



# **Neurology and primary care**

## **Improving the transition from primary care for people with neurological conditions**

**August 2016**

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## About us

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

The Neurological Alliance  
c/o Parkinson's UK  
215 Vauxhall Bridge Road  
London  
SW1V 1EJ

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

## Foreword

For many people living with neurological conditions, primary care is a crucial stage of the care pathway. It is frequently the first point of contact with the health system for people who have begun to notice that something may be wrong. As such, patients rely on primary care services to provide an accurate initial assessment and subsequently an appropriate referral to the right specialist. This enables patients to receive a diagnosis and access the correct treatment, support and advice as soon as possible.

Unfortunately, as our previous research has revealed, the transition from primary to secondary care services can be a lengthy process. A survey of just under 7,000 people carried out in 2014 found that the majority of people with neurological conditions wait over 12 months between first presenting in primary care and receiving a confirmed diagnosis. For the majority of patients, this wait involves five or more visits to a GP before receiving a referral to a specialist.

Delays of this nature are not acceptable for any patient. When patients' access to an appropriate pathway is delayed, there are significant ramifications for patient outcomes and experience throughout their care. For example, many neurological conditions are progressive in nature and early access to appropriate treatments and support can have a major impact on the speed and severity of disease progression.

This project aims to look in greater detail at the issues within primary care for people with neurological conditions, focusing on the initial assessment and referral of people presenting with possible neurological symptoms. In particular, we wanted to get the perspective of GPs themselves on this vital issue. We carried out a nationwide poll of 1,001 GPs, which we followed up with a discussion event to examine the survey findings in more detail, bringing together GPs with patient representatives and a range of other health professionals from across the system. The survey is intended to provide an indication of GPs' views and to act as a starting point for discussion of the issues.

Our findings provide the clearest case yet that there are major issues to be resolved relating to neurology in primary care. These relate both to the confidence, expertise and training of GPs themselves, as well as the availability and accessibility of local specialist services. Drawing on the views and experiences of GPs themselves, this report aims to set out a number of recommendations that would strengthen people's experience of primary care services and have a significant impact on the experience of people presenting with suspected neurological conditions.

It is essential that people with neurological conditions are able to access an effective and well-integrated pathway of care, with well-managed and timely transitions from primary to secondary care. We urge NHS England, the Department of Health and other key stakeholders identified in this report to implement our recommendations as soon as possible.

Arlene Wilkie

Chief Executive  
Neurological Alliance

## Introduction

The Neurological Alliance published [\*The Invisible Patients: Revealing the state of neurology services\*](#)<sup>1</sup> in January 2015. A landmark report within the neurological community, *The Invisible Patients* brought together the findings of the Neurological Alliance's inaugural quality of commissioning audit and neurological patient experience survey.

Detailing significant variation in the quality of the commissioning of neurological services among clinical commissioning groups (CCGs), the report also identified a number of key themes regarding patient-clinician engagement and the neurological patient pathway, including:

- The majority of respondents saw their GP five or more times before they were referred to a neurological specialist.
- The majority of respondents waited more than 12 months from first noticing their symptoms to seeing a neurological specialist.

In order to build on this work, *Neurology and primary care* aims to examine in more detail the issues affecting patients' transition from primary to secondary care. It also explores the primary care perspective on the key issues and challenges facing the neurology specialism and people living with neurological conditions today.

The research methodology for the report is set out in Annex 1. Underpinned by a national GP omnibus survey (Annex 2) and expert roundtable (page 3) the report is broadly broken down across four key themes: confidence in assessment and referral; training needs; access to services; and system architecture. Each section includes a brief overview of what we found, our key considerations and recommendations designed to drive further discussion and debate. The analysis and recommendations presented in this report focus on England only. Additional UK-wide statistics are available in Annex 3.

The results strongly suggest that there are significant issues affecting the primary care transition for people with neurological conditions. GPs do not have confidence that the people they refer with a suspected neurological condition are accessing services in a timely manner, with significant concerns around levels of access to secondary care services including neurological specialists, multidisciplinary teams (MDTs), and CT and/or MRI scans. Furthermore, our findings indicate that the significant majority of GPs feel that they may benefit from further training and support on identifying the signs and symptoms of neurological conditions and how to best manage them.

With resources becoming tighter, the system is struggling to provide the timely support needed to ensure the best possible outcomes for people living with neurological conditions. We look forward to continuing to working closely with our colleagues within the community to drive change and represent the voices of people living with neurological conditions in the future.

## Summary of survey findings

### *Confidence in diagnosis*

- **94% (n=777)** of respondents in England are either 'somewhat confident' or 'extremely confident' in making an initial assessment and referral for people presenting with the different signs and symptoms of diabetes.
- However, this falls to **81% (n=674)** for epilepsy; **73% (n=608)** for Parkinson's disease; and **47% (n=392)** for multiple sclerosis.

### *Access to services*

- **85% (n=708)** of respondents in England are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to seeing a consultant neurologist.
- **74% (n=612)** of respondents in England are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to accessing a multi-disciplinary assessment.
- **61% (n=507)** of respondents in England are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to accessing an MRI/CAT Scan.

