

# 2019 UK Parkinson's Audit

## Summary report

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## Foreword

The 2019 UK Parkinson's Audit provides the largest ever dataset on the quality of care provided to people with Parkinson's across the UK. There's been an uplift in services participating at each audit cycle since 2010 and it's superb to report that there's been a 21.6% increase in the numbers of services involved this time around. There's been a significant increase in participation from occupational therapy, physiotherapy and speech and language therapy services, with a remarkable 61% uplift in the numbers of physiotherapy services participating. This, in turn, means that just over half of participating services have done so for the first time ever. Thank you to you all - we hope you see this as testament to your work and as a highlight of the Excellence Network's work.

This amazing level of participation speaks volumes to the commitment and dedication of so many doctors, nurses, occupational therapists, physiotherapists and speech and language therapists and of people living with Parkinson's. Everyone involved has taken time out to do the work, in turn supporting us to provide the data and insight that we need to improve services for people living with Parkinson's.

The 2019 Audit results are being published at a key moment for people living with Parkinson's. Parkinson's UK has just launched its 2020-24 strategy.

Improving access to multidisciplinary services is a key aim of that strategy, and the UK Parkinson's Excellence Network will be working with renewed vigour in a challenging NHS landscape, to support the clinical community to deliver the services that people living with Parkinson's deserve. We're marking 2020 by launching an innovative multicentre collaborative approach to service improvement which we believe will drive forward service improvement and benefit many living with Parkinson's. Please read on to find out more.

The results demonstrate ongoing commitment to developing and delivering high quality evidence based standards, and I believe individual services will be encouraged by the progress they are seeing when they receive their individualised reports. And by the positive feedback received from the 8000 plus people living with Parkinson's who took part in the PREM across the UK. It's heartening to read that well over 90% of people can have access to a nurse specialist, occupational therapy, physiotherapy and speech and language therapy. However, the domain scores suggest that there is still work to do, to ensure that that access is provided at the right times for individuals in all cases. And indeed, audit results suggest that it is more of a challenge for professionals in the different disciplines to work together.

Good mental health is identified as a key priority for people living with Parkinson's, and this is borne out through the NICE guideline, which recommends that there should be a treatment pathway for clozapine and for monitoring the treatment of hallucinations and delusions. This is a new standard, so it's encouraging that a third of services have such access, but clearly work to do to improve this across the UK.

The UK Parkinson's Excellence Network provides the environment where the clinical community shares and develops best practice, where colleagues can find tools, share learnings, draw from Parkinson's UK resources to support service redesign, using all of this to play into the principles of continuous improvement that the audit approach triggers. Please use it as a support as you develop your service.

2020 marks a new approach for the Excellence Network. The audit results demonstrate that bone health continues to be a significant issue for people living with Parkinson's, and that as our focus on providing multidisciplinary care and support for people with Parkinson's develops, the need for high quality induction and support for "new starters" in the therapist world stands out as a priority. We're launching a new, collaborative multicentre approach to service improvement by inviting centres to test and evaluate a consistent model of care to treat bone health, and to induct and support "new starters" in therapy services. We know that tackling service improvement can be daunting, but believe this UK-wide approach will enable us to minimise the work for colleagues carrying out the projects yet maximise the impact of service improvement work, supporting you all to deliver better care and support for people living with Parkinson's.

It's extremely encouraging, in this biggest ever audit of Parkinson's services, to see the sustained commitment to delivering high quality services, to read of the high levels of patient satisfaction and to use the data to pinpoint how the Excellence Network can position itself to inspire, encourage and nurture improvement culture and practice across the UK.

## Introduction

This summary report outlines the most significant findings of the 2019 UK Parkinson's Audit. Complete data tables of all the audit results are also available on the audit website, along with details of the audit's design and methods, the participating services, the dataset and the Patient Reported Experience Measure (PREM) questionnaire.

The 2019 UK Parkinson's audit (the seventh to be completed) represents the largest UK audit of Parkinson's to date. This summary report refers to the PREM results where they relate to 2019 audit data, and also reports on key PREM findings (the complete PREM results are available in the complete data tables).

