and Transformation Partnerships (STPs) that have been established across the country. Through ICSs, commissioners will make shared decisions with providers on population health, service redesign and Long Term Plan implementation.

The move towards ICSs presents both opportunities and challenges for neurological service improvement. Neurological conditions are by their nature complex and people with neurological conditions therefore require care and support from a range of professionals, as well as from less formal networks such as family carers. Ensuring pathways are joined up is essential to good neurological care, and ICSs present an opportunity to make this a reality. Similarly, many people with neurological conditions access social care services, so integration across both health and social care, including across funding boundaries, is central to maximise people's experience and outcomes. These moves towards improved local service integration are particularly important given the high levels of comorbidity seen amongst people with neurological conditions: 57% (n=5,743) of survey respondents have at least one other additional condition.

*The biggest challenge that local and regional decision making presents for neurology is that, in the absence of any national prioritisation of neurology, there are few incentives for local areas to focus on neurology.*

# Section 1: Policy context

The biggest challenge that local and regional decision making presents for neurology is that, in the absence of any national prioritisation of neurology, there are few incentives for local areas to focus on neurology. Our 2017 report *Going the distance 2: national calls to action to improve neurology services in England*, jointly authored with Sue Ryder, included an analysis of the extent to which neurological services are proportionately prioritised in local and regional plans. Using audit data, the report highlighted that Clinical Commissioning Group (CCG) engagement with neurology is poor, compared to that with other condition groups. This engagement ought to be improving, given the regional and local engagement work carried out by the RightCare Delivery Partners. Yet, data obtained via a Freedom of Information request by the Alliance in 2018 showed that for 2018/19 only 37 of 195 CCGs had submitted delivery plans that included neurological problems as improvement projects as part of their NHS RightCare programmes.<sup>xii</sup> Moreover, most of these referenced improvement efforts being made for individual neurological conditions, rather than neurology as a whole.

## Unwarranted geographic variation

Given the low levels of regional and local engagement with neurological service improvement, it is unsurprising that neurology is subject to wide unwarranted geographic variation. The likelihood of a person attending A&E with a neurological problem being seen by a neurologist varies dramatically depending on where an individual is admitted. There are a handful of hospitals with no acute neurology service at all and others which only have access to a neurologist on three days or fewer a week.<sup>xiii</sup> Amongst district general

hospitals 72% do not have access to 24/7 MRI,<sup>xiv</sup> which is an essential diagnostic tool for neurology. Evidence from Public Health England shows that access to neurology outpatient services also varies significantly across England. Local rates of new consultant adult neurology outpatient appointments varied from 165 (per resident 100,000 population) in Doncaster CCG, to 2,531 in Camden CCG.<sup>xv</sup>

We also know there is potential for savings to be made locally by prioritising neurology. For the neurological condition groups for which we have non-elective admission data,<sup>1</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>xvi</sup> Similarly there is an opportunity to reduce spend on inpatient bed days. If this data was available for all neurological conditions, this figure would be even higher. The forthcoming (unpublished) neurology Getting it Right First Time (GIRFT) findings and new research by The Association of British Neurologists are likely to add further weight to the evidence around geographic variation.

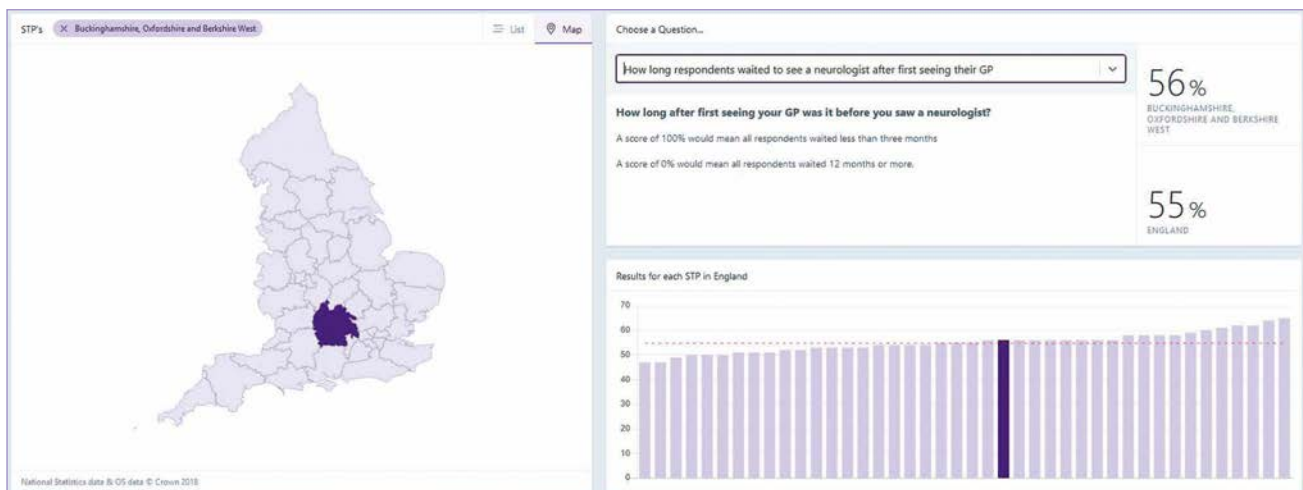
For the first time we have been able to present a regional analysis of our patient experience survey data, broken down into STP footprints. The emerging regional picture is one of significant variation whereby an individual's experience of care is better or worse depending on the area in which they live. Moreover, we see distinct trends arising with a handful of STPs dominating the top spots across the different measures included in the survey, indicating better experiences, while others predominantly bring up the rear. A full region breakdown

<sup>1</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.

# Section 1: Policy context

can be read at [2019survey.neural.org.uk](https://2019survey.neural.org.uk). These findings correlate to the service performance data, suggesting that differences in how care is organised and delivered impacts on patient experience and outcomes. It is indicative of scope for significant improvement in a number of areas of the country, if levelling up were to be achieved. We hope that STP/ICS leaders will use our data to benchmark existing levels of satisfaction with their services, and undertake improvement initiatives, using the increasing number of resources available to them to do so.

*The emerging regional picture is one of significant variation whereby an individual's experience of care is better or worse depending on the area in which they live.*



## Living with a neurological condition

The wide variety of different types of neurological conditions – sudden onset, progressive, intermittent, long term and life shortening – means we would expect a degree of difference in people's experiences. Despite this, we actually see a lot of commonality in relation to the impacts of living with a neurological condition for the individual and their family. This includes impact on quality of life, day to day activities, and experiences of pain and discomfort, but also extends out to the patterns we can see

arising in relation to people's financial wellbeing, employment situation and social care needs. Sadly, too many people report that their needs are not being met. This in turn can impact on people's health. As such, a holistic, public health type approach is needed to see what can be done outside the health sphere in order to keep people as well as possible and reduce unnecessary burdens on the NHS. Taking a holistic approach to individual care and support is in keeping with the wider prevention agenda which is a priority within the NHS Long Term Plan.

# Section 1: Policy context

## Social care needs

In terms of social care, we see a policy context which is even more challenging than the health policy environment. Our ageing population means there are increasing numbers of people with complex needs who require social care. This, coupled with austerity measures and increasing costs of providing care, means the gap between need and resources for social care is ever increasing. Local authorities are having to manage social care funding pressures by taking measures including service reductions, smaller care packages, stricter eligibility criteria, and reducing the prices paid to providers.<sup>xvii</sup> There is also evidence that care providers

*A holistic, public health type approach is needed to see what can be done outside the health sphere in order to keep people as well as possible.*

are facing quality challenges and the care provider market is becoming increasingly precarious.<sup>xviii</sup> Consequently, there are concerns that more people than ever who need social care are not having their needs met.

The additional pressures resulting from unmet social care needs are also increasing demand in the health service. People's social care needs not being met can lead to unnecessary A&E attendances and emergency hospital admissions. According to the National Audit Office, one-fifth of emergency admissions to hospital are for existing conditions that primary, community or social care could manage.<sup>xix</sup> A lack of suitable care

services can also delay hospital discharge – a particular issue in neurology – putting pressure on acute services. The NHS Long Term Plan addresses the need for improved integration with social care and improved social care provision, through initiatives such as the accelerated roll out of Personal Health Budgets. Yet, social care policy experts have said that the NHS Long Term Plan will be jeopardised without extra funding for the wider health system including social care.

The long term funding settlement for the NHS sparked calls for a similar multi-year funding plan for social care the NHS. This follows the 12 Green Papers that have been published since 1998 and the five independent commissions aiming to make social care sustainable that have reported in the same period. At the time of writing this report, we are awaiting another Green Paper, although it is looking doubtful whether it will be delivered during this Parliament. There is a lack of political party consensus about the solution to the mounting social care crisis, and a lack of drive to overcome this. Given the low levels of public understanding about social care, it seems unlikely to be something political parties prioritise in any future policy positions or election manifestos.

In this context it is probably unsurprising that our survey has found that people's experiences of social care tend to be worse than their experiences of healthcare. While fewer people with neurological conditions access social care than healthcare, for those who do this is often a hugely important enabler to being able to get on with their lives. Much of the policy debate about social care has focussed on older people, yet many working-aged people with neurological conditions also require social care. Here, we see a distinct neurological social care need emerging; a recent report from Sue Ryder has

# Section 1: Policy context

shone a light on the issues of working-aged people with social care needs being placed in generalist older people's nursing or care homes, and of people with neurological conditions being placed in care settings that lack the specialist expertise needed to address their individual needs, such as the management of complex symptoms or challenging behaviours.<sup>xx</sup>

## Financial security

With regard to financial security amongst people with neurological conditions, the dual – though interlinked – topics of employment and welfare benefits are key. The social model of disability focusses on the social and institutional barriers which restrict disabled people's opportunities, and argues that it is the environment they face, and not simply their impairments, that disable them. Since this changed understanding of disability came to the fore there have been a number of national initiatives aimed at addressing workplace inequality. These initiatives aim to level the playing field by addressing the environmental and institutional barriers, such that undertaking paid employment becomes a viable option for many more disabled people.

Key amongst these has been the introduction of the duty to make 'reasonable adjustments' under the Equality Act 2010. This puts a legal duty on employers to undertake reasonable actions in order to address barriers, in proportion to their ability and means to do so. So, the law recognises that to secure equality for disabled people work may need to be structured differently, support given, and barriers removed. The Equality Act defines disability as having a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on

a person's ability to do normal daily activities. Many people with neurological conditions are therefore covered by this legal definition, whether or not they self-identify as disabled. So, since 2010, people with neurological conditions ought to have had greater access to paid employment than even before, with positive knock-on effects on their financial security.

*Much of the policy debate about social care has focussed on older people, yet many working-aged people with neurological conditions also require social care.*

Other Government initiatives aimed at supporting employment amongst disabled people include:

- **The Access to Work scheme** – discretionary grants to pay for equipment and support over and above the reasonable adjustments that employers would be expected to make.
- **The Disability Confident Scheme** – supporting employers to think differently about disability, improving how they attract, recruit and retain disabled workers.
- **The Fit for Work service** – offering free advice to anyone looking for help with issues around health and work.
- **Employment support programmes** aimed specifically at disabled people, including the Work and Health Programme and the Specialist Employability Support programme.

# Section 1: Policy context

The latter in particular are equally linked to the welfare benefits agenda, discussed below.

Despite these initiatives, the disability employment gap (the gap between the rates of employment amongst disabled versus non-disabled people) remains high, at over 30%.<sup>xxi</sup> Pan-neurological labour market data is not available, but we do know that employment rates amongst people with different health conditions are amongst the lowest for people whose main condition is epilepsy.<sup>xxii</sup> While the disability employment gap appears to be improving,<sup>xxiii</sup> there is clearly still much work to be done to achieve more equal levels of employment. A parallel employment equality issue is pay discrepancy: disabled people are paid less on average than non-disabled people. This is partly – though by no means fully – accounted for by the higher numbers of disabled people in part-time work.<sup>xxiv</sup> It is perhaps suggestive of the continuing discrimination against disabled people in employment, despite the Equality Act legislation. Indeed, our survey findings provide a picture of people still struggling to work or having withdrawn from the labour market. The results also suggest that many people with neurological conditions have experienced employment discrimination.

For those unable to work due to the impacts of their condition, the welfare benefits system is essential to avoid many facing destitution. The welfare system is also needed to help alleviate the extra costs of living with a neurological condition, whether or not a person is in work, and to help tackle some of the disabling environmental barriers that can leave people struggling to live independently. As such, benefits such as Employment and Support Allowance, Personal Independence Payments (gradually replacing Disability Living Allowance), Blue Badges, Universal Credit, and Attendance

Allowance, are a hugely important source of financial security and dignity for many people with neurological conditions.

Yet, for many years now, disabled people have been reporting that they struggle to access welfare benefits and consequently miss out on the financial security and dignity that they should afford them. Disabled people's organisations and charities have been struggling to get the Government to re-structure them to make them easier to access. Although there have been some key 'wins' in this respect, the Government and its contractors have often resisted or denied the changes being asked for. This can be linked to the reasons for having restructured some of these benefits in the first place: namely the cost to the public purse of having so many people claiming benefits, especially when some of these people could potentially work with the right support and shouldn't be 'written-off', as well as fears relating to the number of fraudulent benefit claims being made.

Against this backdrop, our survey results show that people with neurological conditions face familiar challenges in accessing the benefits to which they should have access. With further

*People with neurological conditions need care and support that is accessible, personalised and holistic.*

reform of the welfare benefits system in the offing at the time of writing, combining the assessments for ESA – an income replacement benefit for those out of work, and PIP – designed to pay for extra costs associated with disability, there is potential for change. Yet



# Section 1: Policy context

disability organisations remain sceptical about whether Government will agree to the much-needed improvements that would make a positive difference to many vulnerable people's lives.

The NHS is overstretched, though the 2019 five year funding deal attached to the long term plan is moving us back from the brink. The social care system is in crisis, with little clarity around when and how this will be resolved. The welfare system, which is meant to support the most vulnerable in society, is beset with problems.