### *System architecture*

- The majority of respondents in England (**59%, n=492**) feel that the local services and systems in place mean that people with neurological conditions frequently do not receive a timely diagnosis.
- Just over a quarter of respondents in England (**28%, n=233**) feel the local services and systems in place enable people with neurological conditions to receive a timely diagnosis.
- **13% (n=106)** of respondents in England feel that the local services or systems in place mean that people with neurological conditions often have to travel outside of their local area and beyond in order to receive a timely diagnosis.

### *Training needs*

- The overwhelming majority of respondents in England (**84%, n=701**) feel that they could benefit from further training on identifying and managing people presenting with neurological conditions.

## Summary of recommendations

1. Stakeholders across the neurological and clinical communities should locate their condition-specific messaging within the broader neurological context where appropriate.
2. In order to improve the confidence of GPs in making an initial assessment and referral for people presenting with the different signs and symptoms of neurological conditions, key neurology stakeholders, including the Association of British Neurologists, should convene to devise a pan-neurological 'watch list' of the ten signs and symptoms GPs should be aware of during patient interactions in primary care settings. This should support the National Institute for Health and Care Excellence's forthcoming clinical guideline, *Suspected neurological conditions*<sup>2</sup> expected for publication in January 2018.
3. Actively supported by Health Education England, and in partnership with universities across the country, a national neurological curriculum built around the neurological 'watch list' should be developed. This should be rolled out across medical schools, reflecting the significant impact and burden of neurological conditions across the country.
4. Utilising the agreed medical school curriculum as a benchmark, Health Education England, in partnership with the Association of British Neurologists and Royal College of General Practitioners, should work to develop and make available a practical and accessible training programme. This should work to develop and support on-the-job training of GPs across the country in regards to making an initial assessment and referral for people presenting with the different signs and symptoms of neurological conditions.
5. In order to support the spread and adoption of models of best practice within primary care, a suite of dedicated national neurology case studies should be collated by NHS England's Academic Health Science Networks and Clinical Networks across the country. These should be centrally hosted for use by local health economies and service providers, with a specific focus on the development and delivery of innovative services underpinning timely patient referral along the patient pathway and speed of diagnosis.
6. NHS England should introduce national minimum access standards and ensure the effective roll-out of commissioning for value data packs to both hold commissioners and service providers to account. This will ensure that patients are not disadvantaged from accessing neurological services due to their geographical location across the country, and enable clinicians along the neurological patient pathway to understand and transform the way care is delivered.
7. CCGs must give an appropriate level of consideration to the service pathway for people with neurological conditions, including the transition from primary to secondary care, and ensure that neurology is included in short- and long-term strategic planning, including five-year Sustainability and Transformation Plans.
8. In order to support people living with neurological conditions access those services they require in a timely manner once referred from primary care, the role of specialist nurses in freeing up the capacity and resources of neurologists, who receive such referrals, within secondary care should be locally assessed and augmented. This should be done in line with the recommendations of the Public Accounts Committee's *Services to people with neurological condition: progress review* report<sup>3</sup>, with a particular focus on their role

in managing and directing the pathway of a person living with a neurological condition and reducing variations in access to care.

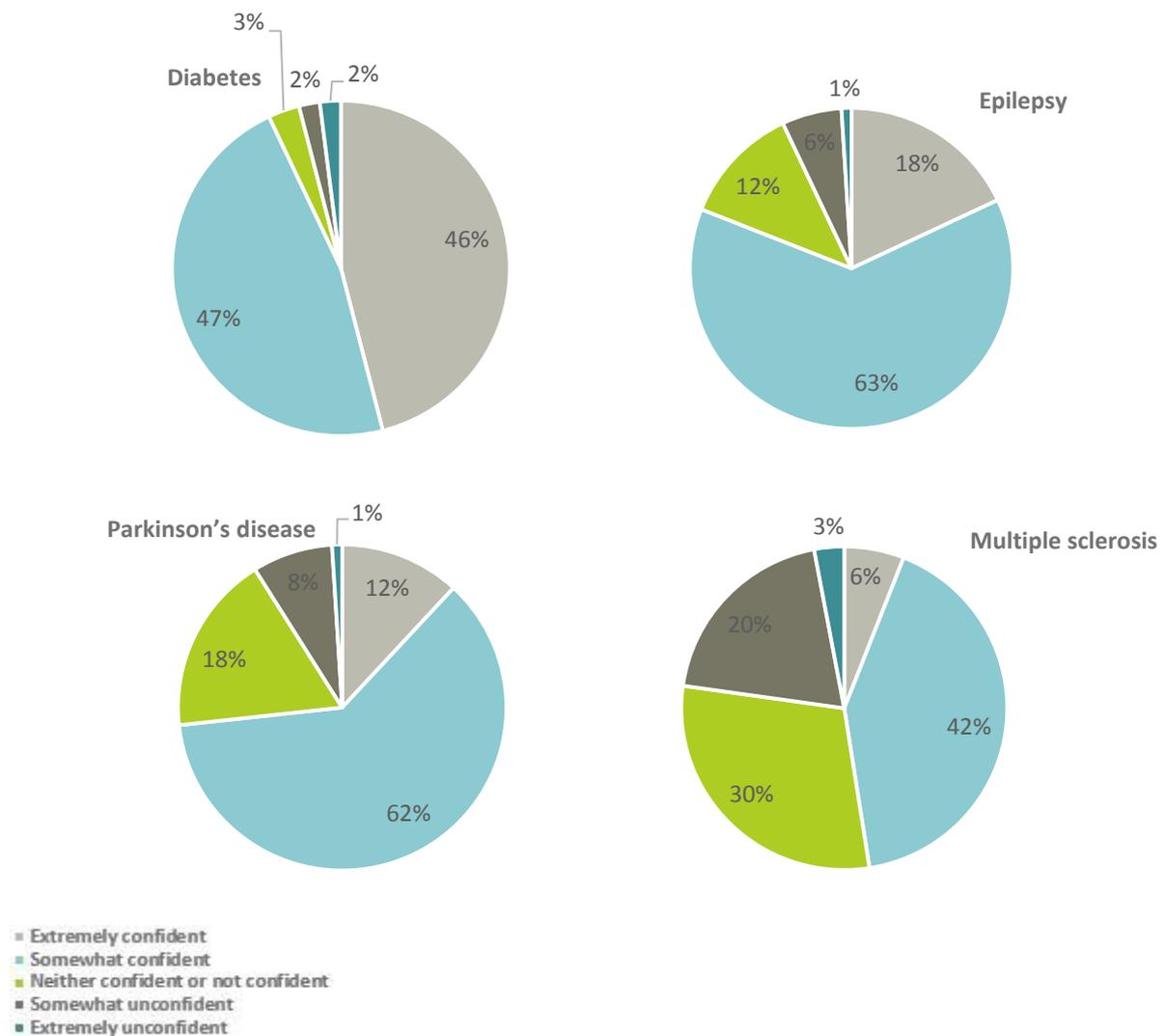
9. Funding should be ring-fenced by Public Health England and NHS England to support the Neurology Intelligence Network in collating and publishing data demonstrating the time taken to see a neurologist across different geographical regions. Data should also include the number of neurologists per region to help the targeted development of localised neurology services and ensure appropriate workforce capacity is in place.