## Background

The UK-wide clinical audit was originally developed to address the concerns of professionals, patients and their representatives about the quality of care provided to people with Parkinson's. The audit uses evidence-based clinical guidelines as the basis for measuring the quality of care in the outpatient setting. In 2015, the PREM was introduced, offering patients and carers the opportunity to identify areas of good practice or highlight deficiencies in their own care.

The NHS continues to face unprecedented challenge. This makes it more important than ever to look closely at what Parkinson's services are delivering and how teams are being supported to help work together through the UK Parkinson's Excellence Network to share evidence and best practice that can improve standards of care.

The design of the audit has changed from cycle to cycle. This reflects a shift in focus from early diagnosis and intervention for people newly diagnosed with Parkinson's, to the effective continuous management of patients within a multidisciplinary team. As a result this report draws on separate audits from doctors and Parkinson's nurses, occupational therapists, physiotherapists, and speech and language therapists. Where relevant, the results presented here (as percentages, as audited services differ from cycle to cycle) are compared with those from previous cycles. The questions are identical to those in the 2015 and 2017 audits, with a few exceptions, thus allowing direct comparison.

In February 2018 the *National NICE quality standard for Parkinson's disease* was published<sup>1</sup>. The five quality statements describe high-quality care in priority areas for improvement. This UK-wide audit underpins the NICE quality measure process for these statements and has official recognition from NHS England HQIP

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<sup>1</sup> National Institute for Health and Care Excellence (NICE) (2018) *Parkinson's Disease* [QS164]

The audit continues to serve two main roles within the UK Parkinson's Excellence Network. It provides an important baseline against which progress can be measured and informs national, regional and local service improvement priorities and plans to achieve better services for people living with the condition.

## **Executive summary**

This executive summary outlines the key findings of the 2019 UK Parkinson's Audit. The audit measures the quality of care provided to people living with Parkinson's in comparison with a range of evidence-based guidance about the care of people with the condition.

This UK-wide audit takes a multi-professional approach. It involves Elderly Care and Neurology consultants, who care for people with movement disorders. It also includes Parkinson's nurses, occupational therapists, physiotherapists and speech and language therapists who also care for people with Parkinson's. The audit engages services within these professions to measure the quality of their practice, within their model of care provision, and to trigger service improvement plans.

This audit reports on the care provided to 10,335 people with Parkinson's during the five month data collection period. This is a 9% increase in the number of patients compared with the 2017 audit.

8,247 people with Parkinson's and their carers contributed to the Patient Reported Experience Measure (PREM) questionnaire, giving them the opportunity to provide their views on the service they attend.

### **Key messages:**

- There have been improvements in many areas since 2017
- There is still work to be done across all specialties in the following areas:
  - specialised multidisciplinary working
  - standardised practices
  - communication and information sharing
  - medicines management
  - supporting the workforce
- The Summary Report provides examples of work being done in response to the challenges highlighted by the audit.

## **Elderly Care and Neurology**

### ***Evidence of good practice***

- Timely specialist review.
- Access to a Parkinson's Nurse or equivalent.
- Written information routinely available.
- Significant improvement in the percentage of patients given advice about Lasting Power of Attorney.
- Signposting to Parkinson's UK.

### ***Areas for Improvement***

- Multidisciplinary team approach.
- Documentation regarding potential side effects of medication.
- Mental Health: screening, referral access and clozapine.
- Review of bone health.
- Care of people in work who have Parkinson's.
- Uptake of Parkinson's related continuing professional development (CPD) by clinicians, especially Neurologists.

## **Occupational therapy**

### ***Evidence of good practice***

- Increase in occupational therapy services participating in the audit.
- Use of practical guidance and support.
- Access to Parkinson's related CPD.
- Goals are set in collaboration with the individual and carer.

### ***Areas for improvement***

- Provision of induction and support for new occupational therapists working with people with Parkinson's.
- Use of evidence-based practice rather than reliance on clinical experience and peer support.
- Use of standardised assessments and outcome measures to guide occupation-based intervention.
- Use of outcome measures to support service development.
- Earlier referral to occupational therapy with optimal communication exchange.

## **Physiotherapy**

### ***Evidence of good practice***

- Increase in physiotherapy services participating in the audit.
- Provision of advice and intervention regarding physical activity and exercise.
- Increase in the number of people with Parkinson's referred to physiotherapy within two years of diagnosis.

