



Not NICE Enough

A qualitative study of MND, MS and Parkinsons Pathways in accordance with the National Institute of Health and Care Excellence (NICE) Guidance

March 2017

Healthwatch Staffordshire

INTRODUCTION

In the summer of 2016, a joint venture between Healthwatch Staffordshire, Healthwatch Stoke-on-Trent and the Staffordshire Neurological Alliance resulted in a largescale Neurological Survey, conducted across Staffordshire and Stoke on Trent. An initial survey was carried out with the aim to understand the broad experiences of patients with neurological conditions, to identify any gaps in the services and key areas to be looked at for further research.

The survey identified some large gaps in services, particularly amongst people with MS, MND and Parkinsons. It concluded that a more in depth qualitative study should be carried out with a more focused sample in order to capture the stories of people and their experience of these conditions since first experiencing symptoms.

The aim of Phase 2 of this research was to map the in-depth experience of people with MS, MND and Parkinson's against the NICE guidelines to identify gaps and barriers in the pathways, through stories gathered from participants across Staffordshire and Stoke-on-Trent. This phase of the research therefore, hopes to provide a much clearer picture of the quality of care received by people living with the three conditions. We hope to provide insights and recommendations to services to ensure that people with these neurological conditions are able to lead a good quality of life and begin planning our approach to support improvement of some of the issues raised. As part of this process, for the next phase we plan to explore current tools to improve the diagnosis part of the pathway and providing robust evidence of their effectiveness.

BACKGROUND

In a national study, the prevalence of neurological conditions was reported to be 1/100,000 in the UK (Hoppitt, 2011). According to the National Council of Palliative Care, there are 120,000 people living with Parkinson's disease, 100,000 with Multiple Sclerosis and 5,000 with Motor Neurone Disease in the UK (The National Council for Palliative Care, 2015). These three conditions are also in the top 5 most common neurological conditions within the UK. According to the results of Phase 1 of this project, these three conditions are also the most commonly reported conditions in Staffordshire.

Parkinson's disease (PD)

Known as one of the most common neurological conditions, Parkinson's is a progressive neurodegenerative disease (Foltnie, Brayne, Robbins, & Barker, 2004). Symptoms of Parkinson's include motor difficulties (Khoo et al., 2013), involuntary movement or shaking of particular parts of the body known as tremors, stiff muscles and slow movement (bradykinesia) (Foltnie, Brayne, Robbins, & Barker, 2004; NHS Choices, 2016a)

Parkinson's occurs in people who have a reduced level of the chemical dopamine in their brain, due to the death of some nerve cells. Without the dopamine, movement and motor function becomes compromised, causing movements in individuals to slow down (Parkinson's UK). As the condition progresses, these symptoms

can progressively get worse, making it very difficult for people affected with Parkinson's to carry out their daily tasks with help (NHS Choices, 2016a).

It is estimated that 1 in every 500 people are diagnosed with Parkinson's, which is around 127,000 people in the UK (Parkinson's UK; NHS Choices, 2016a). Development of symptoms generally occur over the age of 50, although approximately 1 in 20 people who have the disease, develop these before they are 40. There is currently no cure for this disease although treatment is available to help to combat these symptoms and enable people affected with Parkinson's disease to maintain a good quality of life.

Some of these treatments include physiotherapy and occupational therapy, medication and sometimes, brain surgery. Treatment may not be necessary in the early stages of the disease when the symptoms are milder and more infrequent, although regular monitoring of the condition by a specialist is advised (NHS Choices, 2016a)

Multiple Sclerosis (MS)

Multiple Sclerosis (MS) affects the central nervous system (MS Society, 2014), causing wide ranging issues such as blurred vision, problems with movement, fatigue etc. (NHS, 2016b). MS affects the brain and/or spinal cord, and can reduce life expectancy of those affected by it (NHS, 2016b).

MS occurs when the coating of nerves, known as myelin becomes damaged, causing disruptions in the signals that travel through these nerve fibres. This can either slow down, distort or not send the signals at all, therefore affecting different parts of one's body (MS Society, 2014). While the reason behind why this happens is relatively unknown, it is hypothesized that genetics makes certain individuals more susceptible to environmental triggers that may cause the disease (Multiple Sclerosis Trust, 2014).

It's estimated that there are more than 100,000 people diagnosed with MS in the UK (NHS, 2016b). In the UK, MS is more common in Scotland (BBC News, 2013). It is more commonly diagnosed in people in their 20s and 30s (NHS, 2016b). It is also more common in women than in men; in 2010, 72% of people living with MS were women (BBC News, 2013). Like Parkinson's, MS has no cure currently but there are multiple methods available to manage symptoms and deal with relapses that occur.

While there is no cure, treatments such as disease modifying therapies, complementary therapies, drug therapy as well as diet and nutrition, (MS-UK) are typically offered to help relieve symptoms of MS and reduce relapses.

Motor Neurone Disease (MND)

Motor neurone disease (MND), also known as amyotrophic lateral sclerosis (ALS), is a neurodegenerative, progressive disorder (Leigh, & Ray-Chaudhuri, 1994; NHS Choices, 2015; Talbot, 2002) which causes weakness in muscular function, due to

dysfunctions in the brain and spinal cord. This condition is fairly rare (Brain and Spine Foundation, 2013), and can eventually affect the ability to walk, talk, swallow and breathe (MND Association). It can lead to premature death, due to ventilator or respiratory failure (Talbot, 2002)

The reasons behind why MND occurs is unknown, although some clarity around genetic inheritance has been identified in patients with familial ALS. It has been hypothesised the genetic inheritance alongside a predisposed vulnerability to environmental stressors that contribute to the development of the disease (Talbot, 2002). In 5% of patients with MND, there is normally a family history of MND or the related frontotemporal dementia (NHS Choice, 2015).