## Confidence in diagnosis and training needs

### What we found

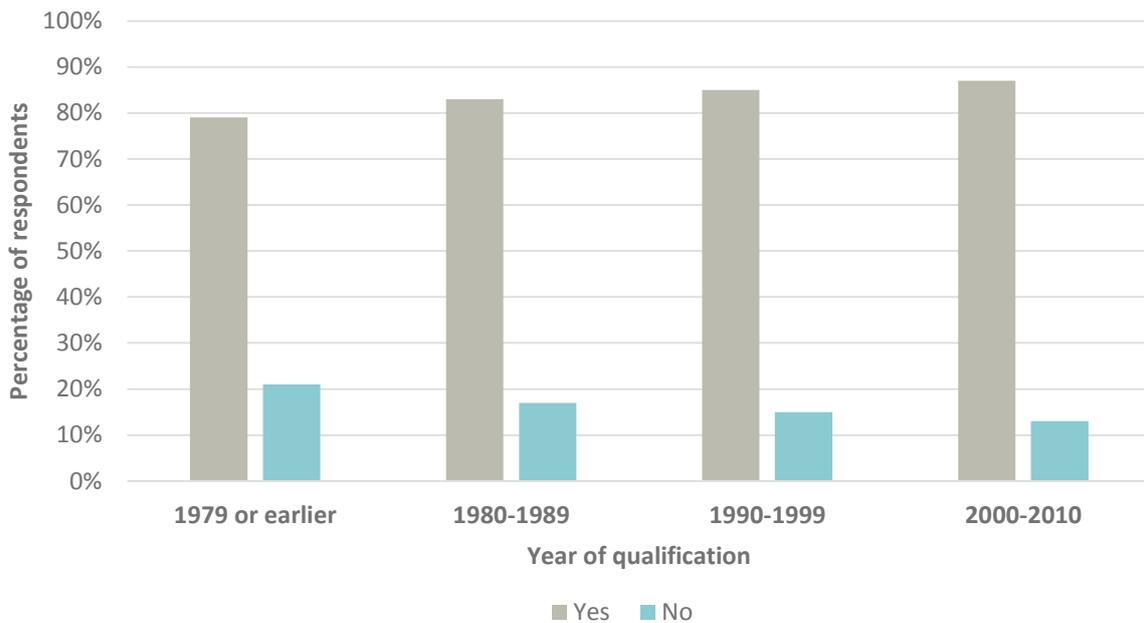
Our survey compared GPs' confidence in assessing and referring patients with diabetes, one of the most commonly-presenting long-term conditions in primary care, with three different neurological conditions (epilepsy, Parkinson's disease and multiple sclerosis). The results of our survey suggest that GPs are less confident in assessing and referring patients with neurological conditions than those with diabetes, with a further degree of correlation between the prevalence of the condition and GP confidence levels. Across England, **94% (n=777)** of respondents are either 'somewhat confident' or 'extremely confident' in making an initial assessment and referral for people presenting with the different signs and symptoms of diabetes. However, this figure falls to **81% (n=674)** for epilepsy; **73% (n=608)** for Parkinson's disease; and only **47% (n=392)** for multiple sclerosis.