### ***Areas for improvement***

- Provision of induction and support for new physiotherapists working with people with Parkinson's.
- Initial assessment should be carried out by qualified physiotherapist rather than unregistered therapy support staff (e.g. Band 4).
- Use of appropriate outcome measures for people with Parkinson's based on guidelines and best practice.

## **Speech and Language therapy**

### ***Evidence of good practice***

- For the first time more than half of services offer Lee Silverman Voice Treatment.
- Good documentation of the impact of Parkinson's on communication and communication participation.
- There was a clear plan of management based on assessment outcomes documented for most patients.

### ***Areas for improvement***

- Provision of induction and support for new speech and language therapists working with people with Parkinson's
- Earlier referral: most continue to be referred in the maintenance phase.
- Recording whether patients were "on" or "off" at assessment.
- Use of standardised intelligibility assessments for people with Parkinson's.
- Few communication assessments included an audio/video recording.
- Few had word finding difficulties included as part of communication assessment.

## **PREM**

### ***Areas of satisfaction***

- As in the 2015 and 2017 audit, most people with Parkinson's or their carers are satisfied with the frequency of review by their Parkinson's nurse.



- Small but significant increase in access to physiotherapy and speech and language therapy and ability to contact these services between scheduled visits.
- Three quarters of respondents had been signposted to Parkinson's UK.
- Just over three quarters had an enquiry into balance and falls.

### ***Areas of concern***

- A small but significant decrease in the percentage of respondents who feel that the frequency of review by their Parkinson's specialist doctor meets their needs, despite 90.4% rating that the quality of service they receive is excellent or good.
- As in 2017 only 61% felt that they received enough information at diagnosis.
- One third felt that they were not given enough information, or were not sure if they were given enough information, when starting new medication.
- Just less than half of those admitted to hospital always received their medication on time.
- Only two in five were asked and/or raised concerns regarding constipation.

## Services taking part and patients included

Table 1: Number of each type of service and characteristics of people with Parkinson's included in the audit

	Elderly care		Neurology		Occupational therapy		Physiotherapy		Speech and Language therapy		Total	
Services	142		124		82		153		79		580	
Patients	3370		2886		958		2099		1022		10335	
Patient characteristics												
Age (years)												
Mean (SD) (range)	77.2 (8.2) (20-99)		72.0 (9.9) (33-98)		75.5 (9.0) (31-99)		73.7 (9.5) (29-99)		73.7 (9.6) (34-95)		74.5 (9.4) (20-99)	
Gender												
		%		%		%		%		%		%
Male	2011	59.7	1779	61.6	571	59.6	1318	62.8	686	67.1	6365	61.6
Female	1359	40.3	1105	38.3	386	40.3	781	37.2	336	32.9	3967	38.4
Prefer not to say	0	0	2	0.1	1	0.1	0	0	0	0	3	0
Duration of Parkinson's (years)												
Mean (SD)	5.6 (5.3)		6.0 (5.3)		5.7 (5.7)		5.1 (5.2)		6.6 (6.0)		5.7 (5.4)	
Median	4		5		4		3		5		4	
(range)	(0-34)		(0-55)		(0-46)		(0-33)		(0-36)		(0-55)	
Phase of Parkinson's												
		%		%		%		%		%		%
Diagnosis	351	10.4	236	8.2	133	13.9	280	13.3	75	7.3	1075	10.4
Maintenance	1711	50.8	1437	49.8	466	48.6	1225	58.4	629	61.5	5468	52.9
Complex	1220	36.2	1112	38.5	330	34.4	564	26.9	289	28.3	3515	34.0
Palliative	88	2.6	101	3.5	29	3.0	30	1.4	29	2.8	277	2.7

The services taking part are not necessarily the same ones which took part in the audit in 2017, although many are re-auditing their practice this time.

## The PREM questionnaire

In addition to the audit data, 8,247 people with Parkinson's and their carers attending 451 (77.7%) of the participating services completed the PREM questionnaire. These are not necessarily the same patients as those included by the services in their patient audit.