## Conclusion

This is the policy backdrop to the findings from our patient experience survey. The NHS is overstretched, though the 2019 five year funding deal attached to the long term plan is moving us back from the brink. The social care system

is in crisis, with little clarity around when and how this will be resolved. The welfare system, which is meant to support the most vulnerable in society, is beset with problems. Over the next three sections of the report we outline the findings from our patient experience survey which illustrate that people with neurological conditions are, often disproportionately, being failed by the health, care and welfare systems. We use our survey data to illustrate that people with neurological conditions need care and support that is accessible, personalised and holistic. We cannot expect improvement efforts to coalesce into improved patient experience without distinct efforts to realise change on the ground. We have made a number of recommendations from our findings, contained in section three of this report. We plan to use these to guide our own influencing work and hope that readers will consider their role in helping attain them.

*The NHS is overstretched, though the 2019 five year funding deal attached to the long term plan is moving us back from the brink. The social care system is in crisis, with little clarity around when and how this will be resolved. The welfare system, which is meant to support the most vulnerable in society, is beset with problems.*

## Section 2: Key themes – Accessible

### 2.1 Accessible

#### Sean's story

Sean\* is eight years old and has cerebellar ataxia. From early on, I realised Sean wasn't meeting his milestones, but I was told every child is different and I should be patient.

However, nothing could prepare me for the devastating news we received when he was just two years old: 'We have the results of Sean's brain scan, we think your child's brain is shrinking and feel he's lucky to have even lived past two years.' I felt completely numb. I don't know how I got through that year. I felt like we were living on borrowed time; I was torn apart with how to parent my child. It took three years for an official diagnosis of cerebellar ataxia. I only realised how rare the condition was after searching online.

We've been left in the dark since the diagnosis. There are no specialist ataxia services in our area for children and some professionals haven't even heard of ataxia. At the moment, Sean understands that he has wobbles, but he doesn't really understand the bigger impact ataxia will have on his life and still hopes to be a rugby player or join the army one day.

**Sean's\* mother**

\*The name has been changed to protect the privacy of individuals.

Getting a diagnosis is important to anyone with symptoms that are giving them pain or discomfort, preventing them from getting on with their day to day life, or causing them anxiety. With this in mind, one of the primary goals of care for people with neurological conditions is to get a quick and accurate diagnosis. For many people with a neurological condition, a diagnosis means that treatment can be started and in some cases the progression of disease can be slowed or halted. For individuals with multiple sclerosis for instance, the earlier they are treated, the less damage occurs to their

nerve cells, meaning that the accumulation of debilitating symptoms is deferred, even halted. Treatment can also be important to manage symptoms. For example, for people with epilepsy, having seizures controlled by anti-epileptic drugs reduces the risks associated with the condition and may enable an individual to drive again. Even for conditions where treatments are not available, having a diagnosis is still important. It ends the uncertainty around why they are experiencing neurological symptoms and enables them to plan for the future.

## Section 2: Key themes – Accessible

### CASE STUDY: The importance of early diagnosis in Motor Neurone Disease

Early diagnosis enables people with motor neurone disease to access vital support services to maintain their independence and quality of life for as long as possible, including services such as physiotherapy and occupational therapy. It also enables people to make provision to prepare for the rapid progression of the disease, such as accessing home or vehicular adaptations, communication aids, or services such as voice banking which enables people to record their own voice for when they lose the ability to speak. New treatments are also being developed all the time. For example, the drug Riluzole has been shown to extend life by 3–6 months in some MND patients when taken for 18 months. Early diagnosis can allow patients to begin using it earlier when appropriate, giving them more time with their families and loved ones before death.



# 39%

of respondents saw their GP five or more times before being told they needed to see a neurologist\*

### Delays in the pathway to diagnosis and treatment

While a proportion of people with neurological conditions will have their first encounter with the health system through an emergency department attendance (14% n=1,355), for example with a sudden onset condition such as stroke or head injury, the majority of people with neurological symptoms will go to their GP in the first instance. As such GPs usually act as the gatekeepers to the system and have a challenging role to play. NICE recently developed a new Guideline on Suspected Neurological Conditions in Primary Care<sup>xxv</sup> aimed at professionals such as GPs and pharmacists in the community. By

their own admission it was one of the most complex guidelines NICE has ever developed due to the enormity of the task: developing a guide that covers a large and complex clinical area for a generalist primary care audience.

Research carried out by The Neurological Alliance in 2016 showed 84% of GP respondents felt they could benefit from further training on identifying and managing people presenting with neurological conditions. Furthermore, the proportion of GPs who said they felt confident about making an initial assessment of and referring people with neurological conditions – even relatively common conditions such as epilepsy – was lower than the proportion who felt confident in other condition areas such as diabetes.<sup>xxvi</sup> Some neurological conditions are very rare, and a GP may only see one case in their whole career. Add into this mix that appointment times are limited to ten minutes, and we perhaps start to understand why 39% (n=2,829) of respondents who saw a GP before being told they needed to see a neurological specialist saw their GP five or more times, and a further 20% (n=1,471) saw their GP three to four times.

## Section 2: Key themes – Accessible

*‘I find it very difficult to discuss things with [my GP] as their answer is always ‘just wait.’ I am at a loose end with my health and wellbeing deteriorating and not having anywhere to turn. Seeing a neurologist would help on so many levels but unfortunately my GP will not refer...and I don’t feel well enough to fight.’*

SURVEY RESPONDENT

### Jenna’s story

Jenna is a 32-year-old teacher from Leicester. She was diagnosed with multiple sclerosis aged 22, while studying teaching at university. Since her diagnosis, Jenna says she has received ‘amazing support’ from her MS specialist team, in particular her MS nurse.

‘When I met my MS nurse everything started to make sense. I could ask the questions I wanted to: What is MS? How is it going to affect me and my life? I left my first appointment thinking, ‘I can do this. Yes I’ve got this condition, but I can deal with it’. I’m a natural worrier and I need answers to my questions or they will just fester in my mind and that’s where [my MS nurse] comes in. Whether it’s having issues with a DVLA application or concerns about my holiday, he is able to give me an answer instantly, and if not, he calls back when he does have the information. I am so grateful and I have always felt so blessed that I have a nurse who is constantly there to support me in every way. It’s worrying for me to know some areas don’t have that support.’

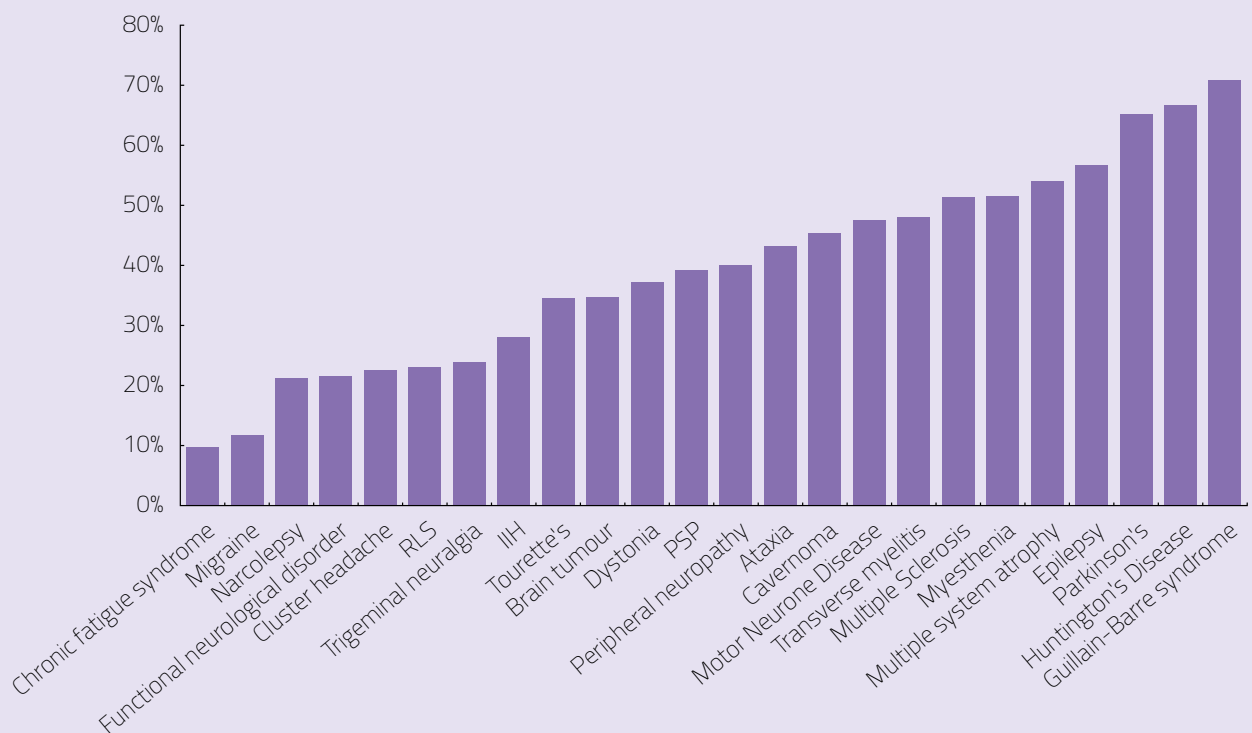
Another important factor to consider is that waiting lists for neurology appointments are often long, so GPs are aware of the need to appropriately refer patients in order that the most urgent cases are seen quickly by specialists. Not everyone with neurological symptoms will require a neurology referral, indeed 5% of respondents (n=488) stated they did not need to see a neurologist. There is a marked difference across conditions in terms of the number of GP visits before getting a referral to a neurologist,<sup>2</sup> as shown on the chart below. For some conditions GPs will, appropriately, be

trying to manage symptoms in primary care and only refer when this is not possible. There does however need to be clear guidance in place for when GPs need to refer. Guidance does not uniformly exist across the country, perhaps contributing to the wide regional variation discussed below. The ‘choose and book’ system which enables patients to select where they will have their appointment is regarded by some neurologists as encouraging unnecessary referrals. The electronic system does not encourage a conversation between GP and neurologist before referring.

2 Amongst respondents who stated they saw a GP before seeing a neurologist.

## Section 2: Key themes – Accessible

**How many times did you see a GP about the health problems caused by your condition before you were told you needed to see a neurologist? (by condition)**



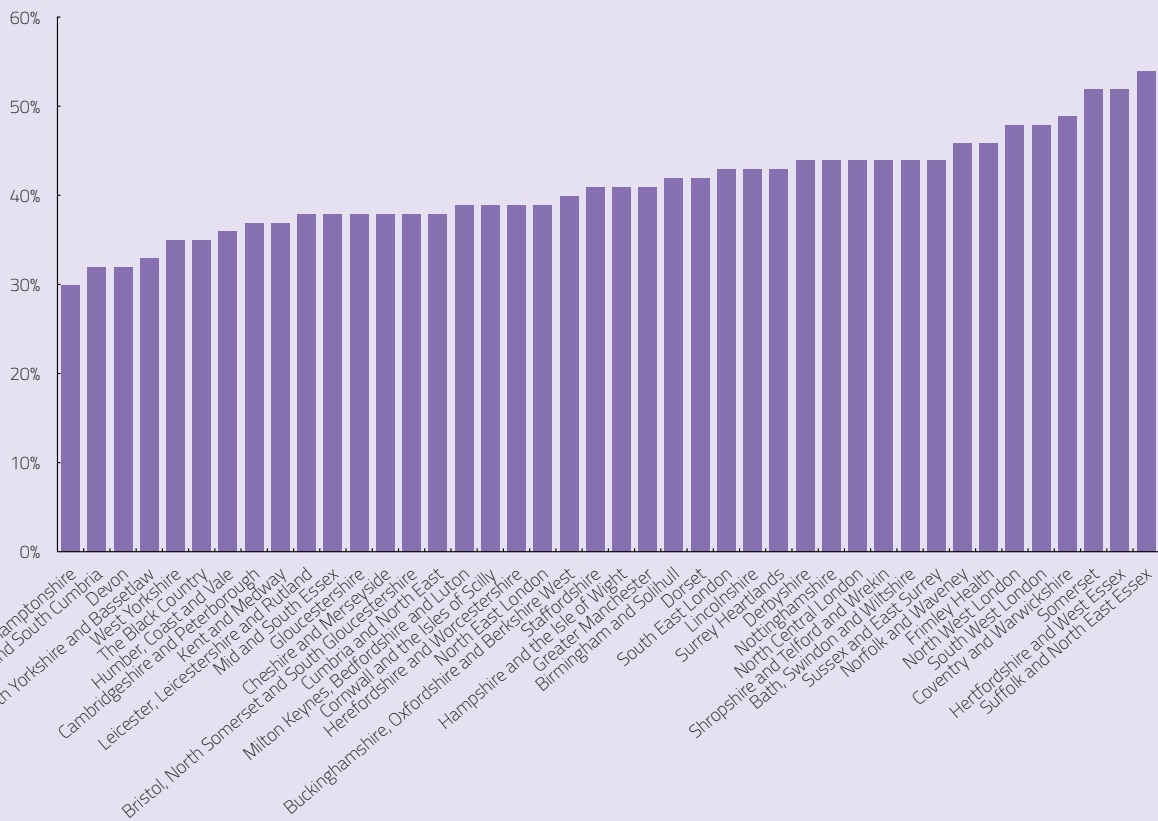
We found wide regional variation in the number of times respondents visited their GP before being referred to a neurologist as shown on the chart below. This may be down to local reasons such as availability of GPs with a special interest, research interests of specific GPs, specific funding to support GPs and neurologists in triage, or even rapport between GP and patient. It is also possible that waiting lists may play a part, with GPs more reluctant to refer to services which are already over stretched. Our evidence from 2016 suggests significant concern among GPs about unnecessary

*‘If it hadn’t been for my GP, who having seen Guillain-Barré syndrome earlier in their career sent me back to Peterborough Hospital with a letter in hand, I probably would not be here now, as your body shuts down very rapidly with this condition.’*