***How confident are you in making an initial assessment and referral for people presenting with the different signs and symptoms of:***



It is notable that **84% (n=701)** of respondents feel that they could also benefit from further training on identifying and managing people presenting with neurological conditions. Breaking the results down by year of qualification suggests marginally higher rates of support for additional training among more recently-qualified GPs. The survey findings also show that **79% (n=63)** of responding GPs who qualified in 1979 or earlier believe they would benefit from additional training. This increases to **83% (n=183)**, **85% (n=280)** and **87% (n=322)** across 1980-1989, 1990-1999 and 2000-2010 respectively.

***I could benefit from further training on identifying and managing people presenting with neurological conditions:***



***Key considerations***

It is essential that clinicians have confidence in their ability to assess the symptoms of a patient presenting to them in a timely and accurate manner. Effective referral underpins access to the most suitable and qualified clinicians across the patient pathway, enables timely access to possible treatments or condition specific management and support, such as physiotherapy and pain management services, and contributes to both overall patient experience and individualised patient outcomes.

In comparison to the most prevalent long-term conditions such as diabetes, many neurological conditions present relatively infrequently to primary care. This underlines the need for strong sources of support and guidance to help GPs recognise the signs and symptoms of these conditions. In 2014, it was estimated that 2.8 million people in England had diabetes – a prevalence rate of 6.2%<sup>4</sup>. In the same year, the Neurological Alliance published *Neuro Numbers*<sup>5</sup> which, drawing on the latest prevalence estimations of over 40 neurological conditions, including epilepsy, Parkinson’s disease and multiple sclerosis, and working closely with members of the neurological patient community, estimated that the number of neurological cases in England alone had reached 12.5 million. This equates to approximately 59,000 per CCG. This has significant implications for local services and reinforces the need for effective guidance and support for managing patients presenting with neurological conditions.

Awareness of the scale of neurological conditions as a group is low, partly due to a lack of focus on the wider disease group as a whole. Patient and professional representatives should therefore consider how to locate their condition-specific messaging within the broader neurological context. A shift is required within the neurological community to raise and maintain clinical awareness and understanding of neurological conditions, and help support primary care upskilling and confidence in managing neurological conditions in the broadest sense. To make such a transition more manageable, an approach focussing on the four neurological categories may be helpful, looking at the broad signs and symptoms of sudden onset; intermittent; progressive; and stable with changing needs conditions, in line with the Neurological Alliance's publication *Neuro Numbers*.<sup>6</sup>

It is important to note that there is existing guidance from the National Institute for Health and Care Excellence (NICE) on the conditions referred to in the poll (epilepsy, Parkinson's disease, and multiple sclerosis). However, the current guidance focuses more strongly on the ongoing management of these conditions than on initial assessment and referral. NICE is currently developing guidance on the assessment of suspected neurological conditions in primary care, expected to be published in January 2018. Consideration will need to be given to how to ensure that guidance is translated into practice throughout the NHS, with the support of relevant professional and patient organisations.

Regarding the training needs of GPs, further evidence provided to the Neurological Alliance during the development of this report recognised the lack of consistency in the provision of training specific to understanding how to diagnose, manage and treat people living with neurological conditions. In a number of instances, neurology does not appear in the finals of some medical school curriculums or examinations. Such a lack of consistency in approach is of concern and, unless rectified with a national neurology curriculum, will undoubtedly exacerbate the postcode lottery of care received by people living with neurological conditions across the country.

In addition, the widespread support among GPs for additional training on neurological conditions suggests the need for a stronger focus on postgraduate training and ongoing professional development resources for qualified GPs. Proactively supporting GPs in on-the-job training covering the signs, symptoms, diagnosis and management of neurological conditions would help to drive improvements in patient outcomes and experience across the country.

### **Recommendations**

1. Stakeholders across the neurological and clinical communities should locate their condition-specific messaging within the broader neurological context where appropriate.
2. In order to improve the confidence of GPs in making an initial assessment and referral for people presenting with the different signs and symptoms of neurological conditions, key neurology stakeholders, including the Association of British Neurologists, should convene to devise a pan-neurological 'watch list' of the ten signs and symptoms GPs should be aware of during patient interactions in primary care settings. This should support NICE's forthcoming clinical guideline, *Suspected neurological conditions*<sup>7</sup>, expected for publication in January 2018.
3. Actively supported by Health Education England, and in partnership with universities across the country, a national neurological curriculum built around the neurological 'watch list' should be developed. This should be rolled out across medical schools,

reflecting the significant impact and burden of neurological conditions across the country.

4. Utilising the agreed medical school curriculum as a benchmark, Health Education England, in partnership with the Association of British Neurologists and Royal College of General Practitioners, should work to develop and make available a practical and accessible postgraduate training programme. This should work to develop and support on-the-job training of GPs across the country in regards to making an initial assessment and referral for people presenting with the different signs and symptoms of neurological conditions.

