

# Falling short

How has neurology patient experience changed since 2014?

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# FOREWORDS



The challenges facing neurology should not be underestimated. Yet, at the time of writing this foreword, I have a degree of optimism that the tide is beginning to turn for neurology.

The new National Neuro Advisory Group brings together all the different parts of the health system to develop a shared approach to improvement; and work has begun apace. We have the green light from NHS England to begin development of not only a revised specialised neurosciences specification, but also a specification for CCG commissioned neurology. Bringing together patient groups and clinicians, we are also developing disease specific pathways.

Together these three pieces of work will seek to clarify commissioning responsibilities and address the fragmented patient pathways that this report highlights. We are also developing a set of neurology outcomes with a view to proving the value of better neurological services both in hospitals and in the community. The end result should be a national neurology audit comparing different regional services, putting pressure on outliers to improve. This will supplement the data that is already available from Right Care, the Neurology Intelligence Network and "Getting it Right First Time" (GIRFT). Data is critical as it enables the system to measure progress and flag where further improvement is needed.

This patient experience survey is another valuable source of data for the health system. It demonstrates that these new national initiatives for neurology are timely and must urgently deliver for patients. Clearer national policies and data on variation help but cannot mandate change at local level. Much of the decision making power within the NHS sits within hospital trusts, CCGs or STPs – so we ask you all to use this report to support making neurology a priority in your local area.

**Professor Adrian Williams**

Chair, National Neuro Advisory Group



Neurological conditions or injuries are often mis-characterised as rare and marginal to the activity of the NHS. The reality is that neurological conditions affect millions of people across England and consume a significant proportion of the NHS budget.

According to the most recent estimates, there are around 12.5 million cases of neurological conditions in England and the NHS spends £4.4 billion from its programme budget on neurology services.

Those figures only tell part of the story and this report reveals the rest – what individual patients actually experience, what works and what doesn't. Our work with patients has consistently found that patients want the same things – a timely and accurate diagnosis, support throughout the process and to be informed about their treatment and care. This latest research reveals that not only is neurology patient experience of care consistently falling short of expectations, but that experience of care has got worse across all key measures since our inaugural patient experience survey in 2014.

While I am encouraged by the new initiatives to prioritise improvement of neurological services, patients must not wait much longer to see these initiatives translate to change on the ground. The National Neuro Advisory Group has made a promising start, but The Neurological Alliance calls upon all parts of the health system to ensure that momentum is maintained to bring about the changes that are urgently required to improve patient outcomes.

**Suzanne Dobson**

Chair, Neurological Alliance

# INTRODUCTION

## How has neurology patient experience changed since 2014?

Two years ago the Neurological Alliance published the results of its inaugural patient experience survey. A landmark report that confirmed many people with a neurological condition are not receiving the health and care services they so desperately need, *Invisible Patients: Revealing the State of Neurology Services*<sup>1</sup> highlighted the fragmented patient pathways and variable experience of care across England.

In 2016 we ran our patient experience survey for a second time to see how patient experience in England had changed. This follow up report presents the results of our 2016 survey and compares them to 2014. Focussing on two main themes that reflect the neurology patient journey – (1) the pathway to diagnosis and (2) on-going experience of care – worryingly this report reveals that at every stage patient experience of care is falling short of what we reported in 2014. With resources becoming tighter, it's clear that the system is struggling more than ever to provide the timely support needed to ensure the best possible outcomes for people living with neurological conditions.

There is hope on the horizon with a number of positive initiatives in the early stages including, the establishment of the new National Neuro Advisory Group, a commitment to redevelop the specialised neurology service specification, the dissemination of Right Care Neurology Focus Packs, and the development of a new NICE guideline for suspected neurological conditions in primary care. These new opportunities for neurology will take time to deliver results; particularly given neurology is starting from such a low baseline in terms of the need for improvement.

The need for improvement should not be underestimated. Neurological conditions have a major impact on the lives of patients. 71% (n=4,661) of our survey respondents experience moderate, severe or extreme pain or discomfort and 70% (n=4,561) of patients are restricted in their activities frequently, most or all of the time. It is critical that neurology patients receive an improved experience of care in order to

achieve better outcomes. The numbers of people with neurological conditions will also grow sharply in the next two decades due to improved survival rates, increased longevity and improved diagnostic techniques. The strain on the health service is therefore going to increase over time, which is why action is needed now to improve services.

In order to ensure results are urgently delivered for people living with neurological conditions, in the conclusion of this report we set out a number of recommendations aimed at the different parts of the health and care system – including policy makers, commissioners, providers, professional groups and patient organisations. We are challenging the whole system to work together – along with the Neurological Alliance – to ensure that by 2018 we can report a turnaround in patient experience, with all people with neurological conditions accessing the care they need and deserve.



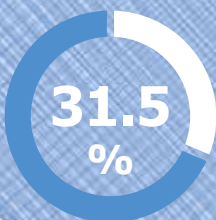
“This report reveals that at every stage patient experience of care is falling short of what we reported in 2014.”

# COMPARISON BETWEEN 2014 AND 2016



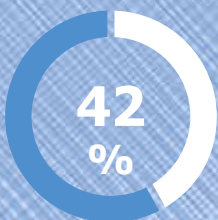
The proportion of patients seeing their GP five or more times before seeing a neurological specialist

2014



31.5%

2016

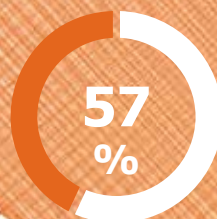


42%

Patients who felt satisfied their diagnosis was communicated appropriately

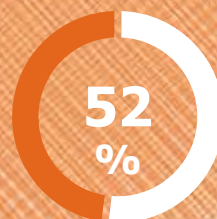


2014



57%

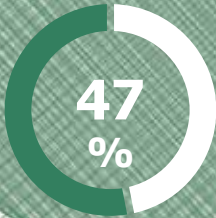
2016



52%

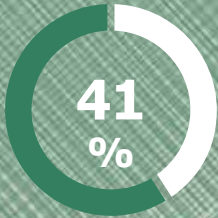
Patients describing the health services received for their neurological condition as 'good' or 'excellent'

2014



47%

2016

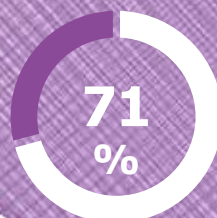


41%

Patients who feel involved in making choices about health services to at least some extent