SURVEY RESPONDENT

## Section 2: Key themes – Accessible

**How many times did you see a GP about the health problems caused by your condition before you were told you needed to see a neurologist? (by STP area)**



waits, with 85% (n=708) of GPs in England either 'somewhat concerned' or 'extremely concerned' about the time taken from referral for patients to see a consultant neurologist.<sup>xxvii</sup>

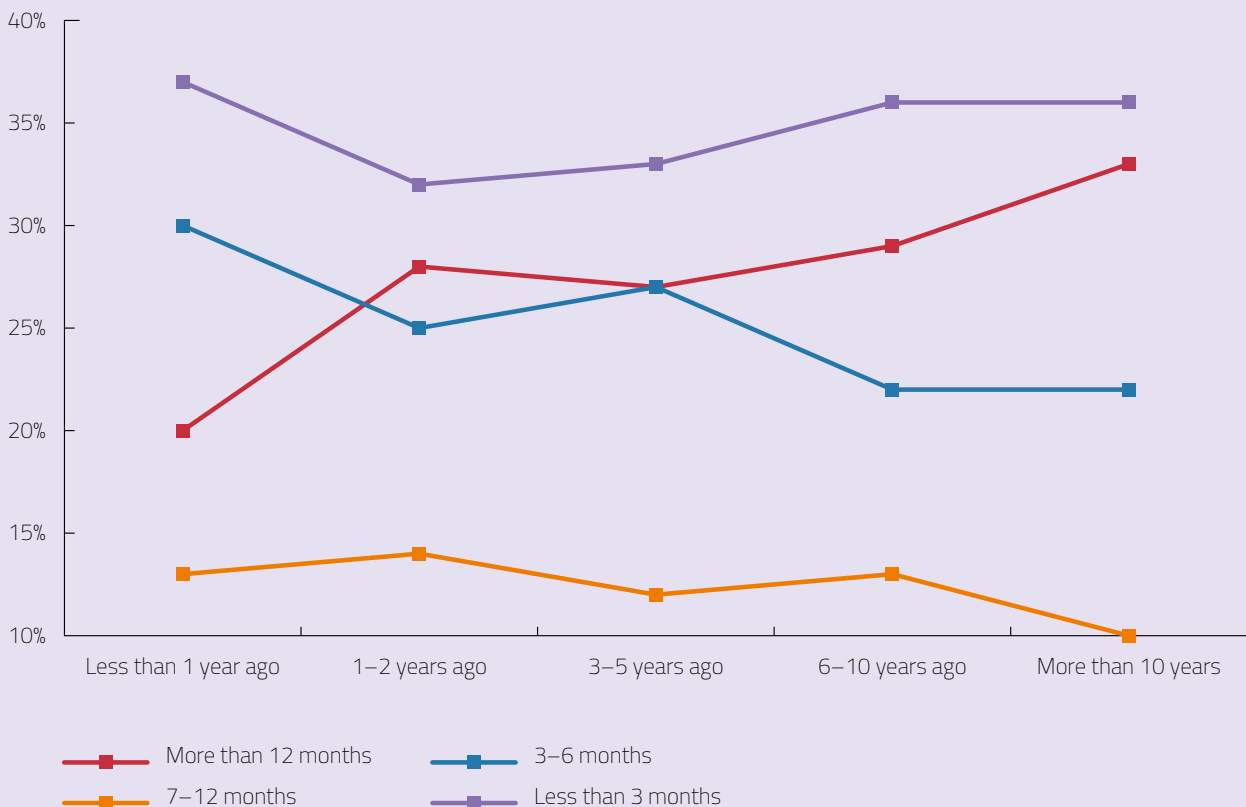
There is also a correlation between deprivation and the number of times people saw their GP before being told they needed to see a neurologist, with those living in the more deprived areas seeing their GP more times than those living in the least deprived areas. It is not clear what the reasons are for this difference, but it could be linked to levels of

health literacy as well as the extent to which people with neurological conditions are able to advocate for the health services they need.

Once people with neurological conditions get a referral to a neurologist, our data shows they then often face lengthy waits before having a neurology appointment, with 28% (n=2,073) waiting more than 12 months. These delays are also not uniform across the country, with people with neurological conditions waiting far longer for a neurology appointment in

## Section 2: Key themes – Accessible

Wait to see a neurologist (by time since diagnosis)



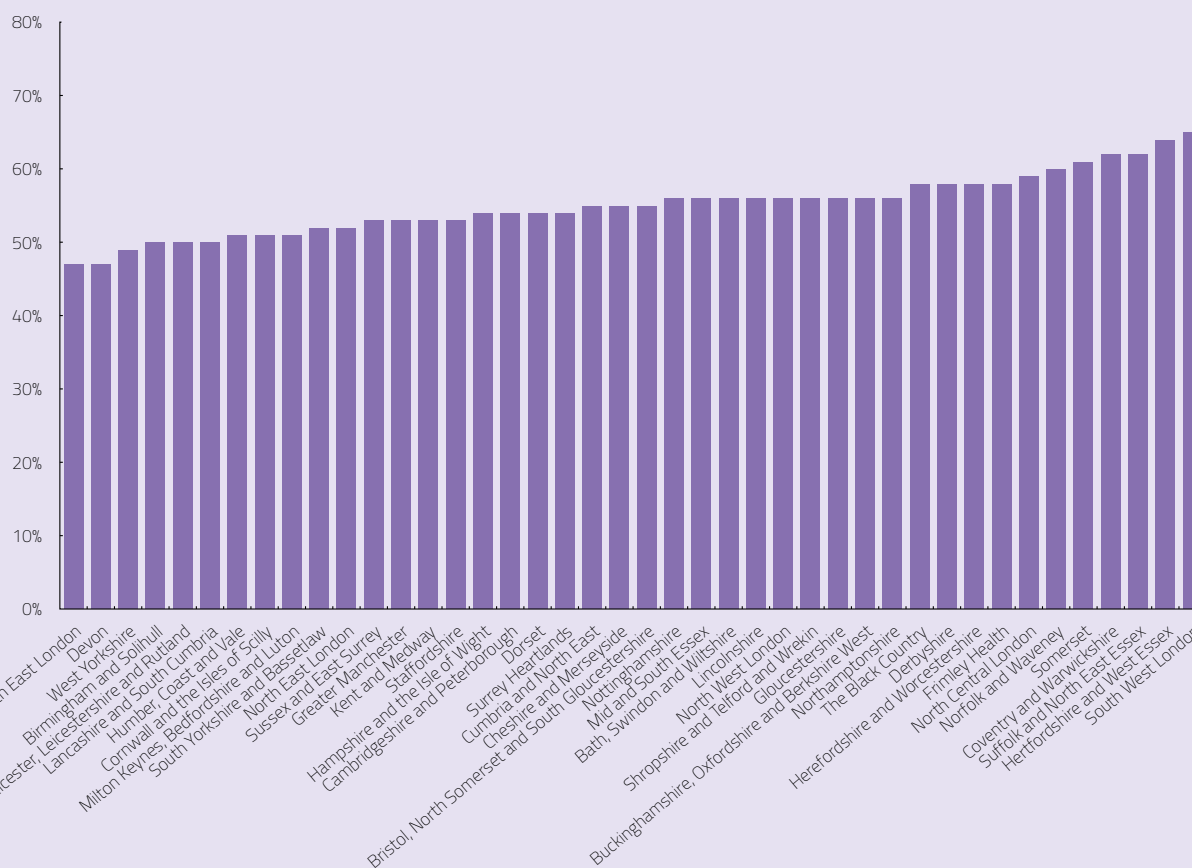
some areas than in others. Here our findings tally with previous work by the Association for British Neurologists on variability of neurologist availability for in-patient care, as well as Public Health England's 2015 work on regional access to outpatient neurology appointments. Similar areas of the country are singled out as requiring improvement in access to neurologists in all three sets of data. There are substantial challenges relating to the neurology workforce including long standing vacancies in some areas of the country, not training enough new neurologists, the potential impact of Brexit, and a relatively high number of neurologists retiring. These

*‘I referred myself privately to a neurologist when I was first affected because the first NHS neurology appointment which I was given was several months away. I had lost my independence, become totally dependent on my partner and we couldn't wait that long.’*

SURVEY RESPONDENT

## Section 2: Key themes – Accessible

Wait to see a neurologist from first seeing GP



factors are almost certainly contributing to delays in some areas. We can see that there has been little change over time in terms of the time people report they have waited to see a neurologist after seeing a GP, although our data would suggest there has been a decrease in people waiting more than 12 months.

Neurological conditions are often complex to diagnose, even for a neurological specialist. 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. Indeed 6% (n=640) of respondents to



**29%**

of respondents who needed to see a neurologist waited more than 12 months

our survey do not yet have a confirmed diagnosis – although this is perhaps lower than we would expect given what we know from other sources about the number



## Section 2: Key themes – Accessible

*‘I have had this condition for over 15–20 years and was misdiagnosed several times, therefore inappropriately treated and advised. I was discharged with no follow up and my GP has very little understanding on my condition or how to treat it. My referral for physio has been passed from pillar to post and I still don’t have an appointment. Things really need to change to help people like me access the treatment we need to be able to function.’*

SURVEY RESPONDENT

of people with undiagnosed neurological symptoms. 34% (n=2,480) of respondents said they were diagnosed within three months of first seeing a neurological specialist, while 29% (n=2,073) of respondents said they waited more than 12 months for a diagnosis after seeing a neurological specialist.

There is wide variation between conditions here. Over 30% of people with chronic fatigue syndrome, narcolepsy, functional neurological disorder, and Tourette’s Syndrome waited over a year for a diagnosis after seeing a neurological specialist. Although 35% of people with Tourette’s also say they were diagnosed immediately, showing wide variation for this condition. The longest waits for a diagnosis are experienced by people with ataxia (42% waited over a year for diagnosis after seeing a neurological specialist) and multiple system atrophy (45%). In terms of people who were diagnosed immediately, as we would expect, the highest figures are for Guillain Barre Syndrome and traumatic brain Injury, both of which are likely to be diagnosed following an emergency admission to hospital. Other conditions where a higher proportion of patients said they were diagnosed immediately on seeing a neurological specialist included Parkinson’s (42%), idiopathic intercranial hypertension (38%), cavernoma (36%) and dystonia (34%).



**38%**

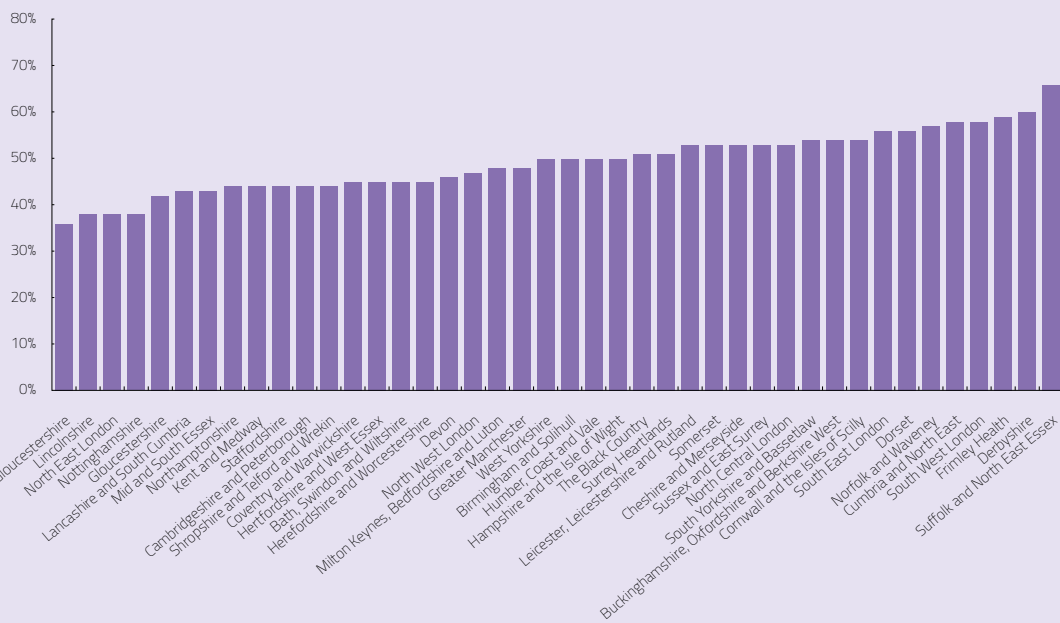
of respondents do not have access to a specialist nurse but would like this support

### Access to other specialists

Neurological conditions are often by their nature complex and people therefore require care from not only a neurologist but also other specialist healthcare professionals. 33% (n=3,423) of respondents were offered physiotherapy, with a further 13% (n=1,365) saying they would have liked to access it, but this was not offered. For occupational therapy, the figures are lower but not insignificant: 16% (n=1,700) of respondents were offered it, with a further 10% saying they would have liked to access it, but this was not offered. We found that respondents who said they would have liked to have accessed physiotherapy or occupational therapy reported a lower overall experience of care and were more likely to say that their healthcare did not meet their needs. A further 13% were offered speech and language therapy, 6%

## Section 2: Key themes – Accessible

### Do respondents see a specialist nurse



optics, 4% dietetics and 3% audiology. This paints a picture of the multidisciplinary approach that is often required to ensure people with neurological conditions are appropriately supported to manage their condition, and perhaps points to a level of unmet need in terms of additional specialist care.

Another important role in relation to care and support for people with neurological conditions are condition specific or neurological specialist nurses. Specialist nurses provide support and specialist clinical advice to people with neurological conditions. They can support with treatment, symptom management and often play a role in coordinating care across the multidisciplinary team, acting as a single point of contact. There is also evidence to suggest that specialist nurses can save money for the health service.<sup>xxviii</sup> Just

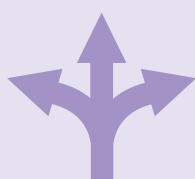
under 40% of respondents<sup>3</sup> see a specialist nurse (39% n=3,634). This is encouraging, yet a similar number of respondents do not have access to a specialist nurse but would like to have this support. It also compares poorly to the Cancer Patient Experience Survey where 91% (n=59,972) of respondents have been given the name of a clinical nurse specialist to support them through treatment.<sup>xxix</sup> Again, we see wide regional variation in access to specialist nurses as shown in the chart above. Our results show that respondents who have access to a specialist nurse are more likely to rate their overall experience of healthcare as good or very good (73% n=2,293) than people who would have liked to see a specialist nurse but do not have access to one (32% n=960 rated their care as good or very good).