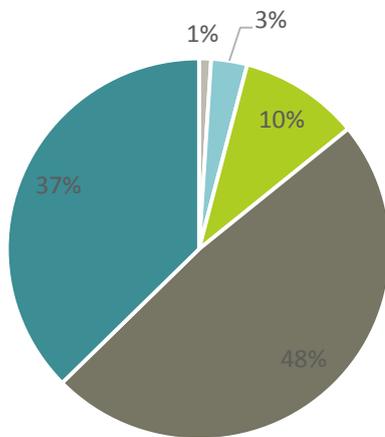
## Access to services and system architecture

### What we found

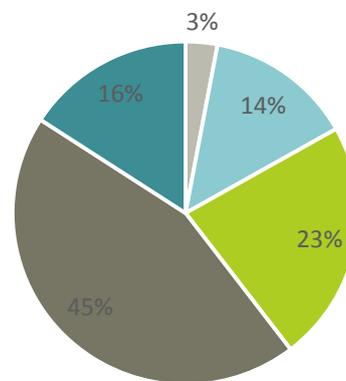
We asked GPs their view on the availability and accessibility of services for people with suspected neurological conditions in their area. **85% (n=708)** of respondents are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to seeing a consultant neurologist. This falls to **74% (n=612)** of respondents when considering delays in patients accessing a MDT and **61% (n=507)** when asked about patients accessing an MRI and/or CAT scan.

### To what extent do the following issues give you cause for concern:

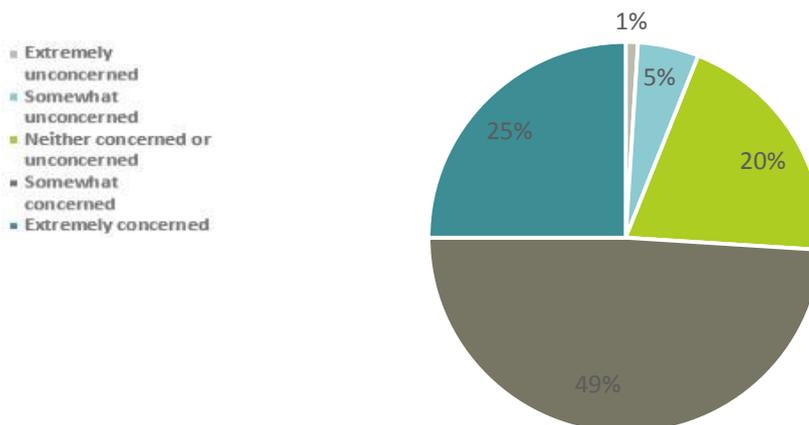
The time taken from referral of a patient to see a consultant neurologist



The time taken from referral of a patient to access an MRI/CAT Scan



The time taken from referral of a patient to access a multi-disciplinary assessment

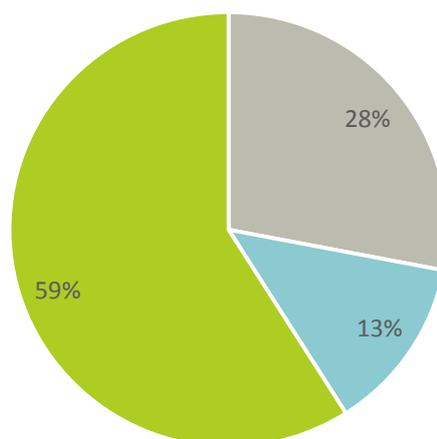


Looking across the UK as a whole, there also appears to be a correlation between the degree of concern GPs have in their patients accessing services in a timely manner and the number of patients on their practice list.

Statement	Number of patients on practice list				
	1-2,500	2,501-5,000	5,001-7,500	7,501-10,000	10,001+
Percentage of respondents either 'somewhat' or 'extremely' concerned by the time taken to see a consultant neurologist	64%	88%	88%	86%	86%
Percentage of respondents either 'somewhat' or 'extremely' concerned by the time taken to access a multi-disciplinary assessment	50%	78%	76%	73%	75%
Percentage of respondents either 'somewhat' or 'extremely' concerned by the time taken to access an MRI/CAT Scan	53%	65%	66%	62%	65%

The majority of respondents, **59% (n=492)**, feel that the services and systems currently in place in their area mean that people with neurological conditions frequently do not receive a timely diagnosis. This compares to just over a quarter of respondents, **28% (n=233)**, who feel the services and systems in place do in fact enable people with neurological conditions to receive a timely diagnosis. Finally, **13% (n=106)** of respondents feel that the services or systems in place mean that people with neurological conditions often have to travel outside of their local area and beyond in order to receive a timely diagnosis.

***The services and systems in place from my CCG and nearest trust(s) mean that people with neurological conditions:***



- ...receive a timely diagnosis
- ...often have to travel outside the area of their CCG and beyond the nearest trust to receive a timely diagnosis
- ...frequently do not receive a timely diagnosis

## *Key considerations*

The majority of GPs noting significant misgivings regarding access to both diagnostic and condition management services is of real concern. Without being able to access such services in a timely manner, patients run the risk of having their diagnosis delayed, access to subsequent management and treatment regimes stalled, and their quality of life and outcomes negatively impacted. Primary care services must be supported by effective and accessible secondary and community services as part of a cohesive pathway of care.

It should be noted that sometimes a longer wait in primary care will reflect an appropriate need for some ongoing monitoring and assessment of symptoms at that level.<sup>8</sup> However, the polling evidence suggests significant concern among GPs about unnecessary waits, with almost three-fifths of respondents noting that the current levels of access mean that people with neurological conditions do not receive a timely diagnosis. There are a number of considerations and steps that could be taken forward to support the system. Specialist nurses in particular may have a key role to play in supporting symptom management, freeing up the time and resources of neurologists who are subsequently able to take on primary care referrals. Such a model currently exists in Oxford,<sup>9</sup> whereby individuals arriving at Accident and Emergency can see a nurse specialist who subsequently identifies the most appropriate care pathway for them.