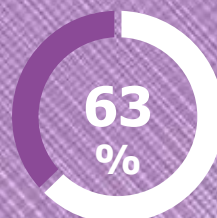


2014



71%

2016

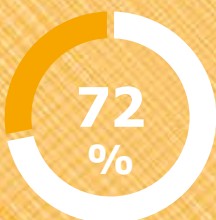


63%

Patients not offered a care plan

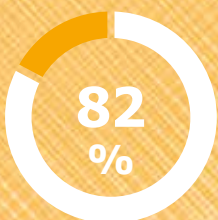


2014



72%

2016

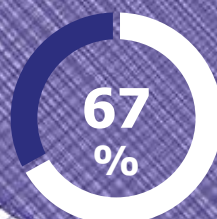


82%

Patients who feel their health and care professionals work well together at least some of the time

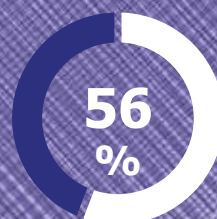


2014



67%

2016



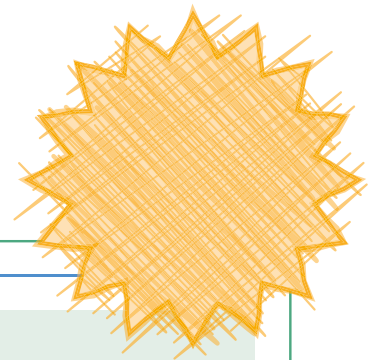
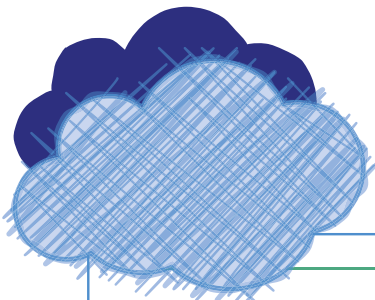
56%

The experience of a neurology patient in the health and care system generally starts in one of two places; at the GP surgery or the emergency department.

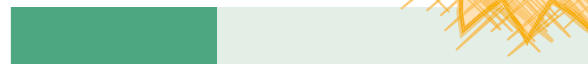
Our survey focussed mainly on experience of GP care and referrals, although we discuss emergency admissions in part 2 of this report. After this first contact with the health service, the priority is for the

patient to receive an appropriate and timely referral and correct diagnosis, as this is the prerequisite for accessing treatment and care for any medical condition. Early diagnosis of neurological conditions

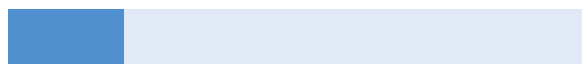
## VARIATION IN PATIENT EXPERIENCE ON THE PATHWAY TO DIAGNOSIS AND TREATMENT



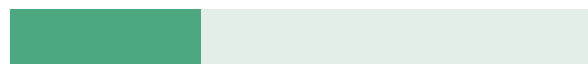
**42%** of patients saw a GP **five or more times** before seeing a neurological specialist



**35%** saw GP **once or twice** before seeing a neurological specialist



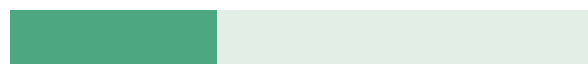
**19%** of patients waited **more than 12 months** to see a neurological specialist after first seeing a GP



**33%** of patients who saw a neurological specialist **within three months** of their first GP visit



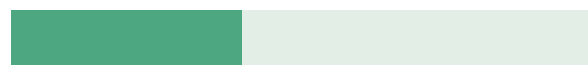
**22%** waited **more than six months** for a diagnosis after seeing a specialist



**35%** waited **less than one month** for a diagnosis after seeing a specialist



**ALMOST 10%** waited **a further 12 months** or more to begin treatment after diagnosis

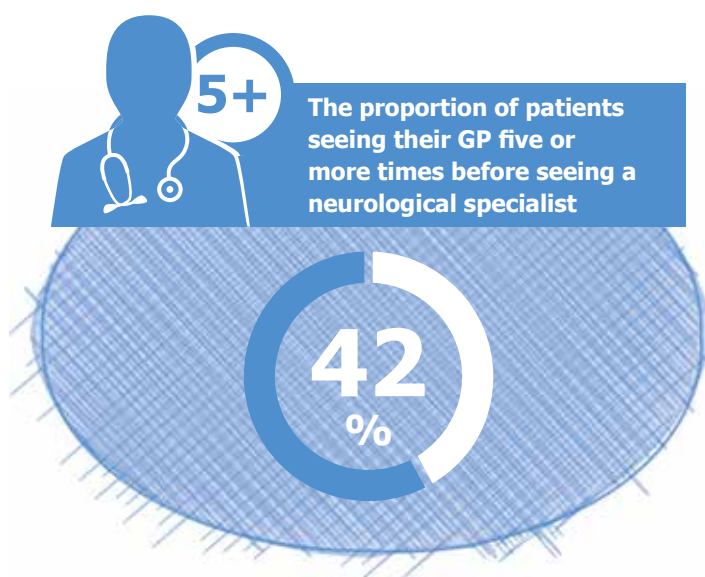


**40%** reported treatment started **within one to two weeks** of diagnosis

# THE PATHWAY TO DIAGNOSIS

is important in order to 'reduce neurological damage, slow down the rate of disease progression, increase survival rates and improve a person's quality of life'.<sup>ii</sup>

Over half of patients surveyed (53%, n=2,497) reported problems or delays in accessing health care services. This headline figure, while on its own suggests poor patient experience, hides the variety of experience across the neurological patient group on the pathway to diagnosis.



## 1.1 Primary care

Primary health care is mainly provided by GPs (general practitioners) but community pharmacists, opticians and dentists are also primary healthcare providers. This report focuses on neurology patient experience of seeing a GP.

Given the importance of a timely diagnosis, it is concerning that our research has found that 42% (n=2,652) of patients saw their GP five or more times before being referred to a neurological specialist. This proportion is the same regardless of whether the patient received their diagnosis in the last five years or more than five years ago. Overall the percentage of patients seeing their GP five or more times before seeing a neurological specialist has increased since 2014 when the proportion was 31.5%.