## Selected audit findings

### Elderly Care and Neurology

#### Aims

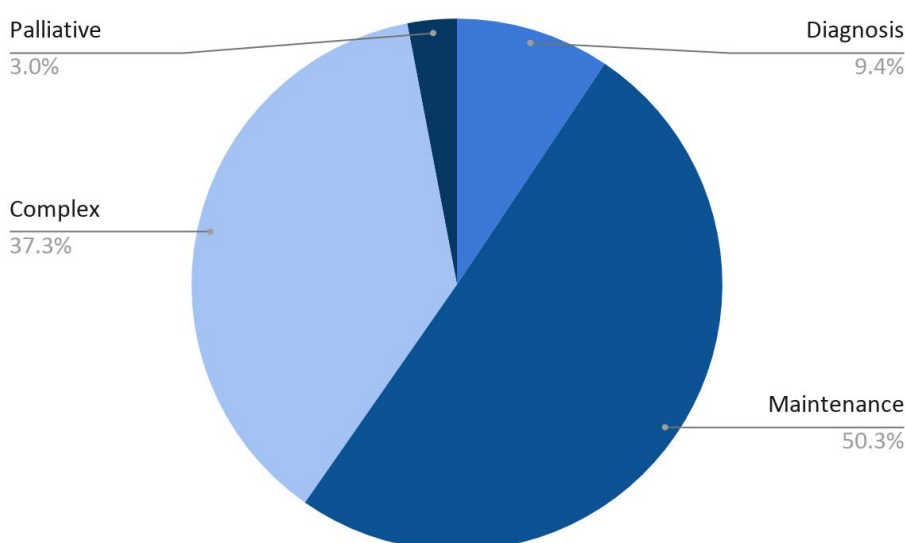
These audits are intended to measure the quality of assessment and management of people with Parkinson's attending Elderly Care<sup>2</sup> and Neurology clinics, and also to describe the models of service delivery used. They allow benchmarking of services against standards of good practice and guidance relating to the quality of care for people with Parkinson's.

#### Demographics

Elderly Care and Neurology services saw 6,256 people with Parkinson's, who were included in the audit. These patients were aged between 20 and 99 years (mean: 74.8, standard deviation (SD) 9.4 years), and the majority were male (60.6%). Patients seen at Neurology services (mean age: 72.0, SD 9.9 years) tended to be younger than in Elderly Care (mean age: 77.2, SD 8.2 years).

Mean age at diagnosis was 69.0 years (SD 10.7 years) (Elderly Care: 71.6 SD 9.8; Neurology: 66.0 SD 10.9), and patients audited had a mean Parkinson's duration of 5.8 years (SD 5.3, range 0–55 years). The distribution of phase of Parkinson's was very similar across Elderly Care and Neurology audits.

Figure 1: Parkinson's phase in Elderly Care and Neurology



<sup>2</sup> Elderly care refers to services provided by a geriatrician.

## Service audit

### *Model of service provision*

Parkinson's is a complex, chronic condition, and people with Parkinson's receive the best care within specialist Parkinson's or movement disorder clinics. In the specialist clinic setting, this is supported by an integrated approach provided by a multidisciplinary team. This ensures the best quality of life for the person with Parkinson's and their families.

#### a) Specialist clinics

91.6% of audited Elderly Care services see all or most of their patients in specialist clinics compared with 95.7% in the 2017 audit. Neurology services have remained at a similar level to previous audits, with 62.9% seeing all or most of their patients in specific clinics (62.8% in 2015 and 57.9% in 2017). Disappointingly 9.8% of all audited services still see few or none of their patients in dedicated clinics, although this figure is lower in Elderly Care (1.4%) than in Neurology (19.3%). This figure is similar to 2015 (11.7%) and 2017 (10.8%) for all services seeing few or none of their patients in dedicated clinics.

Table 2: Patients seen within specific Parkinson's/movement disorder clinics

	Elderly Care	Neurology	Elderly Care and Neurology
All patients	65.5%	32.3%	50.0%
Most patients (>75%)	26.1%	30.6%	28.2%
Some patients (25–74%)	7.0%	17.7%	12.0%
Few patients (<25%)	0.7%	3.2%	1.9%
None	0.7%	16.1%	7.9%
Number of services:	142	124	266

#### b) Integrated clinics

There has been no significant change in the distribution of clinic model provision since the last audit. The fully integrated clinic model (i.e. a multidisciplinary team consisting of consultant(s), Parkinson's nurse and therapists all seeing patients within the same clinic venue) is available at 17.7% of all clinics (compared to 13.5% of services audited in 2017). Encouragingly, although this continues to be more common for Elderly Care (21.1%), a growing number of Neurology services provided integrated services (13.7% compared with 12.4% in 2017, and 5.5% in 2015). The most common model of service provision continues to be a joint or parallel doctor and nurse specialist clinic (51.1% of audited services in 2019, 58.7% in 2017). An unchanged proportion of clinics in both Elderly Care (29.6%) and Neurology (33.1%) remain staffed by a doctor alone.