In addition, CCGs must ensure that they give sufficient attention to the quality and accessibility of the health and care pathway for their neurological patient populations. Research previously carried out by the Neurological Alliance found evidence of significant disengagement from neurology services between CCGs: responding to Freedom of Information requests, only 15% of CCGs could state how much they spent on neurology services, while only 20% had made an assessment of the number of people using neurology services in their area.<sup>10</sup> This must change. CCGs must take an active approach to developing an effective commissioning model that will ensure access to specialist neurology services for all those who require them. The five-year Sustainability and Transformation Plans currently being developed at sub-regional levels provide an opportunity for much-needed long-term planning for neurology services.<sup>11</sup> In addition, national access standards should be considered, with clear guidelines detailing waiting times and processes for referring people suspected to have a neurological condition from primary care.

## *Recommendations*

1. In order to support the spread and adoption of models of best practice within primary care, a suite of dedicated national neurology case studies should be collated by NHS England's Academic Health Science Networks and Clinical Networks across the country. These should be centrally hosted for use by local health economies and service providers, with a specific focus on the development and delivery of innovative services underpinning timely patient referral along the patient pathway and speed of diagnosis.
2. NHS England should introduce national minimum access standards and ensure the effective roll-out of commissioning for value data packs to both hold commissioners and service providers to account. This will ensure that patients are not disadvantaged from accessing neurological services due to their geographical location across the country, and enable clinicians along the neurological patient pathway to understand and transform the way care is delivered.

3. CCGs must give an appropriate level of consideration to the service pathway for people with neurological conditions, including the transition from primary to secondary care, and ensure that neurology is included in short- and long-term strategic planning, including five-year Sustainability and Transformation Plans.
4. In order to support people living with neurological conditions access those services they require in a timely manner once referred from primary care, the role of specialist nurses in freeing up the capacity and resources of neurologists, who receive such referrals, within secondary care should be locally assessed and augmented. This should be done in line with the recommendations of the Public Accounts Committee's *Services to people with neurological condition: progress review* report<sup>12</sup>, with a particular focus on their role in managing and directing the pathway of a person living with a neurological condition and reducing variations in access to care.
5. Funding should be ring-fenced by Public Health England and NHS England to support the Neurology Intelligence Network in collating and publishing data demonstrating the time taken to see a neurologist across different geographical regions. Data should also include the number of neurologists per region to help the targeted development of localised neurology services and ensure appropriate workforce capacity is in place.

## Concluding remarks

The findings of our survey of GPs suggest that there are a number of issues affecting the transition from primary to secondary care services for people with neurological conditions. Delays in diagnosis and referral have a clear impact on patients' ability to access the most appropriate clinical support and management services as well as other appropriate treatment options. It is therefore essential that primary and secondary care services work effectively together to provide an integrated pathway of care in a timely manner.

Primary care services face significant pressures as a result of growing demand and financial constraints.<sup>13</sup> However, with the number of neurological cases reaching 12.5 million in 2014, as one of the first points of contact patients have with the health care system, GPs must have sufficient confidence to provide an assessment and appropriate referral for people presenting with neurological symptoms. This requires the provision of effective guidance and training opportunities to ensure that GPs are fully supported to manage these patients effectively.

Indeed, with NHS England's *Five Year Forward View*<sup>14</sup> outlining a 'new deal for primary care', reaffirming its role as the foundation of the NHS and giving primary care a leading role in the design and delivery of clinical services across the country, primary care needs to be provided with the necessary resource and support to be able to deliver their functions effectively.

At the same time, primary care services rely on the existence of accessible and effective secondary and community care services in the local area. Our survey data clearly show that many primary care practitioners do not feel confident that their local health systems are capable of providing timely access to these services for people with neurological conditions. The fact that almost 60% of GPs do not believe that the local services and systems are in place locally to provide a timely diagnosis is a cause for real concern, and should be a wake-up call to local commissioners.

As it stands, people presenting with neurological conditions too often do not experience an effective and timely transition from primary to secondary care. Neurological conditions are not given fair attention and consideration by local commissioners and the result is a fragmented pathway of care with highly variable access to services across the country, often characterised by excessive delays. Ultimately, it is the people living with neurological conditions who bear the brunt of these failings. A step-change in approach simply has to happen, otherwise it will be the patients who feel the consequences.

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- <sup>11</sup> NHS England Sustainability and Transformation Plans. Available at <https://www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/stp/>
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## Annex 1: Methodology

The purpose of this report is to provide insight into the challenges facing primary care in the diagnosis, management and treatment of people presenting and diagnosed with neurological conditions across England, and what support mechanisms and structures could be put in place to support improvements in patient experience and outcomes.

### *GP omnibus survey and value of specialism workshop*

In order to underpin the report, the Neurological Alliance commissioned the market research organisation MedeConnect in November 2015 to run a four question GP omnibus survey exploring the challenges and opportunities for neurological specialism in primary care. GP omnibus surveys are monthly online questionnaires gauging GP opinion in a controlled environment, guaranteeing a sample of 1,001 regionally representative GPs from across the UK. Details of the individual survey questions can be found in Annex 2, with a summary of the survey responses found in **Annex 3**.