According to the MND association, the disease kills one third of people within a year of their diagnosis and majority die within 5 years of the onset of symptoms (Brain and Spine Foundation, 2013). In the UK, it is approximated that it affects 5000 people at any point, with 6 people diagnosed everyday with the condition (MND Association). It is more common in men than in women, and is most common in those aged between 50 to 70 years (Brain and Spine Foundation, 2013). There is no specific test to identify MND, it is mainly a diagnosis of exclusion (NHS Choices, 2015). Similar to MS, MND has no cure but has treatments available that will slow down symptoms. Drug treatments, complementary therapies, clinical trials are typically offered to help maintain quality of life.

Within the UK, the NICE pathways provide recommendations to clinicians and medical staff to provide the best quality of care to patients with these conditions, alongside many others. The NICE guidelines are evidence-based recommendations that provide a pathway for the management of the condition. This can include prevention, broader social or psychological services and interventions for patients. This also includes the promotion of integrated care when possible (NICE). This project intends to map the experiences of people with these conditions against the recommendations of the NICE pathways, to identify if there are any gaps or barriers to the quality of care they receive.

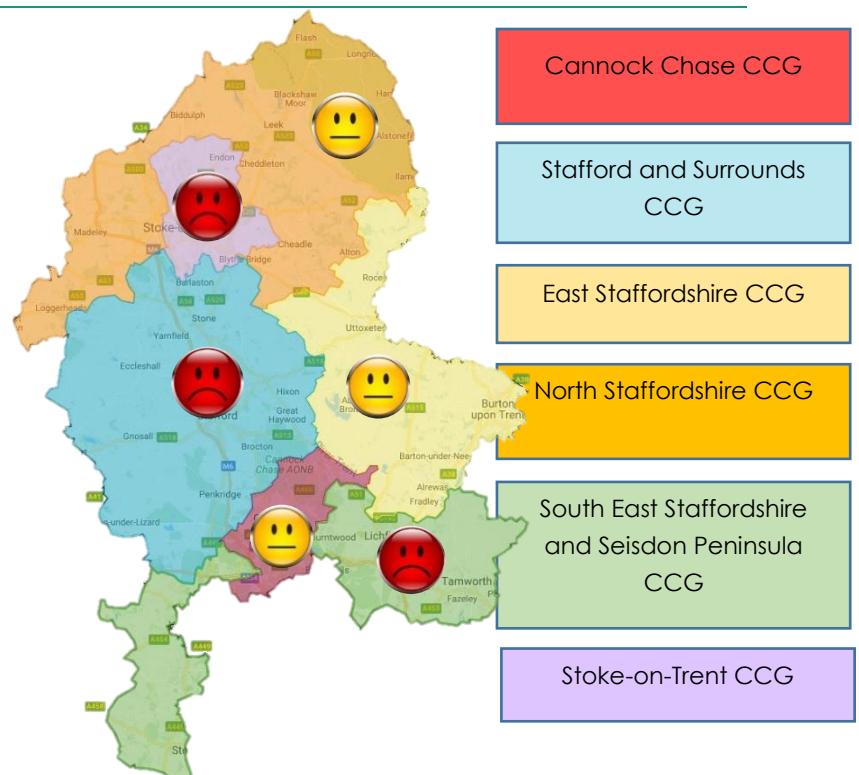
METHODOLOGY

This qualitative study used a deductive methodology that utilised NICE Guidance to explore the experiences of people with Multiple Sclerosis, Motor Neurone Disease and Parkinsons disease across Staffordshire. To do this, we utilised the Healthwatch network to identify a range of key partners that would enable us to access participants to take part in a semi-structured interview (see appendix 1). The interview was designed to explore the pathway for each condition as set out in NICE Guidelines and the sentiment of feedback from participants. The overall objective of the study was to identify gaps, inconsistencies and best practice in the care and treatment of MS, MND and Parkinsons across each CCG area in Staffordshire. The aim was to be able to specify where the pathways were failing and identify what areas needed improvement to develop a more effective model of care that was affordable within the current health and care economy.

A total of 52 participants were interviewed for this research across the 6 CCG areas; with 24 participants with MS, 19 participants with Parkinson's and 9 participants with MND.

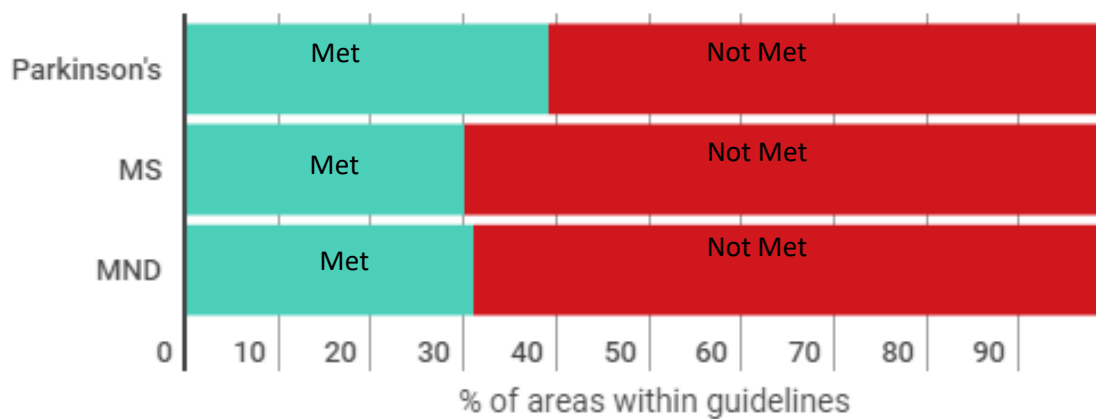
THE STAFFORDSHIRE PICTURE

These overview results show how each CCG area compared with regards to overall MS, MND and Parkinson's care and treatment. It is to be noted that due to the nature of these conditions, it was not possible to interview the same number of participants across the county. Therefore, not all CCG areas are represented for all three conditions and no samples are representative statistically.