Neurological conditions are complex and multifaceted; they present with many different symptoms and have different clinical courses. Many neurological conditions start slowly, with no specific symptoms, making it challenging for GPs to make a judgement on the most appropriate course of action. In the ten minute appointment slot, the GP must decide what condition the patient's symptoms indicate and whether it is appropriate to refer on to a specialist. If all patients presenting with headache, for example, were referred to a neurologist, it is likely that the most urgent cases – for example, a patient with a brain tumour – may experience longer waiting lists and further delay in diagnosis and treatment.

It should also be noted that some neurological conditions, for example migraine, can – and sometimes should – be managed in primary care. 7.5% (n=482) of patients reported they did not need to see a neurological specialist. There was a wide

“*Diagnosis could have been done sooner. It was pure chance that I got referred – my own GP was on leave so I saw someone else and he referred me.*”

“*The diagnosis was very quick after an immediate referral – I cannot fault anything. The diagnosis was made within one day of referral.*”

# THE PATHWAY TO DIAGNOSIS

variety between conditions within this group as we would expect. Just 1.6% of epilepsy patients, 1% of myasthenia patients, and 0% of dystonia patients reported they did not need to see a neurological specialist. Yet for migraine 17% of patients reported they did not need to see a neurological specialist and for Myalgic encephalomyelitis/chronic fatigue syndrome 19% of patients reported they did not need to see a neurological specialist. This highlights

the different patient pathways required for neurology patients to receive appropriate care and complexity involved in achieving continuity of care.

Further assessment of the number of times patients saw a GP prior to referral is analysed below, using the four main *Neuro Numbers*<sup>iii</sup> classifications as a guide. This provides further insight into what lies behind the headline figures in our report.

Category	Condition	Total number of respondents	Most frequently cited answer for number of times GP was seen prior to referral
<b>Intermittent</b>	Epilepsy	542	179 (33%) – I saw my GP once or twice
	Migraine	1838	961 (52%) – I saw my GP five or more times
	Cluster headache	235	143 (60%) – I saw my GP five or more times
<b>Stable with changing needs</b>	Myalgicencephalomyelitis	350	224 (64%) – I saw my GP five or more times
	Tourette's	164	69 (42%) – I saw my GP once or twice
	Transverse myelitis	172	70 (41%) – I saw my GP once or twice
<b>Sudden onset</b>	Idiopathic intracranial hypertension	155	83 (53%) – I saw my GP five or more times
	Stroke	141	55 (39%) – None – I did not see my GP before going to a neurological specialist
	Trigeminal neuralgia	279	143 (51%) – I saw my GP five or more times
<b>Progressive</b>	Dystonia	334	183 (55%) – I saw my GP five or more times
	Multiple sclerosis	824	440 (53%) – I saw my GP once or twice
	Parkinson's	592	370 (63%) – I saw my GP once or twice
	Multiple System Atrophy	153	71 (46%) – I saw my GP once or twice

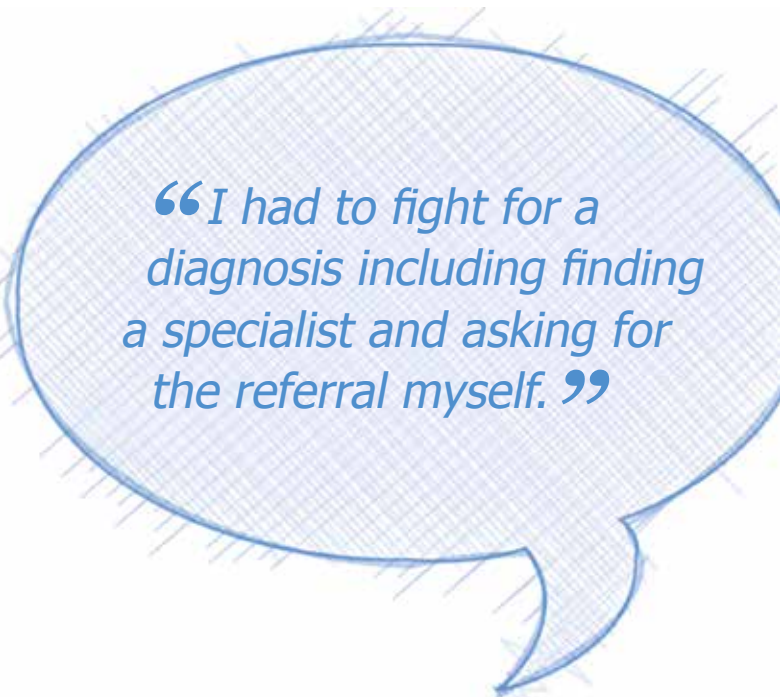


# THE PATHWAY TO DIAGNOSIS

Many neurological conditions are rare compared to other long term conditions. For example, an individual GP may only see one or two cases of motor neurone disease in their whole career. The table on the previous page suggests that for some rarer conditions or conditions that are perhaps less well known, such as dystonia, over half of patients visited their GP five or more times. While for conditions where there are NICE guidelines regarding referral such as epilepsy or Parkinson's, the most common answer was to see the GP once or twice before referral. This suggests that GP knowledge can affect the speed of referral.

Research carried out by the Neurological Alliance in 2016 found that 84% of GP respondents felt they could benefit from further training on identifying and managing people presenting with neurological conditions.<sup>iv</sup> 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 for making an assessment and referral for non-neurological conditions such as diabetes. Additional local and individual factors that can also affect referral patterns include specialist GP interest, local research interests, and the rapport between doctor and patient.