Table 3: Most common model of service provision for medical input in each service

	Elderly Care	Neurology	Elderly Care and Neurology
Doctor alone	29.6%	33.1%	31.2%
Joint/parallel doctor and nurse specialist clinics	49.3%	53.2%	51.1%
Integrated clinics	21.1%	13.7%	17.7%
Number of services:	142	124	266

### ***Access to a Parkinson's nurse or equivalent***

Statement 1 of the NICE Parkinson's Disease Quality Standard states that adults with Parkinson's disease have a point of contact with specialist services. The audit showed that the majority of people with Parkinson's (97.8%) could access a Parkinson's nurse (94.4%) or equivalent.

Table 4: Access to a Parkinson's nurse or equivalent in Elderly Care and Neurology services

	Elderly Care	Neurology	Elderly Care and Neurology
Yes – Parkinson's Nurse Specialist	94.4%	94.4%	94.4%
Yes – other healthcare professional	2.8%	4.0%	3.4%
No	2.8%	1.6%	2.3%
Number of services:	142	124	266

88.7% of PREM respondents reported that they had access to a Parkinson's nurse, with 83.7% reporting being able to contact them between scheduled reviews. As the patients included in the clinical audit were not necessarily the same as those who completed the PREM, this apparent disparity could result from the fact that those with concerns were more likely to complete the PREM. Alternatively it may suggest that some patients were inadequately informed about how to access a Parkinson's nurse.

### ***Access to Occupational Therapy, Physiotherapy and Speech and Language Therapy***

Statement 3 of the NICE Parkinson's Disease Quality Standard states that adults with Parkinson's disease are referred to physiotherapy, occupational therapy or speech and language therapy if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva. The audit demonstrated that nearly all (over

95%) services do have access to these specialists. However the domain 3 scores indicate that referrals are not always considered.

Table 5: Access to occupational therapy, physiotherapy and speech and language therapy in Elderly Care and Neurology services

	Elderly Care	Neurology	Elderly Care and Neurology
Occupational therapy	97.2%	95.2%	96.2%
Physiotherapy	98.6%	97.6%	98.1%
Speech and language therapy	98.6%	96.0%	97.4%
Number of services:	142	124	266

### ***Mental Health***

Standardised assessment tools are routinely available in only 74.1% of all or most clinics to assess and monitor cognitive function, and in 58.3% to assess anxiety and depression. Moreover only 81.2% of audited Elderly Care and Neurology services are able to refer to mental health services that have experience in Parkinson's.

Statement 5 of the NICE Parkinson's Disease Quality Standard states that services for adults with Parkinson's disease provide access to clozapine and patient monitoring for treating hallucinations and delusions. The audit shows that currently two thirds of services do not have local pathways to provide access to clozapine and for patient monitoring. As this is a new recommendation it is encouraging that one in three services do have access, but there is room for improvement.

### ***Availability of written information***

Written information about Parkinson's and Parkinson's medication is routinely available all or most of the time at 86.4% of clinics (no significant increase from 2017). But written information about Parkinson's is still not routinely available in 4.5% of outpatient clinics. However, providing written information in the clinic may not be enough, as the PREM data suggests that only 60.7% of patients feel they are given enough information at diagnosis.

### ***"Get it on time"***

Statement 4 of the NICE Parkinson's Disease Quality Standard states for adults with Parkinson's disease who are in hospital take Levodopa within 30 minutes of their individually prescribed administration time. The audit asked "Does your hospital have a local Parkinson's guideline incorporating a recommendation that Levodopa be

administered within 30 minutes of prescribed time?”, and encouragingly just under three quarters (73.3%) did.