3 Who said whether or not they see a specialist nurse for their neurological condition said that they do

## Section 2: Key themes – Accessible

Our survey also highlights that people with neurological conditions are not getting appropriate specialist care for their mental health, cognitive and emotional needs: 30% (n=2,821) of respondents<sup>4</sup> said they had not been sign posted to a mental health professional but would have liked this. Of those who were signposted to a mental health specialist, 60% (n=1,452) were referred to a counsellor or therapist, with 26% (n=616) being referred to a neuropsychologist or neuropsychiatrist. People who were signposted to support for their mental wellbeing reported a better overall experience of care.

Overall, our survey paints a picture of a health service where many people with neurological conditions are experiencing delays in getting referred to a neurologist and therefore potential for a diagnosis and treatment. Beyond diagnosis, we see variation in terms of access to other specialist healthcare professionals and support from a specialist nurse. A fifth (22% n=2,005) of respondents said they have not seen a specialist for over a year, which perhaps contributes to the



**30%**

of respondents have not been referred or signposted to mental health support but would like this\*\*

34% (n=3,160) who state they are not seen often enough to meet their needs. Overall over half (55% n=3,827) of respondents (excluding those who said 'don't know') stated they had experience delays in accessing healthcare services. Our results also show that delays have an impact on

people's overall experience of care. For example, people who see their GP once or twice before getting a referral to a neurological specialist report a better overall experience of care with 71% (n=1,725) rating their healthcare as good or excellent. This compares to just 41% (n=1,000) of people who saw their GP five or more times giving healthcare the same rating.

### Access to treatments



**34%**

of respondents do not believe they see a specialist often enough to meet their needs

To return to the introductory theme to this chapter of the report, treatment is important to slow disease progression and reduce symptoms. But for too many, effective treatments are still not available. One in ten (12% n=1,163) of our survey respondents said there is currently no treatment available for their condition. While development of new drugs has abounded in recent years for some conditions such as multiple sclerosis, this has not uniformly been the case, particularly for rarer diseases. Moreover, even where treatments are developed, they are not guaranteed to make it through the medicines appraisal regime, meaning they may not become widely available. The current system of medicines appraisal is complex and is felt by patient groups to penalise treatments for rarer conditions. Against this context we look with interest to the forthcoming review of NICE methods, with the hope that this will be addressed.

<sup>4</sup> Who indicated whether or not they had been signposted for their mental wellbeing by a health professional

## Section 2: Key themes – Accessible

*‘I have the MS nurse specialist, superb – they are very caring and helpful. The doctors both at hospital and my GP surgery are all very pleasant and willing to take whatever time I need to answer any questions I have.’*

SURVEY RESPONDENT

Over a quarter of survey respondents<sup>5</sup> (27% n=2,656) said they do not take any prescribed medication to manage their condition or prevent it returning/getting worse. One reason for this might be a lack of available treatments. Other reasons could include people finding that prescribed treatments don't work, the impact of side-effects of treatments, or problems in the care pathway meaning they are not getting access to the medicines to which they ought to have access. We do know that 8% (n=802) of survey respondents said that they had not yet been treated but that they were waiting for this to happen.

Against this context, our survey indicated that some people choose to take non-prescribed substances to help with their condition. Over a quarter of survey respondents<sup>6</sup> 27% (n=2,665)



**55%**

of respondents said they have experienced delays in accessing healthcare

said they currently take non-prescribed medicine, or substances, to help manage their condition. Free text comments show that the range of non-prescribed medicines and substances varies widely, with painkillers, various vitamins (including injections) and minerals, and CBD oil/cannabis dominating the list. At the time of writing cannabis derived treatments are a hot topic in healthcare. The Neurological Alliance wants to see more clinical trials into cannabinoids, as this has the potential to lead to a greater range of licensed cannabis-based medicines, which would improve the range of safe and effective treatment options available to people with neurological conditions.

*‘It took so long to get an appointment, I had forgotten I had been referred. The service is very underfunded and resourced.’*

SURVEY RESPONDENT

<sup>5</sup> Excluding those who skipped the question or said don't know

<sup>6</sup> Again, excluding those who skipped the question or said don't know

## Section 2: Key themes – Personalised

### 2.2 Personalised

#### Lauren's story

Lauren is a subarachnoid haemorrhage (SAH) survivor. She says: 'When I was sent home from hospital in 2004 following my SAH, my consultant handed me a booklet from the Brain & Spine Foundation. But I wasn't given any advice on what to expect when I got home and wasn't given a follow up appointment. I just assumed I'd go home and things would soon be back to business as usual. What a shock it was to discover that my brain would not work on auto-pilot. Without any specialist support or advice, I pushed myself as hard as I could to get back to normal, went back to work after 12 weeks and crashed after four.

I was emotional and exhausted and eventually realised that something bigger was going on than I had expected. I contacted the Brain & Spine Foundation helpline and spoke to one of the nurses. At last I was speaking to someone who understood SAH. Whilst my GP was very kind, understanding and supportive, due to lack of specialist training, few GPs understand the long-term impact of SAH. There are so few specialist support services for survivors of SAH and because we do not receive support it sends out the message that there's probably nothing wrong with us, this makes us feel as if we are failing in some way. If survivors were better supported outside the acute setting, we would not go on to develop some of the long term further problems associated with SAH.'

According to Health Education England, being person-centred is about 'focussing care on the needs of an individual. Ensuring that people's preferences, needs and values guide clinical decisions, and providing care that is respectful of and responsive to them.'<sup>xxx</sup> As National Voices point out, policy makers have been aspiring to a 'patient-centred NHS' in England for at least 20 years. Person-centred care has become an increasingly prominent stated ambition both of national policy and local practice.<sup>xxxi</sup> In this section we discuss the extent to which the key components of person-centred care are being met for people with neurological conditions.

The importance of achieving person centred care for every person with a neurological condition is several-fold. Many people want to play a more active role in their healthcare. There is also growing evidence that approaches to person-centred care can improve a range of factors, including patient experience, care quality and health outcomes.<sup>xxxii</sup> People with neurological conditions also often have particular needs which necessitate a personalised approach to care. Individuals will often see a variety of health and care professionals who need to work together to ensure optimum care. Neurological conditions that

## Section 2: Key themes – Personalised

### Key components of person-centred care

The **provision of information** about an individual's condition, care and treatment options, and what an individual can expect in terms of service provision

**Communication** that is a) in formats tailored to the individual's needs, and b) two-way, to enable the individual to express their needs and preferences

**Shared decision making** on an individual level, as well as opportunities for individuals to participate in planning and making decisions about service provision on an organisational level (co-production)

**Care planning**, to enable people to record their priorities and preferences for their treatment and care, to facilitate their self-management, enable future scenario planning, and generally to help them be, and feel, in control.

Care that is well **coordinated** between the various different professionals involved in an individual's care

are progressive or fluctuating will impact on the individual differently over time meaning care must be responsive. People may also have communication needs which requires an individualised approach to shared decision making. Our data also suggests that person centred care has overall benefits in terms of an individual's experience of care.



# 43%

of respondents were not given written information when they were told they had a neurological condition

### Provision of information

It is particularly important that people with neurological conditions are provided with written as well as verbal information at the point of diagnosis. Receiving a neurological diagnosis – even if suspected – can come as a big hit, with all the psychological implications of altered identity. This is all the more acute where the diagnosis is associated with particular risks to the person's safety, or where the condition is progressive or life shortening. Several neurological conditions are also subject to stigma, which can sometimes make a diagnosis more difficult to accept. Absorbing and retaining any information given in an appointment in which a diagnosis has just been given can be challenging for a newly diagnosed person with a neurological condition. It is therefore disappointing to see that 43% (n=4,430) of survey respondents say they were not offered written information when they were told they had a neurological condition. It should be noted however that while there is still a long way to go, there appears to be an improving picture. For people diagnosed more than ten years ago, just 16% (n=477) said they were given the hospital's own written information, yet for people diagnosed in the last year, the figure rises to 28% (n=399).

## Section 2: Key themes – Personalised

### Advantages of person-centred care

Taken from Health Foundation Report 2016: *Person-centred care made simple: What everyone should know about person-centred care*

- Supporting patients with long-term conditions to manage their health and care can improve clinical outcomes.
- When people play a more collaborative role in managing their health and care, they are less likely to use emergency hospital services.
- They are also more likely to stick to their treatment plans and take their medicine correctly.
- Patients who have the opportunity and support to make decisions about their care and treatment in partnership with health professionals are more satisfied with their care, are more likely to choose treatments based on their values and preferences rather than those of their clinician, and tend to choose less invasive and costly treatments.
- Individuals who have more knowledge, skills and confidence to manage their health and healthcare are more likely to engage in positive health behaviours and to have better health outcomes.
- Person-centred care is good for healthcare professionals too. As patient engagement increases, staff performance and morale see a corresponding increase.

To give this context we have reviewed the Cancer Patient Experience Survey scores. 83% (n=49,533) of cancer patient experience survey respondents said they had been given written information about the type of cancer they had.<sup>xxxiii</sup> In the national neurology patient experience survey, just 42% (n=3,257) of respondents said they had been given written information when they were told they had a neurological condition. This difference can be explained by many factors – not least that cancer has been a national priority – but it is clearly indicative of what is possible in terms of good information provision. Similarly, we also see wide regional

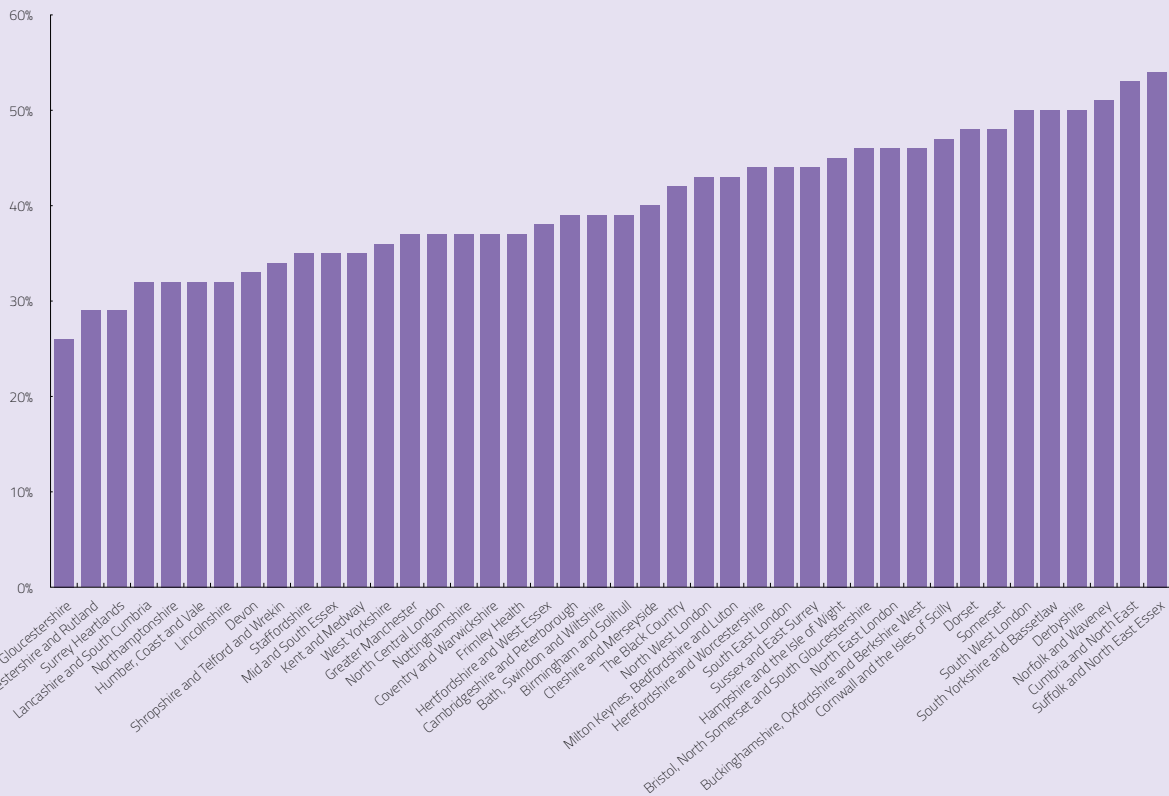
variation in neurological respondents being given written information at the time of diagnosis. Yet, even the area with the top score for this metric is still well below the scores being achieved for cancer patient experience.

Also disappointing was that 45% (n=4,455)<sup>7</sup> were not told anything about finding further information by the healthcare professional who gave them their diagnosis. It is important that people are signposted to further information, particularly those with complex and long-term neurological conditions. The need for information will be recurring

<sup>7</sup> Of those who indicated whether or not they had been given further information

## Section 2: Key themes – Personalised

Were respondents given written information at the time of diagnosis



as their needs change over time or as new treatments and therapies become available. We see variation between different neurological conditions here. There were 60 percentage points between the lowest score (restless legs

syndrome) and highest score (Huntington’s disease) for this measure. Further research is needed to understand why there is such wide variation. Where people then used the internet to find further information, the highest rated sites

*‘I feel that my neurologist doesn’t explain anything to me or offers any kind of additional information such as leaflets, websites etc... I feel that I have basically been left to deal with NEAD [Non Epileptic Attack Disorder – a functional neurological condition] on my own with the help and support from my family and friends, until I see my neurologist again in six months’ time...’*

SURVEY RESPONDENT



## Section 2: Key themes – Personalised

*‘There is no clear information given – for instance, I’ve only just found out in the last 12 months that I qualify for free travel in London and reduced prices on other public transport, so for many years I was paying for travel when I didn’t have to. It took me a decade to find out I was entitled to free prescriptions, which as a young adult was very important – the prescriptions were expensive for me. If I didn’t have relatives who also had epilepsy, I wouldn’t have had a clue about my condition – nobody told me, nobody asked how I felt about being diagnosed...’*

SURVEY RESPONDENT

were charity websites. Yet just 28% (n=1,117) of patients who were provided with written information at the time of diagnosis, were signposted to charities.