*“I had to fight for a diagnosis including finding a specialist and asking for the referral myself.”*

## 1.2 Access to neurological specialists

The causes of delays in referral and diagnosis are not limited to primary care. Although 40% (n=2,096) of patients reporting that they needed to see a neurological specialist had this appointment within three months of their first GP visit, 23% (n=1,204) of patients waited more than 12 months. This is perhaps indicative of varied access to specialists. Data from the Neurology Intelligence Network shows that local rates of new consultant adult neurology outpatient appointments vary hugely by CCG area, from 2,531 per 100,000 resident population in Camden to as low as 165 per 100,000 population in Doncaster. 45 CCGs (22%) offer no local consultant neurology services whatsoever.<sup>v</sup>

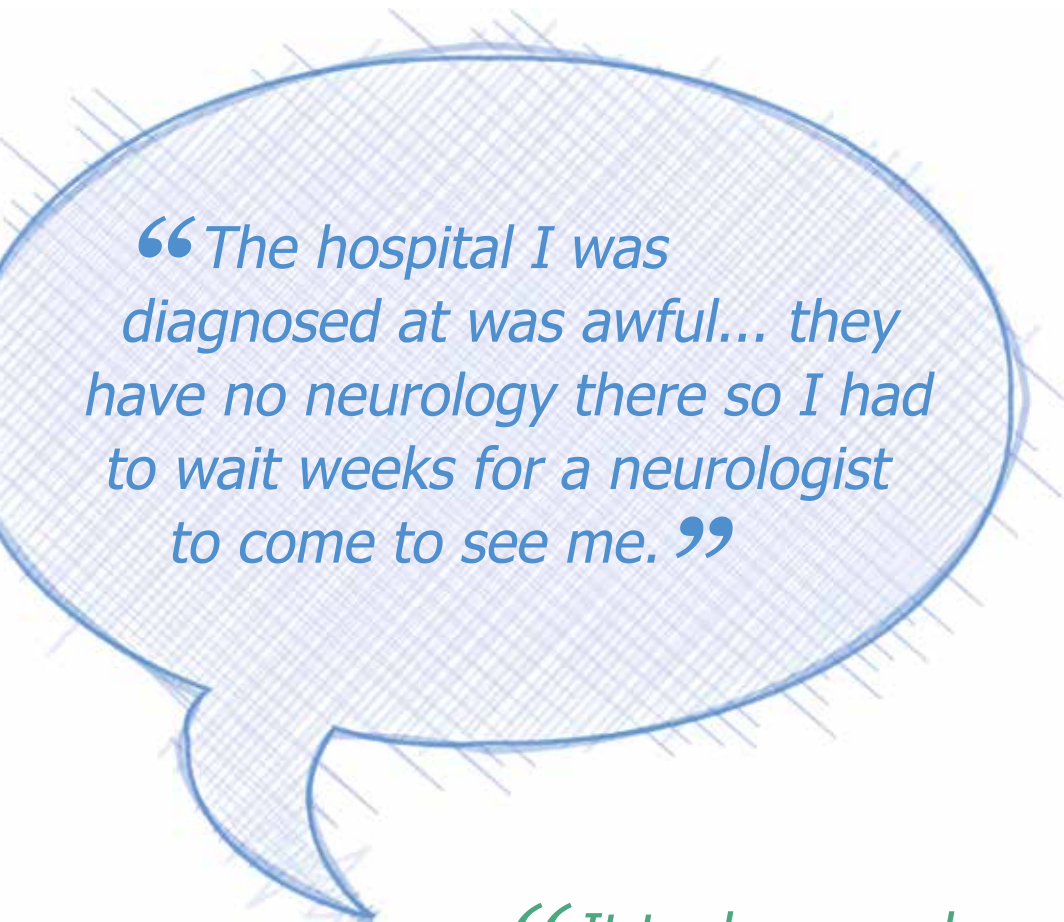
**How long did you wait after your first visit to a GP until your first consultation with a neurological specialist?**

Answer options	Response (%)
Less than 3 months	40
4–6 months	18
7–12 months	9
More than 12 months	23
Don't know/rather not say	9

## THE PATHWAY TO DIAGNOSIS

Our research also illustrates that the process of diagnosis can be lengthy even with the input of a neurological specialist. 22% (n=1,375) of patients waited six months or more for a diagnosis even after seeing a neurological specialist. This highlights the difficulty in diagnosing some neurological conditions – even for a specialist. In order to provide a reliable and accurate diagnosis of a neurological condition, a multi-disciplinary approach is often required.

For example, a patient presenting with symptoms of a movement disorder may require a full multi-disciplinary assessment, ideally including input from a specialist neuro-physiotherapist, in order to ascertain the underlying condition. For many neurological conditions specialist nurses also play an important role in providing care. Variation in access to specialists including nurses and a wider specialist multidisciplinary team may impact on speed of diagnosis.



*“The hospital I was diagnosed at was awful... they have no neurology there so I had to wait weeks for a neurologist to come to see me.”*

*“It took a very long time for me to be referred. I had to go back to the doctors two times to get the ball moving. It then took a further six months to get the medication, and then a year for any further help.”*

# THE PATHWAY TO DIAGNOSIS

## 1.3 Communication of diagnosis

Many patients reported that receiving a diagnosis of a neurological condition is difficult, with typical comments including feeling scared, shocked, or experiencing a sense of loss. The way in which diagnosis is communicated, and the quality of communication with health care professionals, is an important factor in overall patient experience. While it is encouraging that over half of patients (52%, n=3,244) are satisfied with the way their diagnosis was communicated, 41% (n=2,586) believe it should have been done more appropriately or was not at all appropriate. This is true regardless of when a patient was diagnosed; those who received a diagnosis in the last five years report similar experiences of communication about their diagnosis compared to those who were diagnosed more than five years ago.

For patients who had a delay in their diagnosis (those who saw their GP 5 or more times before diagnosis), the satisfaction rate with the way diagnosis was communicated is even lower, with 50% believing it should have been done more appropriately or was not at all appropriate. Overall there is a lower satisfaction than in 2014, when 57% felt their diagnosis was communicated appropriately (57.2%, n=3,573).

Patients who felt satisfied their diagnosis was communicated appropriately



52  
%

*“Thankfully my neurologist is lovely and set aside extra time to console me and discuss my options.”*

*“I was told my diagnosis in a brief conversation over the phone and feel it would have been more appropriate to tell me at a face to face meeting. I was so shocked at the time.”*

# THE PATHWAY TO DIAGNOSIS



## P's story

Around 2009 I started getting frequent chest pains which spread to the left side of my face, shoulder and arm. With a history of heart disease and strokes in my family, the medical professionals I spoke to suggested A&E, where they checked I wasn't having a heart attack or a stroke and sent me home.

I finally got my GP to refer me to a cardiologist who told me as I was young and female, I was unlikely to have heart problems. My GP then sent me to a good cardiologist who confirmed with tests that my heart was slow and irregular but otherwise fine. I was sent to more specialists over the next three years who found nothing to explain these heart attack-like events. A new GP ended up prescribing me four different painkillers to take simultaneously. By this time I was essentially bed ridden, even between attacks.