### ***Uptake of continuing professional development (CPD)***

Attendance at specialist meetings about Parkinson’s and movement disorders is desirable as part of the portfolio of continuing professional development (CPD) for movement disorder specialists. This audit cycle demonstrates that in over 20% of services not all clinicians have attended specific movement disorder CPD in the last 12 months. This is particularly apparent for Neurologists where only 62.9% have attended Movement disorder specific CPD in the last year. Over 94% of Parkinson’s nurses have attended specific CPD in the last year.

### **Patient audit**

#### ***Review by a specialist***

All people with Parkinson’s should be reviewed by a specialist (doctor or nurse) at 6–12 month intervals. 95.9% of patients audited in Elderly Care and Neurology services had received a specialist review in the preceding 12 months, compared with 98.1% seen in the 2017 audit. There was however a statistically significant reduction in the percentage assessed within the preceding 6 months. Of some concern is the feedback from the PREM, in that there was a small but significant decrease in the proportion of respondents who felt that the number of reviews met their needs. This may point to capacity, workforce and other issues.

#### ***Medicines management***

In this audit 97.1% of people with Parkinson’s who are on medication had their current prescription checked and documented at a clinical review (medicines reconciliation). There was evidence of information about potential side effects of new medication for 84% of patients in the audit. This figure was 86.2% in 2017. Concerningly however, the PREM data suggests a significant reduction in the percentage of patients who feel they are given enough information when prescribed new medication, with a third feeling that they were not given enough information, or were not sure if they were given enough information when starting new medication.

Table 6: Patients given information about potential adverse side effects of new medication

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	83.7%	84.4%	84.0%
No	16.3%	15.6%	16.0%
Number of patients:	2085	1858	3943

### ***Monitoring for compulsive behaviours***

Statement 2 of the NICE Parkinson's Disease Quality Standard states that adults with Parkinson's disease taking dopaminergic therapy are given information about the risk of impulse control disorders, when starting treatment and at least annually.

The 2019 audit results demonstrate that 68.9% of patients on dopaminergic therapy have had a recorded discussion about compulsive behaviours in the preceding year. This is an upward trend up from 67.4% in 2017 and 64.2% in the 2015 cycle. Neurology services are better at documenting this (70.3% of patients) than Elderly Care (67.7%). Monitoring for compulsive behaviours is particularly pertinent for patients on dopamine agonists, and 20.5% of these patients still appear not to have received advice about potential compulsive behaviours related to their medication. This compares to 19.3% in the previous audit cycle.

Table 7: Evidence recorded that people with Parkinson's taking dopaminergic drugs are monitored for compulsive behaviours

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	67.7%	70.3%	68.9%
No	32.3%	29.7%	31.1%
Number of patients:	2871	2524	5395

Table 8: Evidence recorded that people with Parkinson's taking dopamine agonists are monitored for compulsive behaviours

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	75.7%	83.0%	79.5%
No	24.3%	17.0%	20.5%
Number of patients:	1152	1271	2423



### ***Driving and excessive daytime sleepiness***

Questioning about excessive daytime sleepiness was recorded in just under three-quarters of cases, as in the previous two audit cycles (72.5% in Elderly Care; 71.1% in Neurology). When excessive daytime sleepiness was recorded, its impact on driving was documented in 67.2% of drivers. This is an increase from 56.6% in 2015 and 62.8% in 2017. This does however mean that one third of drivers with documented excessive daytime somnolence do not have documentation about the effect this may have on driving. This is in addition to those drivers who are not asked at all about this very important and potentially dangerous feature.

Table 9: Documented discussions of the impact of known excessive daytime sleepiness in people with Parkinson's who are drivers

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	70.9%	63.4%	67.2%
No	29.1%	36.6%	32.8%
Number of patients:	781	762	1543

### ***Advance care planning***

Of those people who had markers of advanced Parkinson's (22.3%), discussions regarding end-of-life care issues were recorded in only 36.9% (36.8% in 2017). This raises the question of whether advanced Parkinson's is sufficiently well recognised, and whether appropriate conversations regarding end-of-life care are started early enough.

### ***Power of Attorney***

There was a significant increase from 16.9% to 21.6% (at all phases of Parkinson's) of the patient and/or carer having been offered information about, or having set up, a Lasting Power of Attorney (Power of Attorney in Scotland) (Elderly Care 23.4%, Neurology 19.6%). In the 2015 audit only those with markers of advanced Parkinson's were included in this question. By this stage many patients may have significant cognitive impairment and may no longer be able to grant Lasting Power of Attorney. This highlights the value of discussions taking place earlier.