One positive message that emerges from the data is that for those who are provided by information at the point of diagnosis, this information is highly rated: 65% (n=3,378) of respondents rated information provided as good or excellent. Our data shows that where people are provided with written information at the time of diagnosis, they report a better overall experience of care with 73% (n=1,987) of respondents who were given written information reporting their overall experience of healthcare as very good or good, compared with just 43% (n=1,619) of people who were not given written information reporting the same level of satisfaction with their healthcare.

### Communication

In the context of health and clinical appointments, good communication results in shared understandings between clinician and patient. Good communication is especially important for people with neurological conditions, as many



conditions can include symptoms which can make communication more challenging, and thus not to be taken for granted. Asked whether they/ their family understood the explanation given to them when they were first told about their condition, 38% (n=3,639) completely understood it, and 39% (n=3,798) understood some of it. Very concerningly, 12% (n=1,197) did not understand it and 11% (n=1,046) were not given an explanation at all. This finding backs up our 2016 survey finding that only half of patients felt their diagnosis was communicated appropriately.

For good communication to be achieved, clinicians must make sure that what they are trying to communicate is likely to be understood.

## Section 2: Key themes – Personalised

*‘Often, comments I make about my condition are disregarded; often, the neurologists think they know more, having not experienced it. There’s a lot of arrogance in neurology... Maybe if they listened to their patients more, they’d know a lot more.’*

SURVEY RESPONDENT

They should therefore be thinking about their patients’ communication needs, and trying to tailor their communication style accordingly. We can see a link between people who received written information and people who understood their diagnosis. 50% (n=1,536) of people who were given written information report they completely understood their diagnosis. For people who were not given written information, this figure falls to 31% (n=1,111). There is also a correlation between respondents understanding their diagnosis and their overall experience of care: 74% (n=2,214) of people who reported they completely understood their diagnosis report a good or very good experience of care. Conversely, just 37% (n=371) of those who did not understand their diagnosis, and 25% (n=220) of those who were not given an explanation, reported a good or very good experience of care.

### Shared decision making

Shared decision making is the principle of patient and health professional reaching a healthcare choice together. It is a component of the NHS Comprehensive Model of Personalised Care.

Shared decision making enables the health professional and the person with a neurological condition to decide which is the right course of action for them as an individual. This may be because it is the best medical option or because it is the best option for that patient’s life, at that point in time. We found that over half of our survey respondents felt involved at least to some extent (69% n=5,467). Whereas 30% (n=2,320) of respondents say they do not really feel involved or do not feel involved at all in their healthcare. So, there is room for improvement.

Advantages of shared decision making include people being more likely to be satisfied with their treatment, more likely to adhere to their chosen treatment, and clinical outcomes and safety being



# 30%



of respondents do not feel involved in making choices about their healthcare

improved.<sup>xxxiv</sup> Our survey findings exemplify this. 87% (n=2,423) of people who report feeling fully involved in decisions about their care rate their overall experience of care as good or excellent. For people who report they ‘do not really’ feel involved in choices about their healthcare, this figure falls to 21% (n=266). Written information is very important in supporting people to feel involved in their care. 81% (n=1,964) of people who were given written information at the time of diagnosis state they feel involved with making choices about their healthcare. This compares with 60% (n=2,124) of people who were not given written information stating they feel involved.

## Section 2: Key themes – Personalised

These results are thrown into relief when compared with the Cancer Patient Experience Survey. Nationally 79% (n=51,956) of cancer patient experience survey respondents said they were definitely involved as they would like to be in their care and treatment.<sup>xxxv</sup> For the national neurology patient experience survey, just 39% (n=3,033) of respondents said they definitely felt fully involved in decisions about their healthcare.

### Care planning and coordinated care

Care and support planning is the key that can unlock person-centred, coordinated care. It is an essential tool to integrate a person's experience of all the health and care services they access so they have one joined-up plan that covers their health and wellbeing needs. 57% (n=5,743) of neurological patients surveyed reported living with at least one other co-morbid health condition. In this respect, care planning is perhaps even more essential for patients with neurological conditions given the range of healthcare professionals they are likely to come into contact with.

#### What is a care plan?

A care plan is a series of facilitated conversations in which a patient actively participates to explore the management of their health and well-being within the context of their whole life and family situation. The plan itself does not have a specified form (and which professional should lead the care planning process is not dictated) but the care plan should document what has been discussed, be included in the person's health and social care records, owned by the person and shared with other professionals involved in their care (across health and social care) with their explicit consent, and a date for review agreed.



# 10%

of respondents have been offered a care plan

It is therefore disappointing that our survey showed that just 10% (n=1,084) of respondents have been offered a care plan to help manage their neurological condition. This compares with 35% (n=18,304) of cancer patients saying they have been given a care plan.<sup>xxxvi</sup> We also found that 27% (n=2,788) didn't have one but would like one, while 36% (n=3,729) felt they didn't need one. A significant majority, 69% (n=2,323) of those who have a care plan felt that having one improves their quality of life to a great or moderate extent. We also see that having a care plan improves respondents' overall healthcare ratings with 79% (n=531) of people who have been offered a care plan by their healthcare team reporting a good or very good overall experience of care. This compares to just 31% (n=766) of people who have not been offered a care plan reporting the same.

We have heard many health professionals report anecdotally that many of their patients have care plans in place. This perhaps suggests that the real figures in terms of proportion of people with neurological conditions who have a care plan are higher than reported. 17% (n=1,756) of respondents said they didn't know what a care plan is. A care plan is however, by definition, something that the individual is involved in developing, suggesting that professionals perhaps have more to learn about the nature of care planning. Care planning is another area where we also see wide regional variation, with 28 percentage points between



## Section 2: Key themes – Holistic

### 2.3 Holistic

#### Jack's story

Jack has Spinal Muscular Atrophy, Type 2. He says: 'I have had relatively strong success in accessing the workplace, getting onto a graduate training programme straight after University. I have worked since then until now (approximately three years) for a high street Bank, who have been able to fund suitable adjustments to the workplace (electronic doors, IT equipment etc.). I had struggled previously at University trying to access suitable internships/work experience, applying on several occasions to organisations, then learning that they were inaccessible for a wheelchair user.'

To continue thriving in the workplace and living independently, I am absolutely dependent on the individualised care budget I receive from the local council to fund my live-in carers. This has been put at threat recently... and if this [budget reduction] is the case I would need to give up my role and return home to my parents. This is currently a cause of great concern and uncertainty.'

The focus of themes 1 and 2 of this report are predominantly on healthcare. Perhaps rightly so, given the poor experiences we report upon here. It is important to remember however, that while waiting for a diagnosis, during treatment, between appointments and even during hospitalisation, other aspects of people's lives go on – even if this is in a significantly curtailed or altered state from what they previously experienced. Ensuring a person is as well as they can be, both physically and mentally, entails a holistic approach to wellbeing over the life-course. This section of the report addresses the impacts that living with a neurological condition has on people's lives. We report on experiences of support for mental health, social care and financial security, though it is important to note that this is far from an exhaustive list of the domains of people's lives that can be affected.

#### Living with a neurological condition: overall impacts

Our survey findings show that having a neurological condition has a significant impact on both quality of life, and on the extent to which their condition affects their day to day activities.

- Of the respondents who rated the impact of their condition on their quality of life, almost half (46% n=4,663) said it impacted them to a great extent, and a further third (35% n=3,597) said it impacted them to a moderate extent.
- Of the respondents who rated the extent to which their condition affects their day to day activities, 42% (n=4,229) said it affected them to a great extent, 36% (n=3,591) said it affected them to a moderate extent.

## Section 2: Key themes – Holistic

Additional detail on the wide variety of ways in which people's lives are affected by having a neurological condition is seen in the free text responses collected. From the difficult and worrying experience of having symptoms but no diagnosis, through to the impact of medical appointments and treatments, as well as side effects, on daily life, to impacts on work, leisure activities and family life, there seems to be almost no part of life that having a neurological condition doesn't affect in some way. The impact seems to be most significant where the person's condition is more severe, and when their mental wellbeing/resilience is compromised. Individual symptoms can have distinct impacts, such as communication difficulties affecting socialisation in particular. The uncertainty associated with a fluctuating condition such as migraine or epilepsy can also take its toll on being able to plan family activities or hold down a career. Many individuals report their condition has led them to become isolated from family, friends and wider society. This impact is perhaps unsurprising given 66% (n=6,683) report they are living in pain all or most of the time.

*‘...now that I'm severe, my future career and family plans have been entirely shattered, life as I knew it has evaporated, my contribution to and place in society removed. Even hobbies are out of reach, so identity has been well and truly shattered.’*

SURVEY RESPONDENT

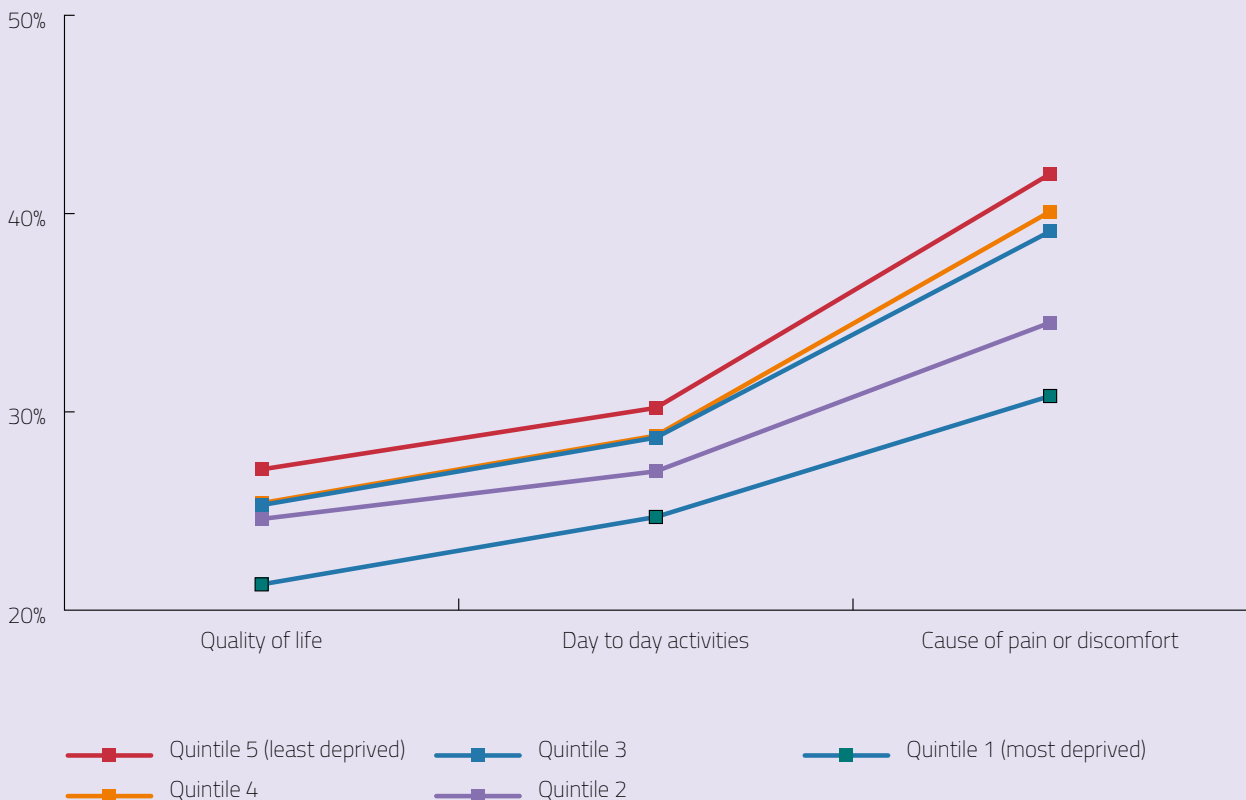
Respondents' scores are markedly worse for those living in the most deprived areas, as compared to the least deprived areas. There is a difference of six percentage points between the most and least deprived for quality of life, five for day to day activities, and eleven for pain and discomfort. So, the impact of neurological conditions is exacerbated by socioeconomic deprivation, particularly in relation to pain and discomfort. It is already known that some neurological conditions

*‘I need a lot of support at times, none at others. I seem to fall through the net. Life is a daily struggle when you don't know how you will feel from one hour to another, yet have a constant baseline of debilitating, frightening and painful symptoms. I am getting more isolated, more depressed. The benefits system has added a lot of stress, anxiety and depression to my situation. It's the fear of constantly being threatened when you are so ill by DWP that is not conducive with trying to work with your neurology team on getting better pain control or management.’*

SURVEY RESPONDENT

## Section 2: Key themes – Holistic

Impact of neurological condition by deprivation quintile



– epilepsy in particular – are more prevalent in more deprived areas. But this data suggests a need for further research into deprivation and experience of living with a neurological condition.

### Mental health

Mental health is obviously not a domain of life, but it is critical to how one feels about life: people who are more mentally resilient are able to weather life's difficulties more easily than those with less resilience, or who are mentally unwell. There is an increasing understanding of the importance of addressing the mental health needs of people living with long term conditions, who are more likely to have a higher level of mental health



**40%**

of respondents reporting their mental health needs are not being met at all

needs than the general population. People who have their mental health needs met are more likely to attend medical appointments, and more able to undertake self-management activities.<sup>xxxvii</sup> Costs to the health system are significant – by interacting with and exacerbating physical illness, people's co-morbid mental

## Section 2: Key themes – Holistic

### Andrew's story

Andrew was assaulted in an unprovoked attack at the age of 42. This left him with a life-threatening brain injury and needing brain surgery to remove a blood clot in the brain. He also suffered a fractured eye socket and bruising to the brain. After being discharged from hospital and spending time recovering, Andrew tried to return to his old job, but only lasted only two days. This only served to heighten his anxiety about his future.