I was then referred to a neurologist who mentioned 'atypical migraine' and prescribed a different drug, which at first was a miracle cure! I was able to find a job, move house, and was finally becoming myself again.

Three months into my new job the old symptoms started creeping back until one morning I came round on the floor of my office with a colleague looking down at me, more scared than I was. I was taken to A&E where I spent the rest of the day and night. As I was now also getting more symptoms, mainly paralysis of my left side and face, I had a CT scan and was referred to another neurologist who suggested an MRI scan. Both came back normal.

So my loose diagnosis is atypical migraines but after reading the information on the Migraine Trust's website I am going to go back for clarification. I've had a huge range of stories from medical professionals over the years yet none of them seem to get the difficulty it causes people. I hate to be a strain on the NHS but if I go to my GP for painkillers with symptoms of a paralysed face or chest and arm pains I'm told to go to A&E. I can't hold down a job because of the frequency of attacks and the long lasting effects, and it is impossible to explain this to the DWP.

## M's story

After retirement, out of the blue I had a suspected stroke and was rushed to hospital. After testing, the doctors said it wasn't a stroke, but told me to see a neurologist.

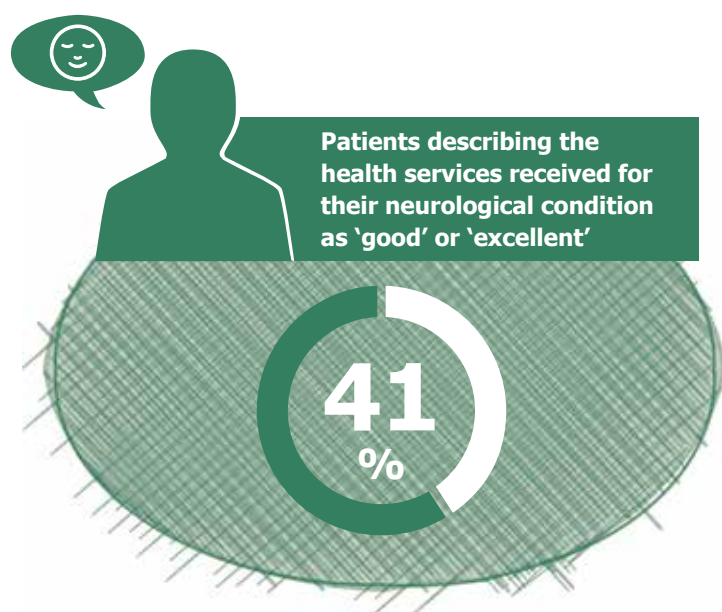
From that moment I started worrying. I know some neurological conditions can be terminal, and had no idea if mine was or not. My stress levels went through the roof. I couldn't sit still and felt very emotional. I literally barely slept from July to September. I never knew stress could impact me in this way. I went to the doctor to ask about when I'd get a diagnosis, he told me he couldn't do anything to speed up the process. I was put on pills for my anxiety – my wife said it was like living with a different person.

By September 2016 I'd waited three months for news. I was so ill with anxiety that one night I thought I was having a heart attack and was rushed to hospital. It was horrendous. At this point we decided we couldn't wait any longer and paid to get diagnosed privately.

Diagnosis confirmed there was something wrong, I had Parkinson's. We were advised to go back to the NHS for advice and treatment. My specialist sent a referral letter saying I needed to see an NHS neurologist. Since then nothing has happened. We've chased this non-stop. We were told in November that they were still working through the list of referrals from June and July. In December we were told to call back in March. We're still waiting.

Since my private diagnosis, I've had absolutely no information or advice about my condition from the NHS, and I've not been given any medication. If we hadn't gone private, I think I'd still be waiting for my diagnosis ten months later. My GP hasn't been able to give any support as they don't seem to know much about Parkinson's, plus I see a different person each time. The only support I've received is from my local Parkinson's UK group who gave me resources, and contact details for the local Parkinson's nurse. This whole process has been awful; we've been to hell and back.

Most neurological conditions are long term, requiring lifelong management. Due to their complexity, diversity and severity, neurological conditions require the highest standards of treatment and care. We outline in section 2.3 the variety of services that may be accessed by patients with neurological conditions. It is disappointing that just 41% (n=2,132) of patients describe the health services received for their neurological condition as 'good' or 'excellent', this is down from 47% in 2014.



## 2.1 Information and choice

Our survey found that 63% (n=3,238) of patients feel involved in making choices about health services to at least some extent. This compares to 71% in 2014. To support patients to make choices about their health services, it is important patients are given timely and appropriate information. In general, patients are more satisfied than unsatisfied with the information they have received throughout their patient journey. This is comparable to 2014, when 24% of respondents said they received no information about additional sources of support.

**How satisfied are you with the type of information that you have received from healthcare professionals throughout living with your condition?**

Answer options	Total satisfied (%)	Total unsatisfied (%)
Information about your condition	55	45
Contact details for a named healthcare professional in charge of your care	57	43
Your care and treatment options	54	46
Risks and benefits of different types of treatment	53	47
Sources of emotional support such as patient support group or counselling	37	63
Additional sources of information such as charities	47	53

# ON-GOING EXPERIENCE OF CARE

It is noteworthy that 45% (n=2,543) were unsatisfied with information they have received about their condition and 46% (n=2,493) are dissatisfied with information they have received about their care and treatment options. We also found that 53% (n=2,830) of patients were dissatisfied with signposting they had received from healthcare professionals to sources of voluntary sector support. A lack of information, particularly at the time of diagnosis, was a common theme in the open text answers to our survey.

Patients who feel involved in making choices about health services to at least some extent

63%

*“I got a letter saying what my diagnosis was. Obviously I googled it and got really scared. A telephone call or some info would have been useful.”*

## 2.2 Care and support planning

Patients not offered a care plan

85%

Care and support planning is a process which helps people set their own aims, and then secures the support and care that are needed to achieve them. It is now well understood that effective care planning and coordination is an essential aspect of care for people living with a long term health condition.<sup>vi</sup> The impact of a neurological condition can vary widely; the same condition is experienced differently from one individual to the next, and a condition may impact differently on the same individual over time. 53% (n=3,458) of patients surveyed also 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.