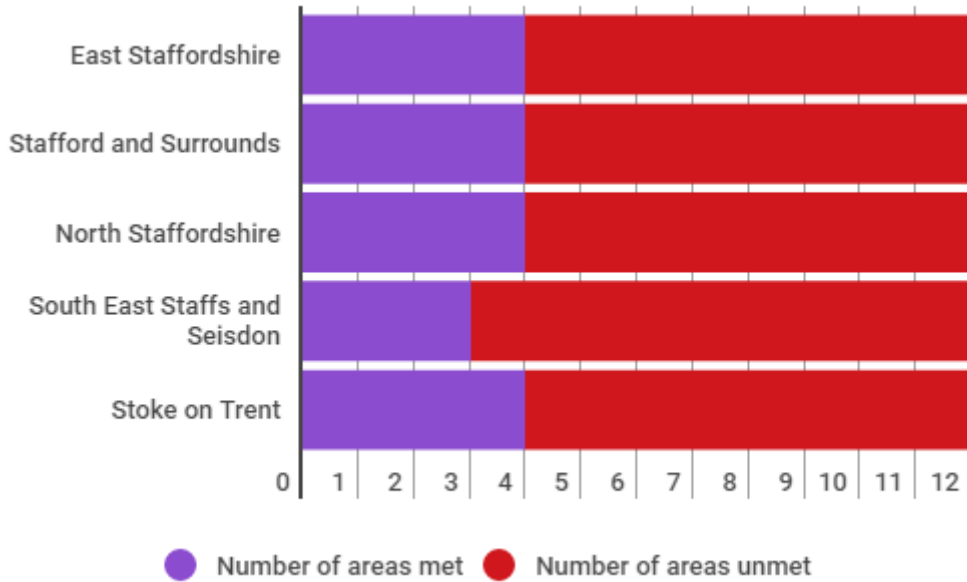
Each condition also has different pathway recommendations (e.g. diagnosis, referral to experts etc.) made by NICE. Parkinson's and MS both have 7 areas of care while MND has 12 areas of care within their pathways. According to the recommendations, each area of care have to be met to the level recommended by the NICE guidelines, so that people with these conditions are able to have high quality, effective and supportive care.

The results below show how many areas within the pathway for each condition that all (100%) of participants felt that their care was provided in line with the NICE Guidelines.

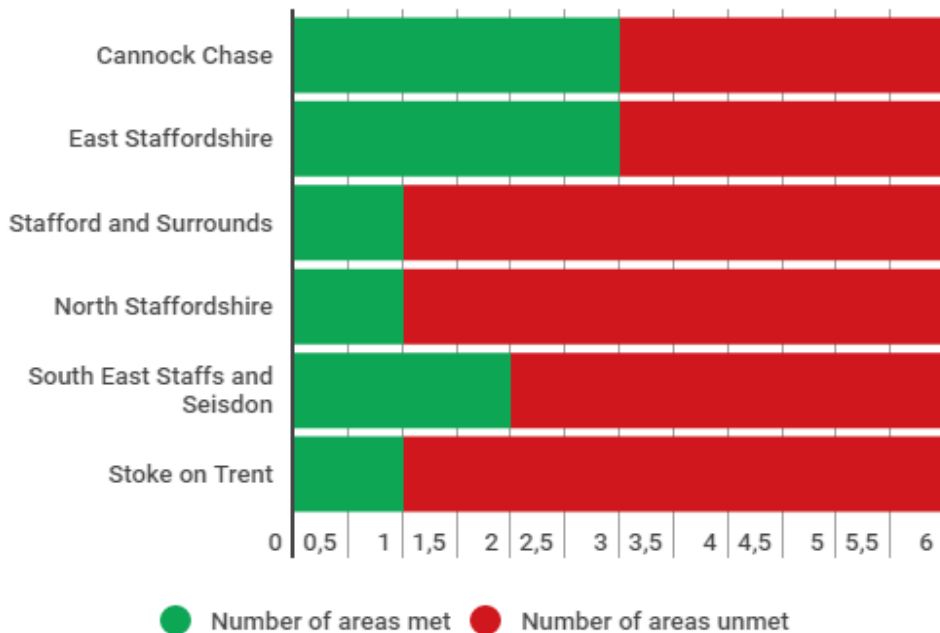


Division by CCG area demonstrated that for MND, the South-East Staffordshire area had a lower number of areas met as compared to other CCG areas. Stafford and Surrounds, North Staffordshire and Stoke-on-Trent CCG areas had a lower number of areas met for MS and Stafford and Surrounds CCG had a lower number of areas met for the Parkinson's NICE guidance areas as compared to other CCG areas.

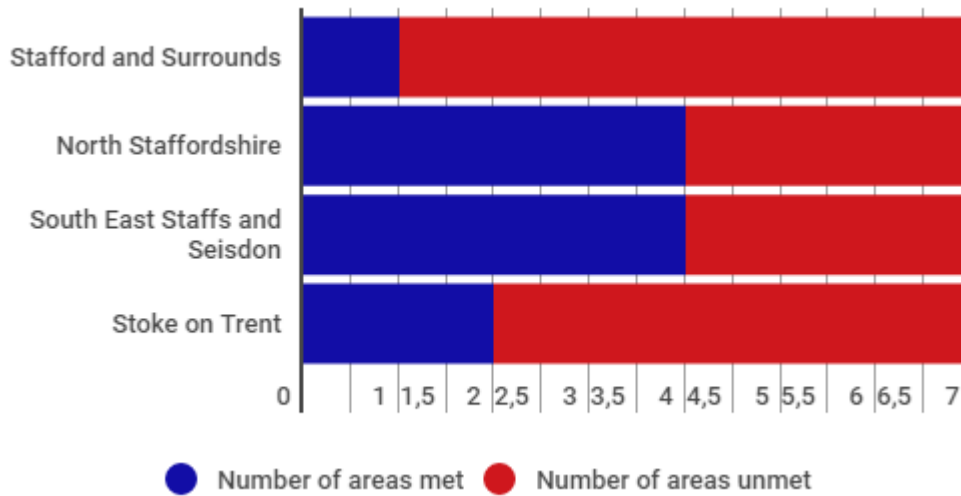
MND (12 areas of the guidelines to meet)



MS (6 areas of the guidelines to meet)



Parkinson's (7 areas of the guidelines to meet)



PARKINSON'S

Known as one of the most common neurological conditions, Parkinson's is a progressive neurodegenerative disease. Symptoms of Parkinson's include motor difficulties, involuntary movement or shaking of particular parts of the body known as tremors, stiff muscles and slow movement (bradykinesia).