Sometime later he was referred to the Brain and Spinal Injuries Centre. Following assessment, they were able to provide Andrew with psychological support, help and advice with his finances and to recoup state benefits he had been refused but was entitled to, cognitive re-training for memory problems, and a computer cognitive training course. He also spent time volunteering on their reception desk to build confidence and gain work experience. Andrew explains:

'Since regularly attending BASIC I have noticed a significant improvement in my wellbeing. Due to help from the vocational worker, my financial situation has become more stable. I have come to a deeper level of understanding of traumatic brain injury. My psychological concerns have been addressed and guidance in attending the memory workshops has inspired me to learn more... the support, understanding and guidance of staff has assisted me immensely in rebuilding my life.'

Andrew has now gone to University to study for a degree.

health problems have previously been found to raise total healthcare costs by at least 45% for each person with a long-term condition.<sup>xxxviii</sup> Improved mental health provision, and better integrated physical and mental healthcare are a particular focus of the NHS Long Term Plan.

In our 2017 report *Parity of Esteem for People with Neurological Conditions* we estimate that more than 50% of people with neurological conditions have a co-morbid mental health condition, and show that people with neurological conditions have distinct mental health needs from the wider population of people with long term conditions.<sup>xxxix</sup> Providing accurate diagnosis and effective treatment for people's emotional, cognitive or mental health needs is challenging, but essential. A first step towards

*'My mental health suffered greatly around the time of my epilepsy and diagnosis, and I feel that proper support with mental health, e.g. counselling, should be offered as standard.'*

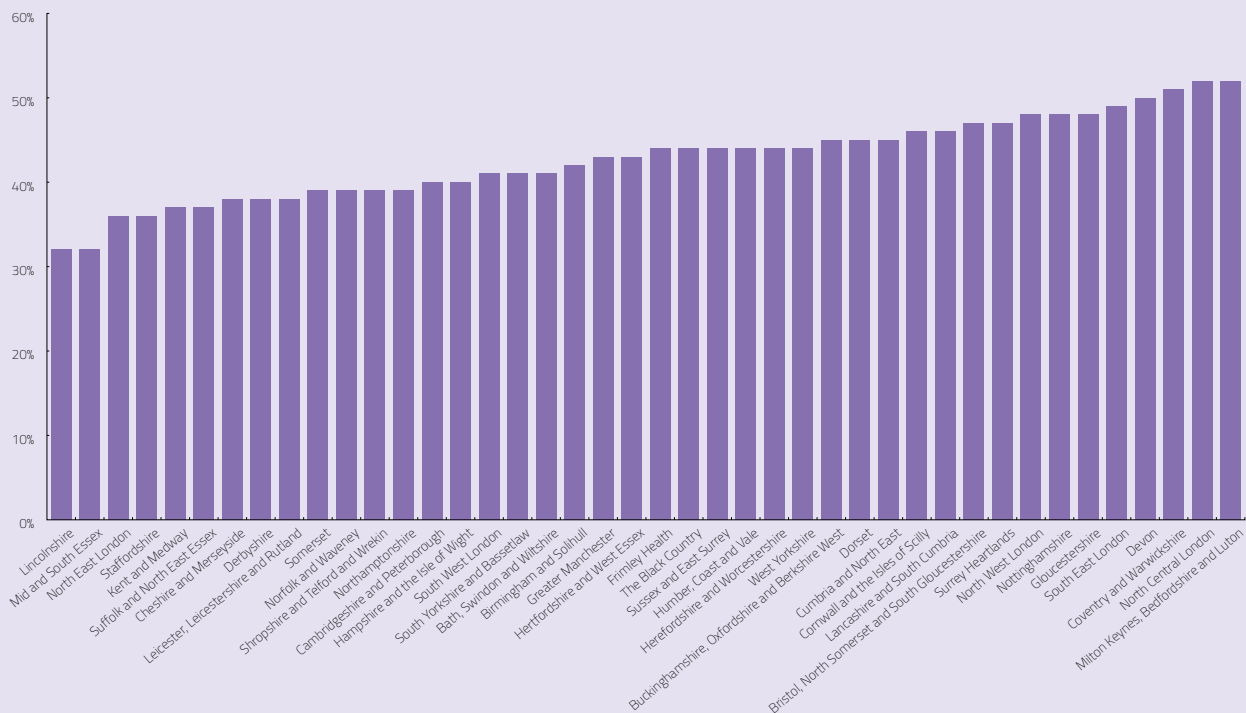
SURVEY RESPONDENT

diagnosis and treatment is the routine discussion of mental health needs during neurological medical appointments. It is therefore slightly disappointing that 58%<sup>8</sup> (n=5,593) of respondents said they had not been asked about their mental wellbeing by a health or social care



## Section 2: Key themes – Holistic

Have respondents been asked about their mental wellbeing (by region)



professional. There was also significant regional variation in relation to whether people were asked about their mental health needs, with 32% being the lowest STP score and 52% being the highest.<sup>9</sup> People who were asked about their mental wellbeing were more likely to report a better overall experience of care.

As many people are not being asked about their mental health, it follows that many people have not been referred or signposted to support for their mental wellbeing by a health professional. Of those who indicated whether or not they had been referred/signposted, almost a third (30% n=2,821) said that they had not but that they would have liked this. Given that only

*‘Nobody at all has ever asked about my mental wellbeing since being diagnosed with a potentially life threatening/ changing neurological condition, which I think is very sad.’*

SURVEY RESPONDENT

26% (n=2,403) said yes they had, the level of unmet need for mental health support is higher than the level of need currently being met. Moreover, the survey results show that just over half of people

<sup>8</sup> Excluding those who said ‘don’t know’ or who skipped this question,

<sup>9</sup> Where a score of 100% would mean all respondents have been asked about their mental health and wellbeing and 0% would mean none were asked

## Section 2: Key themes – Holistic

with neurological conditions want/need mental health support. Overall 40% (n=2,879) of survey respondents<sup>10</sup> say their mental health needs are not being met at all; a far higher proportion than the 26% of respondents who say their physical health needs are not being met. Again, the regional picture is of people's needs being met in some regions much more than in others, with a range of 19% (from 28% to 47%).<sup>11</sup>

In contrast to the rather negative picture of the level of unmet need for mental health support amongst people with neurological conditions are the figures on whether the support provided helped: 72% (n=1,249)<sup>12</sup> said that it helped them feel better/more positive, while just 28% (n=481) said it did not. This is a generally positive picture, though it does indicate there is still more work to be done. This is reinforced by the 270 respondents who said that the support was not suitable for them.

*‘As it’s a rare condition, the additional support available in terms of mental health and other support is severely lacking.’*

SURVEY RESPONDENT

There is striking variation between people with different neurological conditions in the extent to which their mental health needs are being asked about. People with rarer conditions have an average score of 33.1% (n=1,673), while people with non-rare conditions who have a significantly better score of 44.7% (n=6,636).<sup>13</sup> This picture is mirrored in the figures for people's needs being met, as the graph shows.<sup>14</sup> So, fewer people with rarer conditions perceive that their needs are being met than those with non-rare conditions, and that there is an even bigger gap in people being asked about their needs. Rare Disease UK's findings showed a huge emotional impact of living with a rare disease, with difficulties in reaching diagnosis, and lack of treatment options and poor care coordination impacting on people's mental health.<sup>x1</sup>

Another finding that emerges from the free text comments is that many people report having their symptoms dismissed as being emotional or psychological in origin. People with functional neurological disorder (FND) report being labelled as 'hysterical' and 'delusional', often feeling they are dismissed by healthcare professionals.

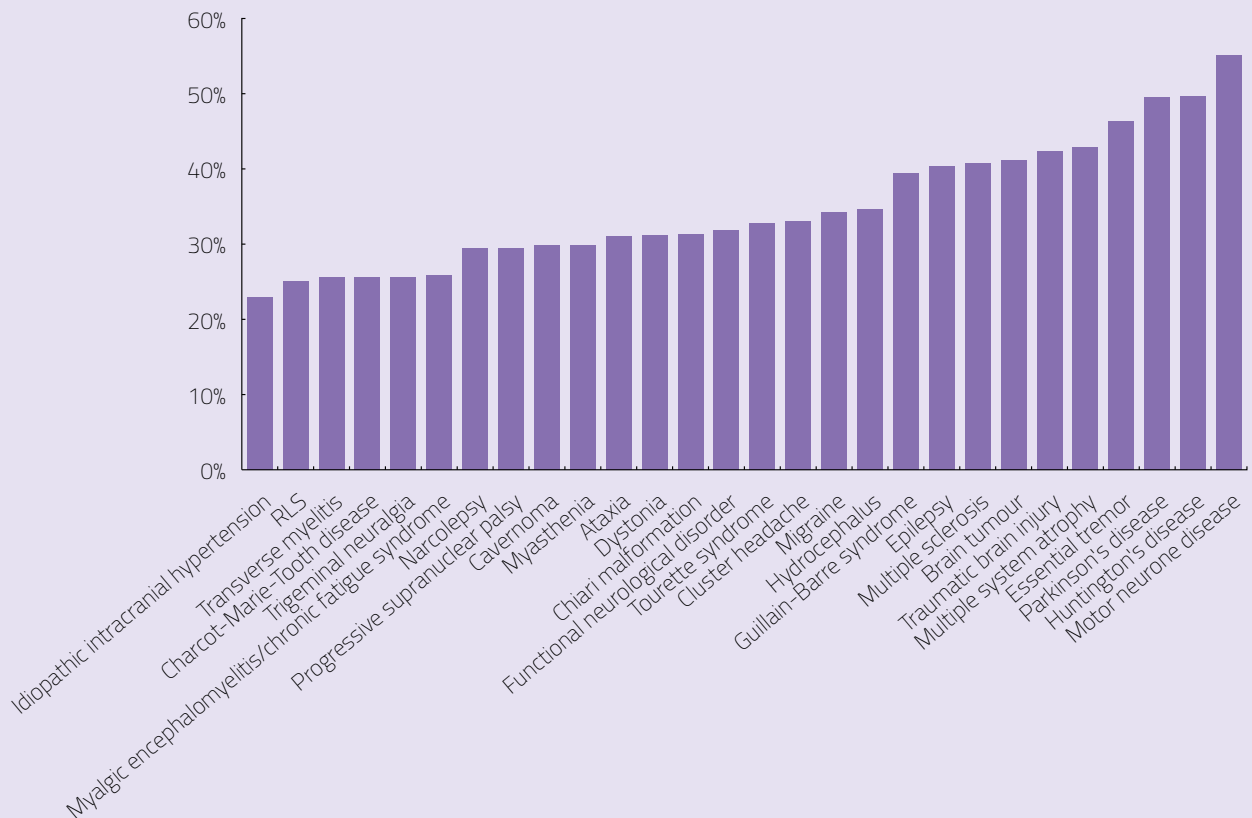
*‘I’ve been to counselling services several times and they have discharged me after a couple of sessions because they say that my case is too complex and they are not trained for it.’*

SURVEY RESPONDENT

- 10 Excluding those who said don't know/can't remember/who skipped this question
- 11 Where a score of 100% would mean all respondents feel their mental health and wellbeing needs are being met to a great extent and a score of 0% would mean all respondents feel their mental health and wellbeing needs are not being met at all
- 12 Of those who received support and who indicated whether or not it helped
- 13 A score of 100% would mean all respondents have been asked about their mental health and wellbeing. A score of 0% would mean no respondents have been asked about their mental health and wellbeing.
- 14 A score of 100% would mean all respondents feel their mental health and wellbeing needs are being met to a great extent. A score of 0% would mean all respondents feel their mental health and wellbeing needs are not being met at all.

## Section 2: Key themes – Holistic

To what extent do you feel your mental health needs are being met (by condition)



A significant number of female respondents mention being labelled as an 'emotional female', and report feeling discriminated against. A parallel theme from the free text comments were people reporting that their neurological symptoms were initially 'dismissed' as being psychological in origin, when it later turned out these symptoms were physiological in origin. Similarly, people with chronic fatigue syndrome/ME repeatedly report having their symptoms trivialised, and told it is 'all in the mind' by medical professionals, particularly neurologists and GPs. Both groups report feeling entirely unsupported by the NHS. This is reinforced by the scores for respondents

with functional neurological disorder and ME about how they rate the care and treatment they have received for their condition overall, which were the lowest two scores for any condition groups. So, whilst for most survey respondents there was a clear need for more psychological support, for people with FND and ME, this is clearly tempered – with some even feeling that the psychological 'help' they had received was entirely misjudged and caused them harm. The results suggest people with ME and FND need tailored support and have distinct needs which are currently not being served.

## Section 2: Key themes – Holistic



**38%**

of respondents reporting their social care needs are not being met at all

### Social care

Social care supports people with both basic activities of daily living, such as getting up, clean and dressed, and to live full, independent lives through getting out of the house and accessing work and education. Not everyone with a neurological condition will need or want social care, yet the numbers of survey respondents who indicated that their condition impacts their day to day activities to a great extent would suggest a significant proportion of people with neurological conditions may have social care needs. Sadly, 49% (n=3,767) of respondents said their social care needs were only being met to a small extent or not being met at all.

For respondents who were able to indicate how they rate social care they have received, the largest proportion (36% n=1,513) rated it as poor, and the lowest proportion (19% n=797) as very good. The overall picture is one of a social care system that people with neurological conditions do not regard as good enough. Furthermore, when it comes to decision making about their social care, a significant proportion of respondents do not feel fully involved. Of respondents to whom this question was relevant, 43% (n=2,306) said

either they did not really, or they did not at all, feel fully involved in making choices about their social care. This figure is rather higher than the proportion who do not feel involved in making decisions about their healthcare, indicating that shared decision making is even more of a problem in social care than in healthcare for people with neurological decisions.