Yet our survey found that 85% (n=4,862) of patients have not been offered a care plan. Fewer than 10% (n=550) have one at the moment and there is also variation across conditions in terms of patients reporting they have been offered a care plan. A higher proportion of patients with Parkinson's, myasthenia and multiple sclerosis reported not having a care plan than patients with epilepsy, traumatic or acquired brain injury and motor neurone disease. The 2016 figures reflect poorer patient experience than in 2014 when 72% of patients had not been offered a care plan and 19% had one.

*“I was given tablets and then sent on my way. I have had to learn everything I know about my condition myself.”*

# ON-GOING EXPERIENCE OF CARE

## 2.3 Multi-disciplinary team and integration with social care

In order to meet the needs of people living with neurological conditions in full, a multi-disciplinary approach is often required, bringing together a range of services with appropriate specialist neurological expertise. Our survey highlighted the wide variety of different specialists involved in patient care.

### The range of professionals that can be involved in neurology patient care include:

- Home care
- Neuro-physiotherapy
- Neuro-rehabilitation
- Neurologist
- Neuropsychiatric support
- Neuropsychological support
- Occupational therapy
- Palliative care
- Residential care
- Self-management support
- Specialist nurse
- Speech and language therapist

*“I would have liked better communication between departments and dealing with me as a whole person and not looking at only parts of me due to their specialised knowledge.”*

Patients who feel that health and care professionals never work together

20  
%

Given 20% (n=1,192) of patients surveyed also report receiving social care, this makes integration of different services, even across funding boundaries, very important. We found that over half of patients (56%, n=2,714) feel that their health and care professionals work well together at least some of the time. It is important to note however that one in five (20%) feel this 'never' happens. In 2014, these figures were 67% and 18%, again demonstrating a worsening experience of care. It is also important that patients have a named health care professional who can lead and support coordination of their care but 43% (n=5,424) of patients said they were unsatisfied with the information they received about a named health care professional.

In terms of professionals working together, one specific example we asked patients about was their experience when leaving hospital. Of those patients who have been hospitalised for their condition, 65% (n=1,666) report that when they were discharged, information about their stay was passed on to the people who care for them outside of hospital (such as GP, nurse or family carer). However 21% (n=536) report that this did not happen and 14% (n=370) didn't know or preferred not to say.

# ON-GOING EXPERIENCE OF CARE

## 2.4 Hospital admissions

A hospital admission as a result of a neurological condition can happen at different points on the care pathway – prior to diagnosis or at a later stage. It can be part of ongoing care, but can be carried out in an emergency situation. 17% (n=1,096) of patients report having at least one planned admission to hospital in the last two years and 26% (n=1,572) of patients reported having at least one unplanned – emergency – admission to hospital in the last two years.

Our survey showed variations across conditions in terms of emergency admissions. 44% (n=238) of epilepsy patients report one or more unplanned admissions to hospital in the last two years, one of the highest rates across conditions. Epilepsy is an ambulatory care sensitive condition, meaning that with the right care in the community and support to self manage, patients should not routinely need to be admitted to hospital. Nationally available data supports the results of our research in relation to high numbers of unplanned admissions.<sup>vii</sup>

Of those patients who reported they had been admitted to hospital as a result of their neurological condition, over 30% (n=757) were dissatisfied with their experience of hospital care.

Our survey revealed a variety of factors underpinning the dissatisfaction experienced by neurology patients during their stay in hospital. A lack of access to neurologists was one theme. A survey of acute neurology providers by the Association of British Neurologists found that the likelihood of a patient with a neurological problem being seen by a neurologist varies dramatically depending on where they are admitted. Hospitals in the top quartile provide daily review by a neurologist on 89% of days, while in the bottom quartile this service is only available on 17% of days.<sup>viii</sup>

**If you have been admitted to hospital as a result of your neurological condition, how satisfied were you with the treatment you received? (Please refer to your most recent visit.)**

Answer options	Response (%)
Very satisfied	25.86
Satisfied	21.08
Fairly satisfied	19.79
Fairly dissatisfied	9.05
Dissatisfied	8.57
Very dissatisfied	12.83
Don't know/rather not say	8.82

*“My local hospital did not have a neurological unit on site so I had to wait 5 days as an inpatient on an overflow ward waiting for a neurologist.”*




# ON-GOING EXPERIENCE OF CARE

## 2.5 Support for mental health

Of the 53% (n=3,459) of neurology patients who reported living with at least one other co-morbid condition, mental health conditions, including anxiety and depression, were among the most frequently cited. As neurological conditions relate to the brain and nervous system, there is an increased complexity in the interaction between physical needs and broader emotional, cognitive and mental health needs. For some people with a neurological condition, a mental health condition can be a clinical symptom of the condition. For others, mental health conditions can be part of coming to terms with diagnosis, the challenges of living with a neurological condition, or medication side-effects.

It is therefore very disappointing that we found some of the highest levels of dissatisfaction for neurology patients are in relation to support for mental health conditions. 13% (n=674) reported health services to meet the needs of a neurological condition as 'excellent', yet this figure was only 5% (n=223) for services to meet mental health needs. At the other end of the scale, 22% (n=1,059) described services to meet their mental health needs as 'no help'. Furthermore, 63% (n=3,364) of patients reported they were unsatisfied with information on sources of emotional support.



*“Bigger focus on the mental health side of things would improve my experience of the health service.”*

	Excellent	No help
<b>Health services to meet the needs of your neurological condition</b>	13%	12%
<b>Services to meet your mental health needs</b>	5%	22%

# CONCLUSIONS AND RECOMMENDATIONS

The Neurological Alliance has consistently heard the same messages about what people with neurological conditions want from their care: a timely and well communicated diagnosis, information and support throughout the process enabling them to be involved in decisions about their care, and for professionals providing care to work together.

These expectations are not unrealistic; indeed much of this is enshrined in the NHS Constitution and the NHS Five Year Forward View. This report shows that, in many cases, patient experience of care falls a long way short of these expectations.

Not only this, but since 2014, patient experience of care has got worse across all key measures. More neurology patients have to see a GP five or more times before being referred to a specialist. A greater number of patients report that the professionals providing care do not always work well together. We have also found that neurology patients are less likely than in 2014 to say that they feel involved in decisions about their care and patients are often given little information or signposting. It is unacceptable that neurology patient experience of care has declined over the last two years, especially as neurology started from a low baseline in terms of patient outcomes.