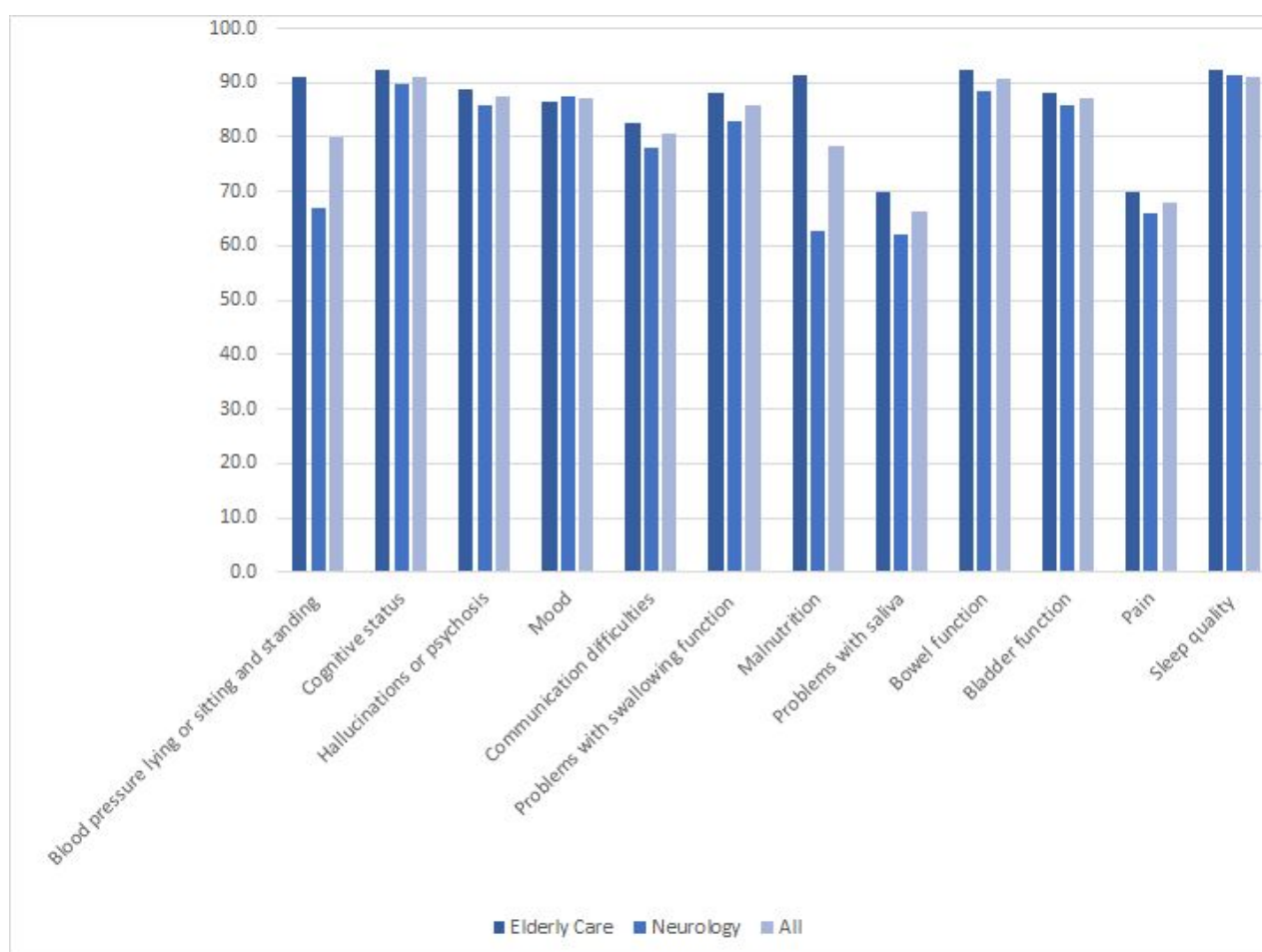
Of note, however, 59.8% of patients in the palliative phase had been offered information about, or had set up, a Lasting Power of Attorney (56.1% in 2017 and 49.5% in 2015).