In Staffordshire, Parkinson's care is overall quite positive, with the majority of participants agreeing that their care was of high quality and met within the recommended time stated in the NICE guidelines. North Staffordshire is reported by all respondents as having the best care when compared to other CCG areas.



All participants were offered care that was high quality and within the recommended time



Most participants (>50%) were offered care that was high quality and within the recommended time







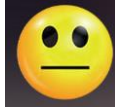

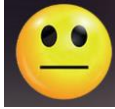






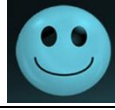



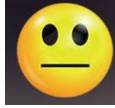








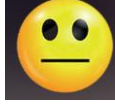
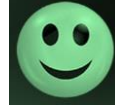


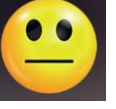
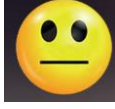
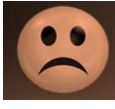

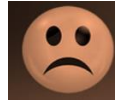
Participants were divided as to whether care offered was of high quality and within the recommended time



Only some (<50%) were offered care that was high quality and within the recommended time



None of the participants were offered care that was high quality and within the recommended time

CCG Area	NICE guidelines' areas of recommendations						
	Referrals to expert for accurate diagnosis	Diagnosis and Expert review	Regular access to specialist nursing care	Access to physiotherapy	Access to occupational therapy	Access to speech and language therapy	Palliative care
Stoke on Trent							
North Staffordshire							
Stafford and Surrounds							
South East Staffordshire and Seisdon Peninsula							
Unreported							

People with suspected Parkinson's must be seen within 6 weeks of a GP referral. However, the lack of quick referrals to neurologists for diagnosis is highlighted as one of the key issues across the county.

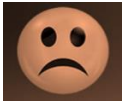






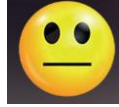








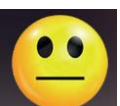
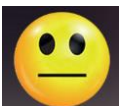

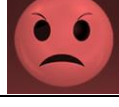






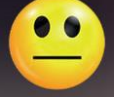









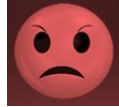


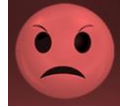

"It was nearly a year to find out and it was a bit frustrating... I had no additional support and I didn't have a clue about anything. I said to him, 'what can I do to help myself?' and he said nothing. That's one of the worst things that anyone can say to you. [I got] no information while waiting for a diagnosis." – **Stafford and Surrounds CCG**

"It took a few months to be seen by a specialist [in the NHS]. I saw a private neurologist within a week." – **Stoke on Trent CCG**

"It took 2-3 years of complaining I wasn't well and still nothing has happened." – **South East Staffordshire and Seisdon**

MULTIPLE SCLEROSIS (MS)

Multiple Sclerosis (MS) affects the central nervous system, affecting the brain and/or spinal cord causing disruptions in the signals that travel through nerve fibres. This causes wide ranging issues such as blurred vision, problems with movement and fatigue. In Staffordshire, care for MS patients is fairly varied, with North Staffordshire CCG area once again providing a higher level of care as compared to the other areas. A comprehensive review at least once a year by a health professional is also reported to be an area that is followed through reasonably well across the county.

CCG Area	NICE guidelines' areas of recommendations					
	Support at diagnosis	Follow-up after diagnosis	Coordinated care	Physical activity	Managing relapses	Comprehensive review
Stoke on Trent						
North Staffordshire						
Stafford and Surrounds						
East Staffordshire						
South East Staffordshire and Seisdon Peninsula						
Cannock Chase	N.A.					
Warwickshire North						

Patients with suspected MS are to be given support at the time of diagnosis to manage and understand the condition. They are also to be offered a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis.

However, this lack of support at diagnosis and follow-up after diagnosis were reported by participants as key areas where the recommended timeline is not met.

"I didn't really get a follow up, I'm not really sure if I'm relapsing and remitting or on the primary and secondary progressive course" – Stoke on Trent CCG



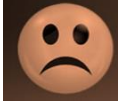


















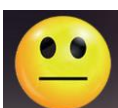




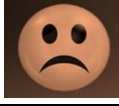









*"The consultant hasn't got a bedside manner and simply gave me two elbow crutches and told me that I will be in wheelchair within 12 months. Get on with it."-
South East Staffordshire and Seisdon Peninsula*

"No information was given, I had to access it myself which wasn't easy. I always have to fight for myself, I feel like I'm on my own. I was given information but couldn't access it." – Warwickshire North CCG












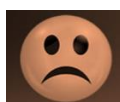
MOTOR NEURONE DISEASE (MND)

Motor neurone disease (MND), also known as Amyotrophic Lateral Sclerosis (ALS), is a neurodegenerative, progressive disorder which causes weakness in muscular function, due to dysfunctions in the brain and spinal cord. This condition is fairly rare, and can eventually affect the ability to walk, talk, swallow and breathe.

In Staffordshire, compared to the other 2 conditions, MND is extremely varied across the county.

NICE Guidelines ¹	CCG Area			
	North Staffordshire	Stafford and Surrounds	East Staffordshire	South East Staffordshire and Seisdon Peninsula
Recognition and referral				
Information and support at diagnosis				
Cognitive assessments				
Organisation of care				
Psychological support				
Exercise programmes				
Equipment and adaptation to aid activities of daily living and mobility				
Nutrition and gastronomy				
Communication				

¹ NICE guidelines for MND have several categories deriving from each area of the guidelines, results shown here are an average of each category. Therefore, they may differ marginally from the main report.

Information about non-invasive ventilation				
Symptoms and signs				
Planning for end of life				

However across the county, quick recognition of MND and referrals without delays are problematic.