We set out below a series of recommendations – grouped into five themes – that seek to address the issues highlighted in this report. A whole system



*“Since 2014, patient experience of care has got worse across all key measures.”*

approach is needed in order to reverse this downward trend in patient experience. The Neurological Alliance is committed to working with partners from across health and care in order to ensure that by 2018 we can report a turnaround in patient experience, with all people with neurological conditions accessing the care they need and deserve.

## 1. A long term commitment to improvement

The new National Neuro Advisory Group (NNAG) is a timely and welcome development, giving a renewed national impetus for improvement. An overhaul of the whole neurology patient pathway is urgently required to ensure all patients can access the same high standard of care. NNAG’s commitment to developing a specification for Clinical Commissioning Group (CCG) commissioned neurology, along with defining condition-specific pathways, should go some way towards addressing this issue. As well as delivering outcomes for patients, addressing the fragmented patient pathways highlighted in this report, should also reduce costs for the system; for example reducing the high numbers of emergency admissions for neurological conditions. The development of

neurology outcome indicators will also help identify where improvement is most urgently needed. Below we set out a number of system-wide recommendations to ensure momentum is maintained with national improvement initiatives.

- NHS England must give a long term commitment to engaging with the NNAG as a national leadership model for neurology, to ensure the identified programmes of work have time to deliver results.
- The NNAG/Clinical Reference Group for Neurology and Neurosurgery should expedite work to develop both the specialised Neurosciences Specification, but also the new CCG neurology specification and condition specific pathways. Patients must be

# CONCLUSIONS AND RECOMMENDATIONS

fully involved in the development of these new commissioning documents.


- The NNAG should not only develop a series of outcome measures for neurology, but ensure this forms the basis for a national neurology audit. NHS England should consider adopting key neurology measures for inclusion in the national accountability and incentive frameworks in order to give further focus to improvement.

- Public Health England should make a long term commitment to funding the Neurology Intelligence Network to ensure the gaps in data are fully addressed and the data is produced in a format that is as accessible as possible to commissioners.
- NHS England should set out plans for how they will encourage CCGs and STPs to make the best use of the Right Care Neurology Focus packs.

## 2. Local engagement and prioritisation

These new national initiatives will not deliver improved outcomes for patients without the engagement of local NHS decision makers. Involving local decision makers in the development of the new commissioning guidance and specifications will be essential to ensure they are both fit for purpose and put into practice. There will also need to be a concerted effort to raise awareness of new guidance once published. We know from previous Neurological Alliance research that CCGs are largely disengaged from neurology, and early indications suggest the majority of Sustainability and Transformation Plans (STPs) make little reference to neurology.<sup>ix</sup> Below, we make recommendations specifically to local decision makers in relation to affording neurology higher priority in long and short term strategic planning.

- CCGs should collate local neurology data, including a full assessment of the costs relating to the provision of neurology services in their area, making use of data available through Right Care's Neurology Focus Packs and the data available through the Neurology Intelligence Network.
- CCGs should appoint or identify leads for neurological conditions and engage with the NNAG's programme of work to develop commissioning guidance for neurology, including national and condition specific away days that are being planned by NNAG for later in 2017.
- STP footprints should give consideration to how prioritising neurology can support local sustainability and transformation agendas such as integration, efficiency, reducing health inequalities and variation in care. STP footprints should engage fully with neurology patients and patient organisations in the development of plans.



*“Patient experience of care falls a long way short of...expectations.”*

# CONCLUSIONS AND RECOMMENDATIONS

Beyond the system-wide improvements that are urgently required for neurology, there are three issues that stand out in our research as most urgently requiring attention and specific action for change.

## 3. Addressing delays in diagnosis

As noted above, a timely and well communicated diagnosis is essential to give patients the opportunity to access the widest range of treatment options. In many cases, delayed diagnosis can lead to poorer outcomes for patients, which is why it is so critical that this issue is addressed. The new NICE Guideline for the Management of Suspected Neurological Conditions in Primary Care should go some way towards providing more clarity in relation to the early stages of the pathway and the shared-care model between primary and secondary care. This will not, however, have traction if it is launched in a vacuum where neurology is afforded little attention. Other issues need to be addressed alongside the publication of the new NICE guidance, such as lack of GP knowledge and variation in access to specialists. Below we set out recommendations to address these barriers to timely diagnosis.

- Health Education England should work with patient organisations, the Royal College of GPs and Association of British Neurologists to develop and promote training programmes and resources for GPs to support the forthcoming NICE clinical guideline for suspected neurological conditions, due for publication in 2018.
- In the short term, patient organisations should work with Health Education England and the Royal College of GPs to better promote existing resources to support GP knowledge.
- NHS England should report on how it will reduce variation in access to specialists – including specialists working in primary and community care. This should also address the issues highlighted in the Association of British Neurologists' latest Acute Neurology Survey published in March 2017.

## 4. Improving access to information, care planning and coordination of care

Another major issue highlighted by our research is the lack of information and support for patients, compounded by poorly coordinated care and often non-existent care planning. The Department of Health no longer includes a commitment to care planning within the NHS Mandate. The Government has noted that support for patients with long term conditions will instead be measured through indicators such as the NHS Outcomes Framework. It should be noted however that neurology is almost entirely unrepresented in such national and local

accountability frameworks. In terms of information and support, patient organisations produce a wealth of information to provide support for specific neurological conditions, but our research suggests that there are barriers to patients accessing such information. We make recommendations below as to how this information could be made more widely available, especially at the time of diagnosis. We also consider some broader recommendations around how care planning could be improved for patients in general and neurological patients in particular.