It is notable that the picture around the country is not uniform; some areas appear to be doing much better than others on social care. The extent to which respondents feel involved in making choices varies hugely with the top STP scoring 62%, and the bottom, 34%.<sup>15</sup> Similarly, on how respondents rate the social care they have received the top area scored 53% and the bottom area, 23%.<sup>16</sup> And the extent to which the social care received meets people's needs varies from 45% to just 9% in one area. So, in parallel to the picture painted in the previous chapter about the postcode lottery on the treatment people receive, the social care a person receives is likely to be far better or worse depending on the area in which a person lives. Moreover, the same areas dominate either the top or bottom of the table, suggesting that some STPs areas in particular are struggling on social care provision.

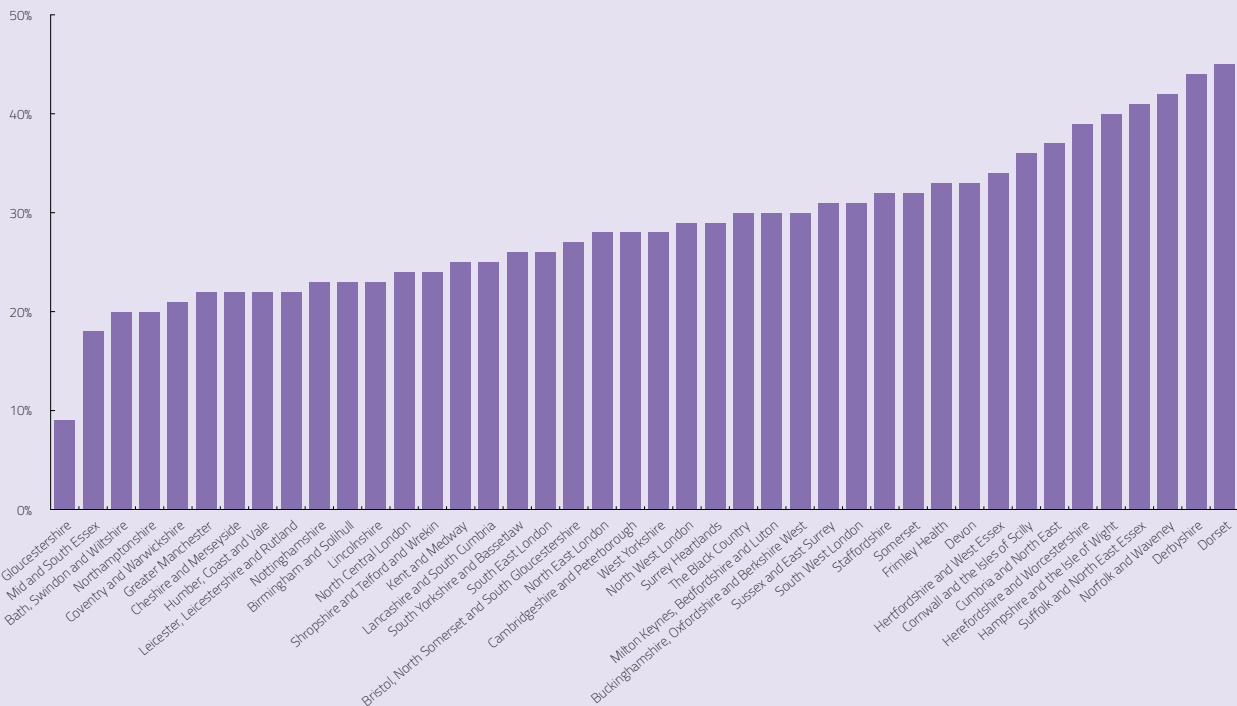
Perhaps because of the absence of a formal social care system that meets their needs, the survey results also suggest that large numbers of people depend on family and friends to support them: 45% (n=4,330) of respondents indicated that they receive care (that they don't pay for) from a friend or family member.

<sup>15</sup> Where a score of 100% would mean all respondents agree they are 'definitely' fully involved in making choices about their social care, and a score of 0% would mean all respondents say they are 'not at all' involved in making choices about their social care.

<sup>16</sup> Where a score of 100% would mean all respondents rate their social care as 'very good' and a score of 0% would mean all respondents rate their social care as 'poor'.

## Section 2: Key themes – Holistic

Extent to which social care meets people's needs



This suggests that at present the social care system for people with neurological conditions is propped up by informal carers. Free text responses indicated that becoming dependent on family and friends can change relationships and people often feel themselves to be a burden.

This survey also investigated the extent to which carers are having Carer's Assessments. Carer's Assessments are provided by local authorities and are important opportunities for carers to be identified and get access to information, help and support. Of those who indicated whether the main person who looks

after them has had a Carer's Assessment, 85% (n=3,810) said they had not. This is a significantly lower proportion of carers having an assessment than has been identified in dedicated surveys of carers.<sup>17</sup> themselves, for instance Carer's UK's State of Caring 2018 survey of carers found 66% had received a Carer's Assessment in the last 12 months.<sup>xii</sup>

Around half of respondents' carers who had had an assessment said that they had received some form of additional financial support<sup>18</sup> (48% n=312). Just 7% of respondents who receive care from a friend or family member told

17 For instance Carer's UK's State of Caring 2018 survey of carers found 66% had received a Carer's Assessment in the last 12 months.

18 Where the respondent indicated whether or not they went on to receive additional financial support.

## Section 2: Key themes – Holistic

*‘I feel, having several rare conditions, unbelievably worthless, isolated and invisible to some service providers (i.e. no one really gives a [obscenity removed] that I’m not able to cook, prepare meals, go out independently, and all assume my mythical family and friends help).’*

SURVEY RESPONDENT

us that their carer is receiving financial support following a Carer’s Assessment. In parallel, just 7% of survey respondents overall told us their carer is receiving Carer’s Allowance<sup>19</sup> (n=673).

Given the numbers who are receiving informal unpaid care from family and friends, it is worrying that more carers aren’t receiving financial support. Carer’s Allowance is widely understood to be under-claimed: in 2017–18, 826,000 carers received Carer’s Allowance, but estimates suggest as many as 400,000 more carers are entitled to the benefit.<sup>xlii</sup>

Returning to a theme explored earlier in the report, in relation to the delays people experience in accessing healthcare, this is also seen in their experiences of accessing social care services. Of those who indicated whether or not they had experienced delays in accessing social care services, 43% (n=1,699) indicated that they had. The proportion of respondents who had experienced delays varied significantly across the country, with the highest scoring STP at 76%,

and the lowest scoring, at 35%. It is interesting to note that a lower proportion of people report delays in social care than in healthcare.

Our survey results strongly suggest that, for too many people with neurological conditions, social care is not working. People with neurological conditions are experiencing delays in accessing social care, not involved in choices about their social care, not satisfied with the social care they receive, and overall not feeling like their needs are being met. Not only does this impact on them as individuals, but there can be knock-on effects on the health service as a result. 40% (n=2,120) of respondents<sup>20</sup> said they did not get the care they needed at home following a stay in hospital, which can only have increased their likelihood of readmittance. The emergent picture is one of people with neurological conditions being let down too often by our ailing social care system.

### Financial security



**43%**

of respondents reporting their financial needs are not being met at all

Having a disability is known to impact on people’s living costs and reduce their income. But it is shocking that 43% (n=3,155) of respondents<sup>21</sup> said that their financial needs are not being met. If we compare this to other aspects of care and support covered in our survey – health, mental health and social care – this suggests that people with neurological

<sup>19</sup> Carer’s Allowance is a nationally administered financial benefit for people who spend at least 35 hours a week providing regular care to someone who has a disability.

<sup>20</sup> Of those who responded to this question.

<sup>21</sup> Who indicated whether or not their financial needs are being met

## Section 2: Key themes – Holistic

conditions are perhaps struggling most in relation to their financial needs. In this section we explore this further, including the additional costs of having a neurological condition, the impact of having a neurological condition on employment and also access to benefits.

People with a limited number of neurological conditions (including epilepsy and myasthenia gravis) are entitled to free prescriptions, and others are entitled on the basis of having a continuing physical disability which means they cannot go out without the help of another person. Yet, one fifth (19% n=1,921) of respondents<sup>22</sup> said that they pay for their prescriptions. This suggests the list of exemptions is outdated and does not relate to current care and treatment regimens for different conditions. Our results show that 53% (n=774) of respondents who pay for prescriptions also report that their financial needs are not being met. The Prescription Charges Coalition has called for an end to prescription charges for people with long-term conditions. An economic modelling report undertaken on their behalf shows that for people with Parkinson's Disease, a condition that is not included in the list of condition specific exemptions, any loss in prescription revenue from removing charges would be more than offset by savings to the NHS in England. These savings come from reduced hospital stays and A&E visits resulting from individuals' inadequate adherence to medication due to cost reasons when prescription charges are in place.<sup>xliii</sup>

Another additional cost of having a neurological condition is in relation to assistive equipment and aids. A fifth (22% n=657) of respondents who were advised to get assistive equipment by an occupational health therapist or other professional self-funded this equipment. Having

*‘When people no longer need to be in a hospital bed, they should then receive good health and social care support to go home. Yet, despite improvements, too often when, where and how care is being delivered is a source of frustration, waste and missed opportunity for patients and the teams looking after them.’*

LONG TERM PLAN FOR THE NHS

to pay for one's own aids can contribute to people feeling worse off and not having money for leisure activities or even essentials. It can also result in people not purchasing equipment they need, precipitating further health problems in both individuals and their carers. Our results showed that 49% (n=266) of people who funded their own assistive equipment and aids said their financial needs are not being met.

Linking back to a theme discussed earlier on in the report, around accessibility of care and delays in diagnosis, a common free text comment was that the respondent had decided to pay to see a neurologist privately in order to get a diagnosis, often at huge financial cost. Some also pay to see a neurologist on an ongoing basis in order to ensure their needs are met. Obviously, this is only an option to those with a certain level of resources in the first place and removes some of the people from the system such that NHS resources are – arguably – concentrated on those most in need.

22 Who indicated whether or not they currently take prescribed medication for their condition

## Section 2: Key themes – Holistic

*‘The lack of suitable equipment is unbelievable; I am told to buy my own! On a state pension with only attendance allowance this is outrageous. Moreover by remaining at home I am saving the state an enormous amount of money, so in my opinion, it is only fair that my spouse has what they need to help me, paid for by the state (their back is already paying the price, as is their shoulder) so at some point in the future she will be asking for medical help, at a further cost to the state, all because you are unwilling to provide suitable equipment in a timely fashion.’*

SURVEY RESPONDENT

However, it is grossly unfair that people who can afford to pay privately are able to get a quick diagnosis and all that entails, yet those who cannot afford to pay often face lengthy delays. That people are paying privately for a diagnosis is another manifestation of the problems in the system in terms of access to care.

The free text comments also highlight that, given the lack of social care funding settlement at present, and the bottleneck on local authority provision, many people

with neurological conditions are also paying for their own social care. There is a sense of frustration and disbelief among respondents at the level of costs they are facing for care.

Not only are people facing extra costs related to their neurological condition, but their income through employment is often reduced, if not ceasing all together. Many respondents find themselves in and of work or reducing their hours. Some have to stop paid employment altogether: over half (53% n=5,504) of respondents indicated that they are not currently in education, employment or training, and only a third (34% n=3,518) said they are in employment. Having a neurological condition appears to be a key contributing factor to this. Over half (54% n=3,015)<sup>23</sup> agreed that they could no longer carry out their job due to the effects of their neurological condition. A huge 61% (n=4,002)<sup>24</sup> disagreed that they have been able to continue working as normal since they were diagnosed – twice as many as agreed (28% n=1,804). Many people also feel that their condition has caused them to miss out on

*‘I had pay for a private neurologist to get a diagnosis. Symptoms started in [date removed] and I had yet to see an NHS neurologist.... I feel forced to go private to get help. Being retired, this was a cost we could do without. This appears to be due to lack of NHS resources.’*

SURVEY RESPONDENT

<sup>23</sup> Of those to whom it was applicable

<sup>24</sup> Of those who indicated whether or not they have been able to continue working as normal



## Section 2: Key themes – Holistic

*‘Due to how poor the care is for my neurological condition on the NHS, particularly in my local area, I self-fund all my healthcare treatment and management costs to ensure I’m able to manage my condition and continue working. I also privately fund and arrange all the social care needs I require myself.’*

SURVEY RESPONDENT

opportunities to develop their career: 68% (n=3,749)<sup>25</sup> agreed that they had missed out.

Given the impact of neurological conditions, resulting in many people living in significant pain as well as experiencing a range of other symptoms, it is not surprising that people’s working lives have been affected. However, this is only part of the picture. There have been increasing initiatives in recent decades aimed at helping disabled people to be able to continue working and seeking to address equalities issues that can act as a barrier to this. Not least of these are employer attitudes, which can sometimes be ignorant or discriminatory. Over a third of respondents<sup>26</sup> agreed that they had been discriminated against due to their neurological condition (35% n=1,799). A further 29% (n=1,191) of respondents<sup>27</sup> agreed that their

contract of employment had been terminated due to their neurological condition. There is huge variation between conditions in relation to the level of discrimination experienced, with the most discrimination being reported by respondents with ME, Tourette’s, brain injury, epilepsy and narcolepsy. We therefore question the extent to which people are making proactive decisions to leave work.