"Nobody was saying what they thought it might be. I suspect they didn't know...They don't know so they couldn't give me any information and for the three years that I was being assessed I carried on working and didn't change anything with my diagnosis." – **South East Staffordshire and Seisdon Peninsula CCG**

No I think there should be somebody there, as well as the consultant, because the consultant knows what he's going to tell you, ideally if there was an MND nurse or someone similar there at the time. – **Stafford and Surrounds CCG**

"There isn't an MND specialist nurse in the whole of the West Midlands as far as I'm aware. They did have one down at the QE in Birmingham but she left last year and I believe they're trying to appoint another one but there isn't a specialist nurse now." – **South East Staffordshire and Seisdon Peninsula CCG**

SUMMARY OF FINDINGS

Overview

- Mapping of the conditions to the NICE guidelines showed that Parkinson's care and treatment is the most consistent of the 3 conditions, although this is not much higher than the 2 conditions.
- Palliative care discussions and delays in referrals and specialist services and equipment have been reported to be the most common issues for people with the 3 conditions across the region.
- Parkinson's care and treatment ranks positively in providing regular access to specialist nursing care and for diagnosis and expert review but is lower in areas such as quick referrals to neurologists for diagnosis, access to physiotherapy and palliative care discussions.
- MS care and treatment is reported to be positive in areas such a comprehensive review of the condition and in managing relapses but lacks provision of support during diagnosis, and lacks consistent follow-up after diagnosis.
- MND care and treatment is the most varied and inconsistent of the 3 conditions. MND ranks highly in symptom monitoring but lacks consistency in providing information, provision of equipment without delay, exercise programmes, psychological support and palliative care discussions.

1. Parkinson's

- Patients with Parkinson's were treated in accordance with the NICE guidelines across the Staffordshire and Stoke-on-Trent region. All of the quality statements were largely met across the region.
- 15 respondents (**78.95%**) reported that they had regular access to specialist nursing care. This was consistently positive across the different CCG areas in the county.
- Respondents from the North Staffordshire CCG area had the most consistent care along the entire pathway. All or most of the respondents agreed that their care was overall very positive in the area.
- Respondents from the Stoke on Trent CCG area reported having some inconsistent care such as delays to being seen by a specialist after referrals and lack of access to physiotherapy

2. MS

- Patients with MS were mostly treated in accordance with the NICE guidelines across Staffordshire and Stoke-on-Trent region. All of the quality statements, except one, were on average in line with the expectations of the NICE guidelines.
- 19 respondents (**79.17%**) reported that they were offered a comprehensive review by their relevant healthcare professional. This was consistently positive across the different CCG areas in the region.
- 13 respondents (**54.17%**) reported that they were not given support at the time of diagnosis to manage and understand the condition by the consultant neurologist making the diagnosis. This was highlighted across all of the 6 CCG areas.
- All the respondents in East Staffordshire, Cannock Chase and Warwickshire North CCG had reported the lack of follow-up after diagnosis.
- A respondent in East Staffordshire also reported the lack of a single point of contact who coordinates their care.
- Even though discussion around palliative care is not listed as an expectation in the NICE guidelines, 8 (**47.1%**) out of the 17 respondents who did not discuss palliative care, felt that they would have liked to have done so.

3. MND

- Patients with MND reported having varied treatment that was not always in accordance with the NICE guidelines across the Staffordshire and Stoke-on-Trent region. Quality statements in the NICE guidelines were largely varied.
- While most of the pathway was reasonably in line with the guidelines, respondents reported the lack of support for family and carers, lack of information and support during the diagnostic process, delays in provision of equipment for communication and the lack of support and advice around advance care planning for end of life.
- Respondents from the South East Staffordshire and Seisdon Peninsula and Stafford and Surrounds CCG area reported as having the most inconsistent care across the pathway.
- Respondents from the North Staffordshire CCG area reported to have the most consistent care.
- All of the respondents agreed that nutrition and gastronomy assessments at diagnosis, assessment and monitoring of respiration function as well as overall monitoring of sign and symptoms by the



clinical teams were areas that were consistently positive and done well across the region.

- All of the respondents also agreed that no support for themselves, their family and or their carers were provided throughout the diagnostic process, particularly during periods of diagnostic uncertainty or delay.

RECOMMENDATIONS

- **Managing expectations with NICE guidelines.** Participants reported that many of them had no idea what to expect after their diagnosis as they did not have the information provided. Patients could be provided with an information pack that has relevant contacts and up-to-date information, as well as a NICE guidance tick sheet. This tick sheet provision of the expected pathway, approximate waiting times etc. may provide clarity for patients who do not know what to expect for the length of their condition. This tick sheet could be created from the Patient Experience guidance: <https://www.nice.org.uk/guidance/cg138/ifp/chapter/About-this-information> and the information for people who use NHS services: <https://www.nice.org.uk/guidance/qs15/resources/patient-experience-in-adult-nhs-services-pdf-121173373> . This will also reduce phone calls and queries from patients regarding their condition and what to expect if they are provided with information beforehand. In addition, this will also help to hold services who follow the NICE guidelines to account, if patients are able to question and challenge their care if they know what service standards are expected to be met.
- **Support during diagnosis and while waiting for a diagnosis.** Highlighted as a key issues for patients, the lack of support and information while awaiting diagnosis or during diagnosis is a source of great stress. Presence of a family member during diagnosis, or presence of their specialist nurse will provide additional support to patients to manage the shock of a diagnosis. Collaborations with the MND association, MS society and Parkinson's support groups will enable patients to be able to seek support while awaiting an official diagnosis. Furthermore, these collaborations will also provide an additional contact point for patients who have questions about their conditions but are unable to be seen by clinical staff quickly. Patients could also be provided with an online portal where they are able to login and identify at what stage of diagnosis their neurologists are, and how long a wait they would have to endure before a diagnosis can also help to manage expectations.
- **Lack of specialist staff.** Participants also highlighted that due to unforeseen circumstances, specialist staff, particularly nurses are no longer available. Some participants reported having gone years without having a nurse to be able to turn to for support. Recruitment of additional specialist nurses as well as rehabilitation and occupational therapists (to support mobility and independence) who are able to travel to patients homes will be helpful. A hub-approach (ie. providing a single venue where all specialist nurses and occupational therapists are available for consultation) for areas where recruitment is difficult or provision of a single point of contact (preferably their neurologist) for current patients without a specialist nurse to turn to while the position is being filled. Use of specially trained volunteers who are able to work with the neurologists to provide non-medical home support, such as

psychological support, check ins with patients etc. can also be helpful to alleviate stress on a stretched workforce.