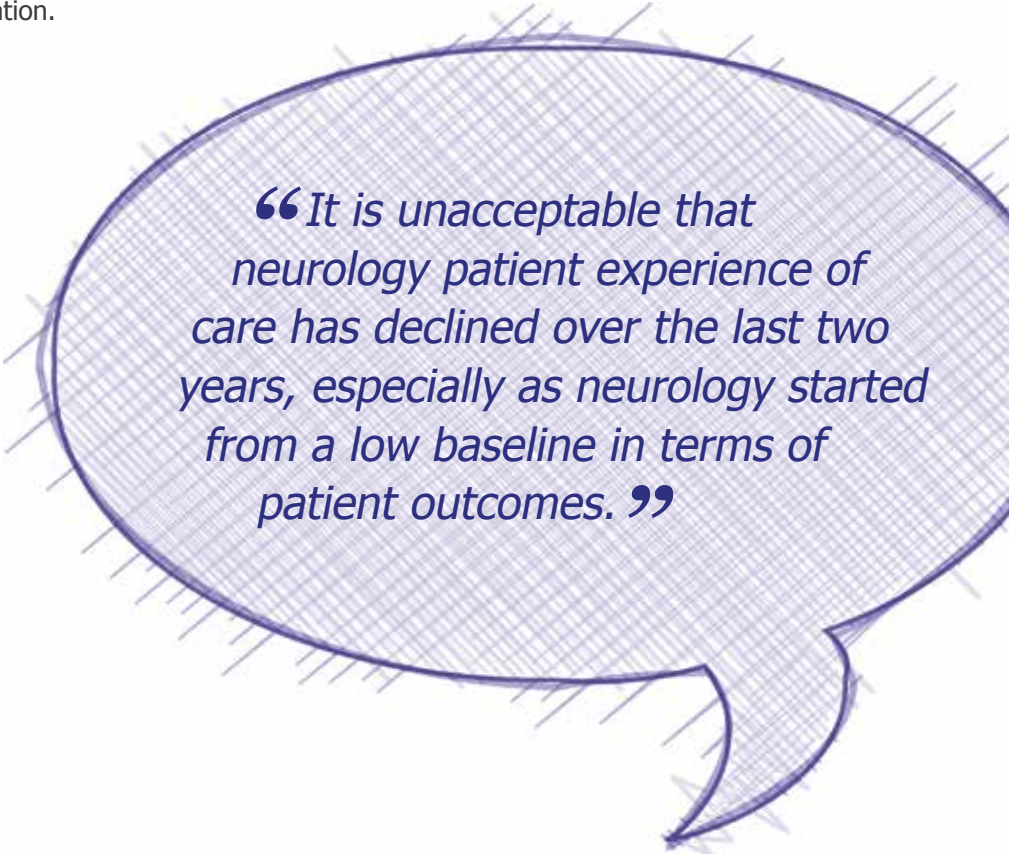
# CONCLUSIONS AND RECOMMENDATIONS

- Local NHS trusts and clinicians working in outpatient neurology clinics should work with patient groups to ensure better access to condition-specific patient information, particularly at the time of diagnosis.
- The Association of British Neurologists should work with patient organisations to ensure consultant letters regarding diagnosis include signposting to appropriate information and support.
- Clinicians working in neurology should ensure their patients are fully involved in a process of care and support planning that gives them an annual opportunity to set their goals in dialogue with their named health care professional. This should also include social prescribing which links patients to further information or community support to meet their needs.

## 5. Addressing mental health needs alongside physical health needs

Last but not least, our research suggests that the poorest experience of care is reported by patients who have mental health needs alongside their neurological condition. With such a high proportion of neurology patients having a co-morbid mental health condition, this is an area that must urgently be given further consideration. The Neurological Alliance has committed to undertaking additional research into this issue and publishing a report on mental health and neurology later this year. In the short term it is important that those planning services take into consideration the following recommendation.

- The mental health needs of neurological patients must be given particular consideration in the design and delivery of services, and it should be a local priority that everyone with a neurological condition should have access to mental health specialists if required.



*“It is unacceptable that neurology patient experience of care has declined over the last two years, especially as neurology started from a low baseline in terms of patient outcomes.”*

## REFERENCES

- i Neurological Alliance, Invisible Patients: Revealing the State of Neurology Services, 2015
- ii Department of Health, National Service Framework for Long Term Conditions, 2005
- iii Neurological Alliance, Neuro Numbers, 2014
- iv Neurological Alliance, Neurology and Primary Care: Improving the transition from primary care for people with neurological conditions, 2016
- v Public Health England, Neurology Outpatient Analysis, 2015
- vi Cochrane, Effects of personalised care planning for people with long term conditions, 2015
- vii Public Health England, Neurology Intelligence Network Neurology Service Profiles, Emergency Admissions to Hospital Relating to a Neurological Condition, 2013/14
- viii Association of British Neurologists, Acute Neurology Services Survey, 2014
- ix Neurological Alliance, Invisible Patients: Revealing the State of Neurology Services, 2015

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We also want to thank the previous members of the team – Arlene Wilkie and Alex Massey – who put so much work into getting the 2016 survey off the ground and raising awareness of it with Neurological Alliance members and the wider neurological community.

# METHODOLOGY AND DATA

The patient experience survey was hosted online using SurveyMonkey, and opened on 30 June 2016 until 30 September 2016. The final response rate was 7,048.

The neurological patient experience survey produced a wealth of data which the Neurological Alliance is committed to sharing with the neurological community, in order to support better understanding of neurology services throughout the country.

After ensuring the data we have collated is entirely anonymised, including the removal of identifiable fields from the patient experience survey, such as elements of a respondent's demographic and free text boxes, we have made the data captured during the development of this report publicly available on our website at [www.neural.org.uk](http://www.neural.org.uk). Here you can also find the full list of survey questions and a demographic breakdown of those who took part in our research.

The Neurological Alliance accepts that this sample of 7,048 is not fully representative of all neurology patients. The conditions receiving the highest responses rates are generally those represented by member organisations who supported promotion of the survey. We have taken this into consideration in our analysis, for example highlighting variations in responses across different conditions.

# FURTHER WORK

This report captures only a proportion of the findings from our patient experience survey research. The Neurological Alliance intends to continue to explore the data as part of our wider programme of work for this year and beyond. Further work will include:

- The needs of neurological patients with mental health conditions
- Prioritisation of neurology by commissioners, STPs and the wider NHS
- The impact of neurological conditions on patients
- The impact of neurological conditions on the wider economy
- Medical research into neurological conditions



## ABOUT THE NEUROLOGICAL ALLIANCE

We are the collective voice of more than 80 national and regional organisations working together to make life better for the millions of people in England with a neurological condition. We campaign for access to high quality, joined up services and information for every person diagnosed with a neurological condition, from their first symptoms, and throughout their life.

### **Contact us:**

Sarah Vibert  
Chief Executive  
[sarah.vibert@neural.org.uk](mailto:sarah.vibert@neural.org.uk)

Web: [www.neural.org.uk](http://www.neural.org.uk)  
Twitter: [@NeuroAlliance](https://twitter.com/NeuroAlliance)  
Phone: 020 7963 3996

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