Given the high proportion of respondents who stated they were not in employment – often directly due to their neurological condition – it is unsurprising to find that the benefits system is all the more important to the financial security of many people with neurological conditions. Personal Independence Payment (PIP) is a welfare benefit specifically intended to help people with the extra costs of living with a long-term health condition/disability, which can be claimed regardless of one’s employment status. A quarter of our survey respondents (24% n=2,525) said that they receive PIP. A further 11% (1,118) of survey respondents said they receive Disability Living Allowance.<sup>28</sup>

Many respondents mentioned their difficulties with accessing PIP in their free text comments, being refused access to PIP, and/or finding experience difficult and distressing. Issues were multifaceted including the complexity of the application process, feeling they are having to justify themselves and proving the impact of their (sometime invisible) condition, problems attending assessments, and factual errors by assessment staff. Respondents also found that the requirement to fill in interim review forms,

25 Of respondents to whom this question was applicable

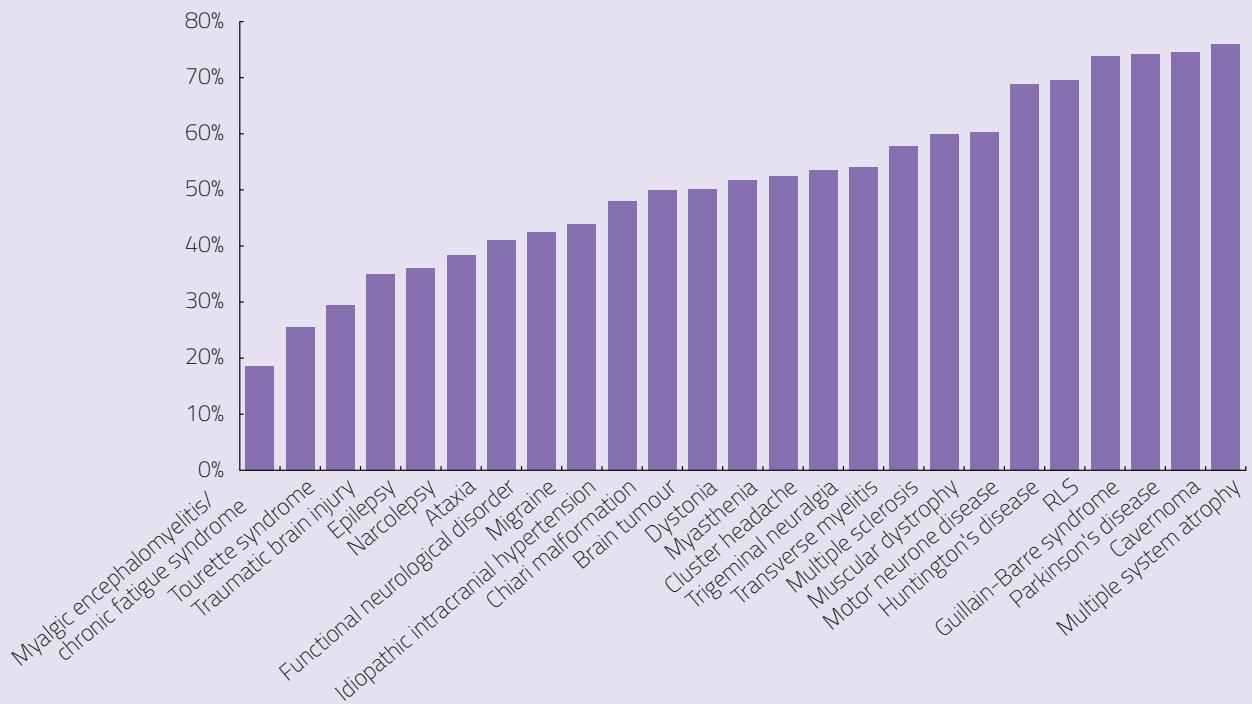
26 To whom the question applied

27 To whom the question was applicable

28 Disability Living Allowance is an older benefit to help with the extra costs faced by disabled people, which is gradually being phased out and replaced by PIP

## Section 2: Key themes – Holistic

Extent to which social care meets people's needs



*‘If there is one area where support could be improved, it is dealing with government agencies responsibility for benefits. I was fortunate enough to have a severe condition and medical proof of such, but the process to claim DLA/PIP and a blue badge was soul-destroying, and I wouldn’t wish anyone to go through the same.’*

SURVEY RESPONDENT

then re-apply for the benefit again once their time-limited award is up, made it a process that keeps causing them stress time and again, with negative consequences on their neurological symptoms. Respondents on DLA spoke of their fears of being re-assessed for PIP.

Another key benefit on which many people rely is Blue Badges: 28% (n=2,844) of respondents had a Blue Badge, and the free text responses suggested that many more had applied for one but been turned down. Blue Badges play an important enabling role in providing people with better mobility, enabling them to get

## Section 2: Key themes – Holistic

around in a way that they might otherwise be prevented from doing. But again, free text responses suggest that the process of applying for them is difficult and debasing.

The overwhelming picture is that the way that the benefits system is currently structured – particularly in relation to PIP – is having a detrimental impact on people's wellbeing. Given the level of financial need amongst people with neurological conditions, and the important enabling role the extra financial support should play in enabling them to live a dignified, fulfilling

life, it seems that PIP is both letting people down, and missing an opportunity. Moreover, given holistic care is needed to prevent people becoming unwell, it seems doubtful that PIP is contributing to the prevention agenda, as things stand. These arguments are well rehearsed by charities in the health and care sector. The Disability Consortium and members of The Neurological Alliance have led the way in seeking to redress some of the problems inherent in the benefits system for people with neurological conditions. Our survey results show there is clearly some way still to go.

*‘[The benefits process] does not take into consideration the days a [condition removed] attack has over you and your body, and the physical and mental exhaustion, just because I was able that day to get to the appointment and talk about my condition, I was told ‘no help’. I have sat many a times in front of HR being told that I am unreliable due to sickness. I work currently day to day with an agency and the last few weeks have worked only a few days. I do not receive sick pay so get into debt’*

SURVEY RESPONDENT

# Section 3: Calls to action

## Care and support for people with neurological conditions must be...

### ...Accessible

#### 1 A national neurology plan for England should be urgently developed

Delays in access and unwarranted geographic variation in neurology patient experience must be addressed as a matter of urgency. We believe a national neurology plan, similar in approach to the plan developed for Scotland, is the only way to achieve this. A national neurology plan will build on the different national initiatives already underway for neurology, providing a coherent pan-neurological action plan for the next five years. The Neurological Alliance would like to work as part of The National Neuro Advisory Group (NNAG), and with the support of NHS England, to develop and deliver this.

The Neurology Intelligence Collaborative has noted the need to bring together the available data on neurology to provide a full picture of neurology services in England. To this end, we look forward to cross-tabulating our survey data with forthcoming (unpublished) research by the Association of British Neurologists, as well as GIRFT's neurology programme. Together these three sources of data will provide clear evidence to inform the national plan in order to improve care for people with neurological conditions.

At a minimum, the national plan needs to address workforce issues – including long standing vacancies and geographic variation in access to neurologists – GP education, community support, triage of outpatients, access to the wider multi-

disciplinary team, and preventative approaches to avoid emergency admissions and attendances.

#### 2 Sustainability and Transformation Partnerships/Integrated Care Systems should include neurology as a priority area for improvement in their plans

The regional data included in this report, which can be read in its entirety at [2019survey.neural.org.uk](https://2019survey.neural.org.uk) shows what is possible in respect to areas of the country which are above average for metrics such as access to specialist nurses, waiting times for neurology appointments and overall experience of care. These innovative models of care must be replicated across the country. We would like to see STP/ICS areas that are consistently falling below average across a number of patient experience metrics adopt neurology as a priority for improvement, and for them to include this in their new five-year strategic plans for delivering on the NHS Long Term Plan.

### ...Personalised

#### 3 Person-centred care should be provided to all people with neurological conditions

Personalised and integrated care is a core element of the NHS Long Term Plan; it is essential that this policy intent is translated into practice for people with neurological

## Section 3: Calls to action

conditions. We are pleased to see that the NHS Long Term Plan Implementation Framework outlines how systems will be expected to set out how they will implement the six components of the NHS Comprehensive Model for Personalised Care. From the results of our survey we can see that aspects of personalised care for people with neurological conditions, such as information provision and coordinated care, are starting from a far lower baseline than other conditions – such as cancer. This also shows, however, that it should be possible for this to improve.

We also see from our survey the critical importance of personalised care to an individual's overall experience. We therefore believe that neurology should be prioritised for further personalisation initiatives/pilots, as seen in the neuro integrated personalised commissioning pilot. We would particularly like to see care planning piloted for people with complex neuro conditions accessing primary, community and specialised care services. The Neurological Alliance will also work closely with the National Neuro Advisory Group (NNAG) to support its care planning priority.

In addition to national policy delivering on the ground improvements, we would like to work with professional bodies including the Association of British Neurologists and the Royal College of General Practitioners to explore further the barriers to information provision at the time of diagnosis in order to better support healthcare professionals to provide information at this critical point in an individual's care journey.

### ...Holistic

#### **4 People with neurological conditions should be afforded the opportunity to live dignified, fulfilled lives, maximising their wellbeing through:**

- a Resolution of the social care crisis including a long-term funding settlement

Social care is essential to many people with neurological conditions and must be delivered by skilled staff to keep people with complex neurological needs functioning and well. Policy experts have warned that the Long Term Plan for the NHS cannot be delivered without a long-term financial settlement for social care. The Government must deliver this, as well as providing short term funding as there is an immediate funding gap undermining the system.

- b Redoubling efforts to tackle structural and institutional barriers to employment

Both Government and employers have a role to play here. The Government must improve awareness of and access to disability employment retention and support schemes. Employers should adopt policies and practices which promote inclusion and opportunity for disabled employees.

- c Reform to the welfare system in line with the Disability Benefits Consortium's calls

The benefits system must change to better serve its purpose in enabling people to get on with their lives in spite of their condition,

## Section 3: Calls to action

rather than impeding them from doing so and negatively impacting their health and wellbeing in the process. We're calling for reform in line with recommendations set out in the Disability Benefit Consortium's forthcoming report, *How welfare became unfair*.<sup>29</sup>

These recommendations relating to holistic care are not new and have been long-campaigned for by the disability sector. The Neurological Alliance pledges to redouble our efforts to support the sector-wide campaigns relating to social care, employment discrimination and welfare reform. These are areas where the needs of people with neurological conditions are least well met.

### **5 Neurology should be included as a priority for mental health improvement initiatives aimed at people with long term conditions**

Mental health is mentioned in every section of this report – quite deliberately. Appropriate mental health support must be accessible to people with neurological conditions, it is a key aspect of personalised care, and it an essential element of taking a holistic approach to care and

support. Ensuring the mental health, cognitive and emotion needs of people with neurological conditions are met is a long-stated priority of The Neurological Alliance, reinforced by the level of need established by our survey. We want to see every person with a neurological condition having their mental, emotional and cognitive wellbeing effectively and systematically screened wherever they live, to pick up on their changing needs, from predictive testing, first symptoms and diagnosis, through to the end of their life. The need for this is particularly acute amongst people with rarer neurological conditions, whose needs are least met at present.

Given both the level of need and the sometimes complex interrelations between people's neurological conditions and their mental health, we believe neurology is well placed to be included in mental health improvement initiatives aimed at people with long term conditions. We urge policy makers to prioritise neurology for such initiatives. Similarly, we look to the forthcoming neuropsychiatry service specification and neuropsychology annex, to improve specialised service provision.

29 Due to be published 16 July 2019

# About the survey

**10,339**

Number of people who responded to our survey



Please note that full details of the methodology and results are provided in the accompanying technical report [www.neural.org.uk/resource\\_library/neuro-patience](http://www.neural.org.uk/resource_library/neuro-patience).

- This is the third iteration of the National Neurology Patient Experience Survey, gathering the views of people with neurological conditions across England. The survey was previously run in 2014 and 2016.
- For 2018/19 we have updated and renewed the methodology – gathering responses in neurology clinics as well as via an online survey.
- The Neurological Alliance engaged survey company Quality Health to undertake the survey. The Neurological Alliance and Quality Health worked in close partnership to develop and test the methodology and survey questions, as well as to analyse and report on the data.
- The new methodology was trialled via pilots conducted during summer and late autumn 2018. Changes were made to the methodology following these pilots.
- The online survey was open from 17 October 2018 to 22 March 2019. The online survey was promoted to people with neurological conditions via Neurological Alliance member organisations and via the Alliance's own channels of communication.
- For the in-clinic survey we engaged with 44 different neurological units (predominantly outpatient services) across England. All were sent paper copies of the survey to hand out to their patients. Some clinics additionally promoted survey completion via an online link. The in-clinic paper survey opened 21 January 2019 and closed in line with the online survey on 22 March.
- The survey received 10,339 responses.
- A rigorous process of data cleaning was undertaken by Quality Health before data analysis commenced.

# Acknowledgements

This report was co-authored by Katharine McIntosh and Sarah Vibert.

First and foremost, we would like to thank the 10,339 people who took the time to complete the patient experience survey. We hope we have done justice to the answers you gave and that by telling your stories we are able to contribute to bringing about the changes you are calling for. Thanks too to the people with neurological conditions who provided essential feedback about the survey during its development.

We also owe a huge debt of gratitude to the patient experience survey steering group who generously gave up their time over the last 18 months to help us to shape the survey, data collection and report. The patient experience survey steering group was made up of:

**Andy Barrick, MSA Trust**  
**Fredi Cavander-Attwood, MS Society**  
**Kim Davis, Parkinson's Association**  
**Alexis Kolodziej/Joshua Edwards, Stroke Association**  
**Joanne Lawrence, Association of British Neurologists**  
**Duncan Lugton, Sue Ryder**  
**Sue Millman, Ataxia UK**  
**Sam Mountney, Epilepsy Action**  
**Daniel Vincent, MND Association**

Thanks too to the people with neurological conditions who provided essential feedback about the survey during its development, and to those who sent us their stories to include in the report, including those we were not able to include for lack of space.

We also want to thank the clinicians and managers from the 35 neurology units across the country who supported the data collection via paper surveys. Special thanks go to Cath Mummery, Greg Rogers, Paul Morrish and Ralph Gregory who read early drafts of this report and provided valuable clinical insight into the findings.

All of our members made a big contribution to the success of the survey by promoting it to their supporters. Particular thanks go to David Martin at the MS Trust for his guidance on communications and messaging.

Finally, we would also like to thank Daniel Ratchford, Charlie Boshier, and the team at Quality Health for all their support in developing and running the survey and reporting on the results.



# About The Neurological Alliance

The Neurological Alliance is a coalition of 80 organisations working together to transform outcomes for the millions of people in England with a neurological condition. We campaign for high quality care and support to meet the individual needs of every person with a neurological condition, at every stage of their life. Our work is shaped by the experiences of people with neurological conditions and aims to address the causes of poor care.

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

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