- **Reducing waiting times for referral.** Participants consistently highlighted that they had presented at the GP several times before being referred to a neurologist. Given the extent of Neurological conditions and complexity of symptoms, it is difficult to determine whether symptoms are isolated issues or if they are a symptom of a wider neurological condition. The MND Association have recently developed a Red Flag Tool to help GPs decide if the patient needs to be referred to a neurologist. Whilst this work is new, Healthwatch are particularly interested in monitoring the impact of the tool with the potential of working with stakeholders in the county to develop similar tools for MS and Parkinsons. This will form the basis of the next phase of this work.

REFERENCES

BBC News. (2013, September 26). *Number of multiple sclerosis patients in the UK 'growing'* Retrieved February 01, 2017, from <http://www.bbc.co.uk/news/uk-scotland-tayside-central-24285893>

Brain and Spine Foundation. (2013). *Motor neurone disease* [Brochure]. UK, London: Brain and Spine Foundation.

Foltynie, T., Brayne, C. E., Robbins, T. W., & Barker, R. A. (2004). The cognitive ability of an incident cohort of Parkinson's patients in the UK. The CamPaIGN study. *Brain*, 127(3), 550-560.

Hoppitt, T., Pall, H., Calvert, M., Gill, P., Yao, L., Ramsay, J., ... & Sackley, C. (2010). A systematic review of the incidence and prevalence of long-term neurological conditions in the UK. *Neuroepidemiology*, 36(1), 19-28.

Khoo, T. K., Yarnall, A. J., Duncan, G. W., Coleman, S., O'Brien, J. T., Brooks, D. J., ... & Burn, D. J. (2013). The spectrum of nonmotor symptoms in early Parkinson disease. *Neurology*, 80(3), 276-281.

Leigh, P. N., & Ray-Chaudhuri, K. (1994). *Motor neuron disease*. *Journal of Neurology, Neurosurgery & Psychiatry*, 57(8), 886-896.

MND Association. (n.d.). *Brief guide to MND*. Retrieved February 08, 2017, from <http://www.mndassociation.org/what-is-mnd/brief-guide-to-mnd/>

MS Society. (2014, February 28). *About MS*. Retrieved January 30, 2017, from <https://www.mssociety.org.uk/what-is-ms/information-about-ms/about-ms>

MS-UK. (n.d.). *Treatment*. Retrieved February 01, 2017, from <http://www.ms-uk.org/treatment>

Multiple Sclerosis Trust. (2014, August 8). *Causes of MS*. Retrieved February 01, 2017, from <https://www.mstrust.org.uk/a-z/causes-ms>

NHS Choices. (2016a, June 9). *Parkinson's disease*. Retrieved January 27, 2017, from <http://www.nhs.uk/conditions/Parkinsons-disease/Pages/Introduction.aspx>

NHS Choices. (2016b, February 17). *Multiple sclerosis*. Retrieved January 30, 2017, from <http://www.nhs.uk/Conditions/Multiple-sclerosis/Pages/Introduction.aspx>

NICE. (n.d.). *NICE guidance*. Retrieved February 10, 2017, from <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance>

Parkinson's UK. (n.d.). *What is Parkinson's?* Retrieved January 27, 2017, from <https://www.parkinsons.org.uk/content/what-parkinson>

Talbot, K. (2002). Motor neurone disease. *Postgraduate medical journal*, 78(923), 513-519.

The National Council for Palliative Care (2015). *Neurological conditions*. Retrieved February 10, 2017, from <http://www.ncpc.org.uk/neurological-conditions>

Appendix 1

MND interview template (NICE guidelines)

DEMOGRAPHICS

1. What is the name of your GP practice? (This is just so we know which CCG area you belong to)

2. What is your gender?

- Female
 Male
 Other (Please specify): _____
 Prefer not to say

3. How old are you?

- 18-29
 30-39
 40-49
 50-59
 60-69
 70 to 79
 80 or over
 Prefer not to say

4. How long ago were you diagnosed as having MND by your neurologist?

- Less than 12 months ago
 1-5 years ago
 Between 5-10 years ago
 More than 10 years ago
 I don't know

NICE GUIDELINES

Recognition and referral

1. Thinking back to when you first noticed your symptoms, how long did it take for you to be referred to a specialist?

Prompts:

- Who were you referred to?
- Were you offered any additional support or information?
- Did you see any other Consultants before you were referred to the Neurologist? (If so, which one(s)?)

- Were you given any information while waiting for a diagnosis?
 - Look for: Verbal/written? Neurologist or other giving the information? DMT? Symptom management? Fatigue management? Newly diagnosed course? Social care and voluntary groups, Charities etc. Benefits and employment considerations? Websites?

Information and support at diagnosis

2. Thinking back to your first appointment, what was your experience of receiving your diagnosis for the first time?

Prompts:

- Who made the diagnosis?
- Were you provided any information about the diagnosis, prognosis and management of MND by the consultant neurologist?
 - Look for: Symptoms of MND, Types and possible causes of MND, Treatment options, How MND may progress, Crisis prevention, opportunities for people with MND to be involved in research, likely needs and concerns of people with MND and their family members and/or carers, advanced care planning
- Were you asked about your preferences for involving your family members and/or carers?
- Were you provided the information about MND if you asked for it? How was this provided (Oral or written information?)
- Did you feel that the services were responsive and/or accessible?

3. Since your diagnosis, have you been given a direct point of contact at the hospital or in the community when you need advice support?

Prompts:

- If yes, who is this person (don't need names, just titles e.g. MND nurse)? Is this the same person you contact every time?
- Were you offered a face-to-face appointment with this healthcare professional? How long did it take to receive this?
- Do you feel able to phone or email them to ask for advice? Was this advice useful and valuable? Are they easy to get hold of?
- Did you have enough time at diagnosis to discuss your concerns and questions? (e.g. Is there a cure?, How long will I live?, What will happen with my healthcare?)