The conditions used as part of the survey – diabetes, epilepsy, Parkinson’s disease and multiple sclerosis – were selected to illustrate variation in primary care awareness and understanding among conditions of varying prevalence. Please note the findings within this report refer to England only, unless explicitly stated otherwise. The total sample size (n) for England is 831.

Further supporting the development process, the Neurological Alliance convened a *Value of specialism* workshop, held in December 2015. The workshop offered the opportunity to discuss and debate the survey’s results and for the Neurological Alliance to gain additional expert insight and opinion, ultimately feeding into this report. A full list of attendees can be found on page 3.

## Data

The GP omnibus 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.

The data is entirely anonymised and can be found on our website, at [www.neural.org.uk](http://www.neural.org.uk).

We fully support and encourage our members and colleagues within the community to use the data as they see appropriate.

## Annex 2: GP omnibus survey questions

**1. To what extent do you agree with the following statements?** *Please select one level of confidence for each statement.*

	Extremely confident	Somewhat confident	Neither confident or not confident	Somewhat unconfident	Extremely unconfident
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of diabetes					
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of epilepsy					
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of Parkinson's disease					
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of multiple sclerosis					

**2. To what extent do the following issues give you cause for concern?** *Please select one level of concern for each issue.*

	Extremely unconcerned	Somewhat unconcerned	Neither concerned or unconcerned	Somewhat concerned	Extremely concerned
The time taken from referral of a patient to see a consultant neurologist					
The time taken from referral of a patient to access a multi-disciplinary assessment					
The time taken from referral of a patient to access an MRI/CAT Scan					

**3. Which of the following statements do you consider to be the most accurate?**

*Please select one option.*

- The services and systems in place from my CCG/health board and nearest trust(s) mean that people with neurological conditions receive a timely diagnosis.
- The services and systems in place from my CCG/health board and nearest trust(s) mean that people with neurological conditions often have to travel outside the area of their CCG and beyond the nearest trust to receive a timely diagnosis.
- The services and systems in place from my CCG/health board and nearest trust(s) mean that people with neurological conditions frequently do not receive a timely diagnosis.

**4. Could you benefit from further training on identifying and managing people presenting with neurological conditions?** *Please select one option.*

- Yes
- No

**Additional demographic questions**

**1. Whereabouts are you currently practicing?**

- NHS London
  - London
- NHS South of England
  - South East Coastal
  - South Central
  - South West
- NHS Midlands and East SHA
  - West Midlands
  - East Midlands
  - East of England
- NHS North of England
  - Yorkshire & Humber
  - North East
  - North West
- Scotland
- Wales
- Northern Ireland
- Retired
- Not practicing in the UK

**2. Which of the following best describes your role?**

- GP Principal
- Salaried GP
- GP Registrar
- Locum GP
- Other

**3. Are you...**

- Male
- Female

**4. When did you qualify as a doctor?**

**5. Are you ...**

- Under 30
- 30 – 39
- 40 – 49
- 50 – 59
- 60 or over

**6. What level of involvement do you have in the governing body of your CCG?**

- I am, or plan to be, an active member of my CCG governing board
- I am, or plan to be, a GP representative
- I do not take an active part in my CCG

**7. Please write in the number of GPs working in this practice (including yourself)**

**8. Is your practice based in a...**

- Rural area
- Urban area
- Semi-rural area
- Suburban area
- Other

**9. Is your practice a dispensing practice?**

- Yes
- No

## Annex 3: GP omnibus survey results

### Confidence in diagnosis

**Q1. To what extent do you agree with the following statements?** *Please select one level of confidence for each statement.*

	Extremely confident	Somewhat confident	Neither confident or not confident	Somewhat unconfident	Extremely unconfident
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of diabetes	46%	47%	3%	2%	2%
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of epilepsy	18%	63%	12%	6%	1%
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of Parkinson's disease	12%	62%	18%	8%	1%
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of multiple sclerosis	6%	42%	30%	20%	3%

Results shown representative of England only

- **93%** of respondents in England are either 'somewhat confident' or 'extremely confident' in making an initial assessment and referral for people presenting with the different signs and symptoms of diabetes.
- However, this falls to **81%** for epilepsy; **74%** for Parkinson's disease; and **48%** for multiple sclerosis.

### Additional UK analysis

- Across the UK, there does not appear to be a correlation between the number of patients on a GP's practice list and how confident they are in making an initial assessment and referral for people presenting with diabetes, epilepsy, Parkinson's disease or multiple sclerosis.
- Across the UK, there does not appear to be a correlation between a practice's location (rural, urban, semi-rural or suburban) and a GP's confidence in making an initial assessment and referral for people presenting with diabetes, epilepsy, Parkinson's disease or multiple sclerosis.

- GPs in Northern Ireland are more likely to be either 'somewhat confident' or 'extremely confident' in making an initial assessment and referral for people presenting with the different signs and symptoms of epilepsy, Parkinson's disease and multiple sclerosis than those in Scotland, Wales or England.