Cognitive assessments

4. Was the information provided to you easy to understand and made clear to you?

- *Were your questions answered well?*
- *Did you feel that you could understand all the discussions that took place?*

Organisation of care

5. Were you provided access to the clinical team as per your needs?

Prompts:

- *Were you able to meet with or speak to the whole clinical team that was working with you? (eg. MND nurse, neurologist, occupational therapist etc)*
- *Were you able to get in touch with them easily?*
- *Were you able to see the same people each time?*
- *Did you feel all the services you used were integrated enough? Or did you feel there was too much duplication?*
- *If you were admitted to hospital, did you feel the communication between hospital team, your community team & consultant as well as your GP was adequate?*

Psychological support

6. Were you informed about the psychological and emotional impact of MND?

Prompts:

- *Were you offered any support including support groups, counselling or online forums?*
- *Was support offered to your family members and/or carers as well?*
- *Who did you ask? Who offered it to you?*
- *How long did you have to wait for the referral?*
- *Was it useful, was it helpful?*

Exercise programmes

7. Were you referred to any exercise programs after your diagnosis?

Prompts:

- *Were you offered any resistance, active-assisted or passive exercise programmes?*
- *Who did you ask? Who offered it to you?*
- *How long did you have to wait for the referral?*

- *Was it useful, was it helpful?*

Equipment and adaptation to aid activities of daily living and mobility

8. Have you experienced any difficulties in carrying out your daily tasks around the house or with your personal care (like eating, drinking, dressing etc.)? If yes, have you been offered any help regarding this?

Prompts:

- *Was access to equipment, wheelchair services and assistive technology offered to you?*
- *Was access to augmented communication/environmental control/suction equipment or cough assist devices?*
- *Who did you ask? Who offered it to you?*
- *How long did you have to wait for the referral?*
- *Was it useful, was it helpful?*

Nutrition and Gastronomy

9. Have you experienced any difficulties or issues with your weight, nutrition or swallowing? If yes, were you provided any help with this?

Prompts:

- *Were you asked about these issues at or after your diagnosis? How soon was this discussed?*
- *Were you provided any information or told about the risks and benefits of placement of a gastrostomy? (Has the possibility of a feeding gastrostomy (feeding tube) been discussed with you?)*
- *If you were referred for a feeding gastrostomy (feeding tube), did this take place without unnecessary delay?*
- *What support was provided to you? (E.g. has a clinical swallowing assessment by the Speech and Language Therapist been provided?)*
- *Who provided you with this help?*
- *Were you satisfied with the help that you received?*

Communication

10. Have you experienced any difficulties with speech and communication? If yes, were you provided any help with this?

Prompts:

- *Were you provided any tests to identify these issues? How were these conducted? Have you been assessed and reviewed by a Speech and Language Therapist?*

- *If necessary, have you been provided with communication equipment (e.g. alphabet board / tablet-based voice output communication aid) to maximise your potential in activities of daily living and maintaining your quality of life?*
- *Were you provided any referrals to NHS AAC hub or anything else?*
- *Who provided you with this help?*
- *Were you satisfied with the help that you received?*
- *What kind of ongoing support were you provided?*

Information about non-invasive ventilation

11. Have you been assessed and monitored regarding your respiratory function (i.e. breathing)? If not, is this because you have been told this is not yet necessary?

Prompts:

- *Were you satisfied with how this information was given to you?*
 - *Do you feel that this information was delivered appropriately and sensitively?*
 - *Were you given adequate, clear information regarding what this is?*
 - *Were you informed about your rights and whether you were allowed to withdraw from any of the tests?*
- Look for: non-invasive ventilation – whether they were told about a care plan regarding this. Were you informed about non-invasive ventilation at any point after diagnosis? If yes, when were you informed about this?*

Symptoms and Signs

12. Do you feel that your symptoms and signs have been monitored well by your specialists and their team?

Prompts:

- *Did you feel that you were empowered to manager your own symptoms by the clinical team?*

Palliative Care

13. Were you offered the opportunity to discuss your preferences about what you would like regarding your care if your health deteriorated?

Prompts:

- *Were you ever been asked about what your preferences would be if your condition worsens?*
- *If yes, did you feel that the discussion was easy to understand and clear?*
- *Were you provided any information or support on advanced care planning?*

- *Was this asked in an appropriate and sensitive manner?*

Multiple Sclerosis Interview Questions

DEMOGRAPHICS

1. What is the name of your GP practice? (This is just so we know which CCG area you belong to)

2. What is your gender?

- Female
 Male
 Other (Please specify): _____
 Prefer not to say

3. How old are you?

- 18-29
 30-39
 40-49
 50-59
 60-69
 70 to 79
 80 or over
 Prefer not to say

4. What type of MS do you have?

- Relapsing remitting MS
 Secondary progressive MS with relapses
 Secondary progressive MS without relapses
 Primary progressive MS
 I don't know

5. How long ago were you diagnosed as having MS by your neurologist?

- Less than 12 months ago
 1-5 years ago
 Between 5-10 years ago
 More than 10 years ago
 I don't know

NICE GUIDELINES

Support at diagnosis

1. Thinking back to your first appointment, what was your experience of receiving your diagnosis for the first time?

Prompts:

- What was the length of time taken to be seen by a specialist?
- Who were you referred to?
- Who finally made the diagnosis?
- Were you offered any additional support?
- Were you given any information while waiting for a diagnosis?
 - Look for: Verbal/written? Neurologist or other giving the information? DMT? Symptom management? Fatigue management? Newly diagnosed course? Social care and voluntary groups, Charities etc. Benefits and employment considerations? Websites?

2. How many times did you visit your GP before you got an appointment to see a Neurologist?

Prompts:

- What symptoms did you experience
- How long were you experiencing these symptoms before consulting your GP
- How were these symptoms affecting your everyday life

Follow-up after diagnosis

3. Following your diagnosis, what was your experience of any follow up support that followed?

Prompts:

- Were you offered any follow-up appointments with the neurologist or other members of the medical team?
- What was the length of time taken?
- Do you know if you are on the relapsing & remitting course or the primary or secondary progressive course?
- Is this the same person you see each time?
 - What kind of things (aside from confidential clinical things) do you recall being asked about?