	<b>Either 'extremely confident' or 'somewhat confident'</b>			
	<b>England</b>	<b>Scotland</b>	<b>Wales</b>	<b>NI</b>
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of diabetes	94%	95%	94%	100%
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of epilepsy	81%	81%	82%	93%
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of Parkinson's disease	73%	81%	73%	86%
I am confident in making an initial assessment and referral for people presenting with the different signs and symptoms of multiple sclerosis	47%	54%	51%	57%

### ***Access to services***

**Q2. To what extent do the following issues give you cause for concern? Please select one level of concern for each issue.**

	Extremely unconcerned	Somewhat unconcerned	Neither concerned or unconcerned	Somewhat concerned	Extremely concerned
The time taken from referral of a patient to see a consultant neurologist	1%	3%	10%	48%	37%
The time taken from referral of a patient to access a multi-disciplinary assessment	1%	5%	20%	49%	25%
The time taken from referral of a patient to access an MRI/CAT Scan	3%	14%	23%	45%	16%

Results shown representative of England only

### *Consultant neurologist*

- **85%** of respondents in England are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to seeing a consultant neurologist.
- **93%** of respondents from the North East are either 'somewhat concerned' or 'extremely concerned' by the amount of time taken from referral of a patient to seeing a consultant neurologist.

### *Multi-disciplinary assessment*

- **74%** of respondents in England are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to accessing a multi-disciplinary assessment.
- **80%** of respondents from Yorkshire and Humber are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to accessing a multi-disciplinary assessment.

### *MRI/CAT Scan*

- **61%** of respondents in England are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to accessing an MRI/CAT Scan.
- **83%** of respondents from the South Central region are either 'somewhat concerned' or 'extremely concerned' about the time taken from referral of a patient to accessing an MRI/CAT Scan.

### Additional UK-analysis

- Across the UK, there appears to be a correlation between the degree of concern GPs have in their patient's accessing services in a timely manner and the number of patients on their practice list.

Statement	Number of patients on practice list				
	1-2,500	2,501-5,000	5,001-7,500	7,501-10,000	10,001+
Percentage of respondents either 'somewhat' or 'extremely' concerned by the time taken to see a consultant neurologist	64%	88%	88%	86%	86%
Percentage of respondents either 'somewhat' or 'extremely' concerned by the time taken to access a multi-disciplinary assessment	50%	78%	76%	73%	75%
Percentage of respondents either 'somewhat' or 'extremely' concerned by the time taken to access an MRI/CAT Scan	53%	65%	66%	62%	65%

Results shown representative of UK

### System architecture

#### Q3. Which of the following statements do you consider to be the most accurate?

Please select one option.

Statement	Percentage respondents
The services and systems in place from my CCG/health board and nearest trust(s) mean that people with neurological conditions receive a timely diagnosis	28%
The services and systems in place from my CCG/health board and nearest trust(s) mean that people with neurological conditions often have to travel outside the area of their CCG and beyond the nearest trust to receive a timely diagnosis	13%
The services and systems in place from my CCG/health board and nearest trust(s) mean that people with neurological conditions frequently do not receive a timely diagnosis	59%

Results shown representative of England only

- The majority of respondents in England (**59%**) feel that the local services and systems in place mean that people with neurological conditions frequently do not receive a timely diagnosis.
- **79%** of respondents from Yorkshire and Humber feel that the local services and systems in place mean that people with neurological conditions frequently do not receive a timely diagnosis.

- Just over a quarter of respondents in England (**28%**) feel the local services and systems in place enable people with neurological conditions to receive a timely diagnosis.
- **35%** of respondents from London and the East of England feel that the local services and systems in place mean that people with neurological conditions receive a timely diagnosis.
- **13%** of respondents in England feel that the local services or systems in place mean that people with neurological conditions often have to travel outside of their local area and beyond in order to receive a timely diagnosis.
- **24%** of respondents from the North East feel that the local services or systems in place mean that people with neurological conditions often have to travel outside of their local area and beyond in order to receive a timely diagnosis.

#### *Additional UK-analysis*

- Across the UK, there appears to be a correlation between the practice location and the respondents' concerns that people with neurological conditions often have to travel outside the area of their CCG/health board and beyond the nearest trust to receive a timely diagnosis:
  - Rural: **23%**
  - Urban: **10%**
  - Semi-rural: **15%**
  - Suburban: **11%**

#### *Training needs*

**Q4. Could you benefit from further training on identifying and managing people presenting with neurological conditions?** *Please select one option.*

Statement	Percentage respondents
Yes	84%
No	16%

Results shown representative of England only

- The overwhelming majority of respondents in England (**84%**) feel that they could benefit from further training on identifying and managing people presenting with neurological conditions.
- **92%** of respondents from the West Midlands feel that they could benefit from further training on identifying and managing people presenting with neurological conditions.

*Additional UK-analysis*

- Across the UK as a whole, those respondents most recently qualified feel they could benefit the most from further training on identifying and managing people presenting with neurological conditions.

<b>Statement</b>	<b>Year of qualification</b>			
	<b>1979 or earlier</b>	<b>1980-1989</b>	<b>1990-1999</b>	<b>2000-2010</b>
Yes	79%	83%	85%	87%
No	21%	17%	15%	13%

Results shown representative of UK