Coordinated care

4. Since your diagnosis, have you been provided a point of contact at the hospital or in the community when you need advice support?

Prompts:

- If yes, who is this person (don't need names, just titles e.g. MS nurse)? Is this the same person you contact every time?
- Do you feel able to phone or email them to ask for advice? Was this advice useful and valuable? Are they easy to get hold of?
- Do they arrange visits?
- What do you they provide you with?

- *If you were admitted to hospital, did you feel the communication between hospital team, your community team & consultant as well as your GP was adequate?*

Physical Activity

5. Have you experienced any problems or difficulties with mobility or fatigue? If yes, have you been given any help regarding this?

Prompts:

- *Was physiotherapy/fatigue management course offered to you? Other support (like specialised gym classes etc).*
- *Were you also able to access services for urology, sexual dysfunction, cognitive and psychological services, access equipment such as wheelchairs, help with employment and social issues (housing adaptations) – if any?*
- *Who did you ask? Who offered it to you?*
- *How long did you have to wait for the referral?*
- *Was it useful, was it helpful?*

Managing relapses

6. Have you ever had a relapse? If yes, have you been given any help regarding this?

Prompts:

- *How quickly were you offered help from the onset of symptoms?*
- *Who did you ask for help?*
- *What was the response like?*
- *Were you provided any disease modifying drugs?*

Comprehensive review

7. Since your diagnosis, was your condition reviewed?

Prompts:

- *How often was your condition reviewed?*
- *What kind of things (aside from confidential clinical things) do you recall being asked about?*
- *Who reviewed your condition? Was this the same person you see each time?*

Palliative Care

8. Were you offered the opportunity to discuss your preferences about what you would like regarding your care if your health deteriorated?

Prompts:

- *Were you ever been asked about what your preferences would be if your condition worsens?*
- *If yes, did you feel that the discussion was easy to understand and clear?*
- *Were you provided any information or support on advanced care planning?*
- *Was this asked in an appropriate and sensitive manner?*
- *If the respondent has not had the opportunity to discuss palliative care- ask if they think this is important or if they would want to discuss it?*

Parkinson's interview template (NICE guidelines)

DEMOGRAPHICS

1. What is the name of your GP practice? (This is just so we know which CCG area you belong to)

2. What is your gender?

- Female
- Male
- Other (Please specify): _____
- Prefer not to say

3. How old are you?

- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70 to 79
- 80 or over
- Prefer not to say

4. How long ago were you diagnosed as having PD by your neurologist?

- Less than 12 months ago
- 1-5 years ago
- Between 5-10 years ago
- More than 10 years ago DIA
- I don't know

NICE GUIDELINES

Referral to expert for accurate diagnosis

1. Thinking back to your first appointment, what was your experience of receiving your diagnosis for the first time?

Prompts:

- What was the length of time taken to be seen by a specialist?
- Who were you referred to?
- Who finally made the diagnosis?
- Were you offered any additional support?
- Were you given any information while waiting for a diagnosis?
 - Look for: Verbal/written? Neurologist or other giving the information? DMT? Symptom management? Fatigue management? Newly diagnosed course? Social care and voluntary groups, Charities etc. Benefits and employment considerations? Websites?

Diagnosis and Expert Review

2. Following your diagnosis, what was your experience of any follow up support that followed?

Prompts:

- Were you offered any follow-up appointments with the neurologist or other members of the medical team
- Is this the same person you see each time?
- Were you informed about the course of your condition?
- Were you offered any access to services such as mental health for treatment of anxiety, depression and managing dementia? – if applicable
- Any help with employment & social factors such as rehousing or provision of equipment/adaptations? – if applicable

3. Since your diagnosis, was your condition reviewed?

Prompts:

- How often was your condition reviewed?
- What kind of things (aside from confidential clinical things) do you recall being asked about?
- Who reviewed your condition? Was this the same person you see each time?
- If you were admitted to hospital, did you feel the communication between hospital team, your community team & consultant as well as your GP was adequate?

Regular access to specialist nursing care

4. Since your diagnosis, have you been provided with a point of contact at the hospital or in the community when you need advice support?

Prompts:

- *If yes, who is this person (don't need names, just titles e.g. Parkinson's' nurse)? Is this the same person you contact every time?*
- *Do you feel able to phone or email them to ask for advice? Was this advice useful and valuable? Are they easy to get hold of?*
- *Do they arrange visits?*
- *What do you they provide you with?*

Access to physiotherapy

5. Have you had any difficulties with your mobility, fatigue or balance? If yes, have you been given any help regarding this?

Prompts:

- *Was physiotherapy/fatigue management course offered to you? Other support (like specialised gym classes etc).*
- *Who did you ask? Who offered it to you?*
- *How long did you have to wait for the referral?*
- *Was it useful, was it helpful?*

Access to occupational therapy

6. Have you experienced any difficulties in carrying out your daily tasks around the house or with your personal care (like eating, drinking, dressing etc.)? If yes, have you been offered any help regarding this?

Prompt:

- *Was access to occupational therapy offered to you?*
- *Who did you ask? Who offered it to you?*
- *How long did you have to wait for the referral?*
- *Was it useful, was it helpful?*

Access to speech and language therapy

7. Have you experienced any difficulties with your speech or with making yourself understood? If yes, have you been given any help regarding this?

Prompts:

- *Was access to speech therapy offered to you? Other support like singing groups etc.?*
- *Who did you ask? Who offered it to you?*
- *How long did you have to wait for the referral?*
- *Was it useful, was it helpful?*

Palliative Care

8. Have you had the opportunity to talk to anyone about any help or support you may need as your disease progresses?

Prompts:

- *Did you and your family have the chance to discuss help and support that may be necessary in the future?*
- *Who were you able to discuss this with? Did they provide you with the necessary information and discuss it clearly with you?*
 - *Look for: Domiciliary care, residential care, respite etc.*