## Domain scores

The audit recorded whether services completed assessments in three domains: (i) non-motor symptoms, (ii) motor symptoms and Activities of Daily Living and (iii) education and multidisciplinary involvement.

For each element within a domain, total scores were calculated by summing passes (a score of 1) and fails (a score of 0) for each patient. A pass was achieved if the assessment was done. However, a pass was also achieved if an assessment was not done but was considered and not felt to be indicated or appropriate. A fail indicates when an assessment was not done and not considered. Total domain scores were then calculated for each domain.

Figure 2: Domain 1 – Non-motor assessments during the previous year

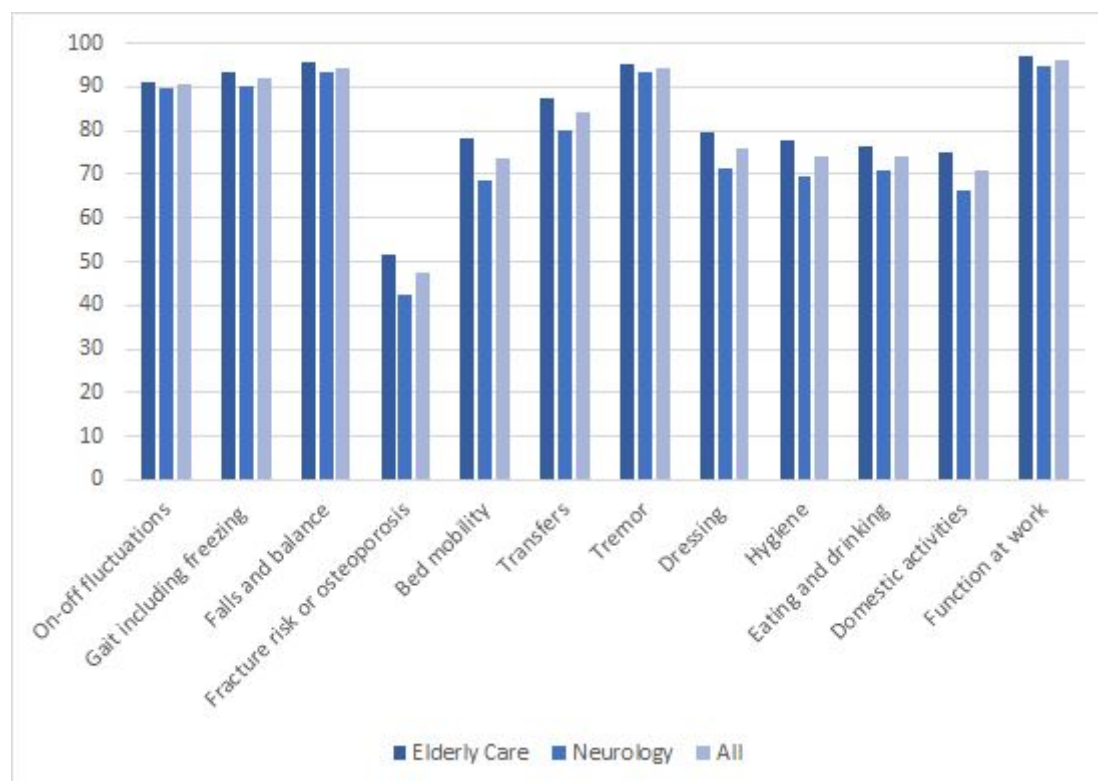


Blood pressure assessment is better documented in Elderly Care (90.9%) than Neurology clinics (67%) though both have improved from 2017 (Elderly Care 86.8%,; Neurology 65.1%). The same continues to be true for malnutrition screening where Elderly Care screen 91.4% of patients and Neurology services screen only 62.7%. Assessments of pain and saliva problems were poorly documented by both services in

2015 and 2017. The services audited in 2019 show no significant improvement at 68.1% and 66.4% respectively.

Mental health however is documented well with 91.1% having evidence of enquiry/assessment re: cognitive function, and 87.4% and 87.1% respectively of patients have been asked about hallucinations/psychosis and mood.

Figure 3: Domain 2 – Assessment of motor symptoms and Activities of Daily Living (ADL) during the previous year



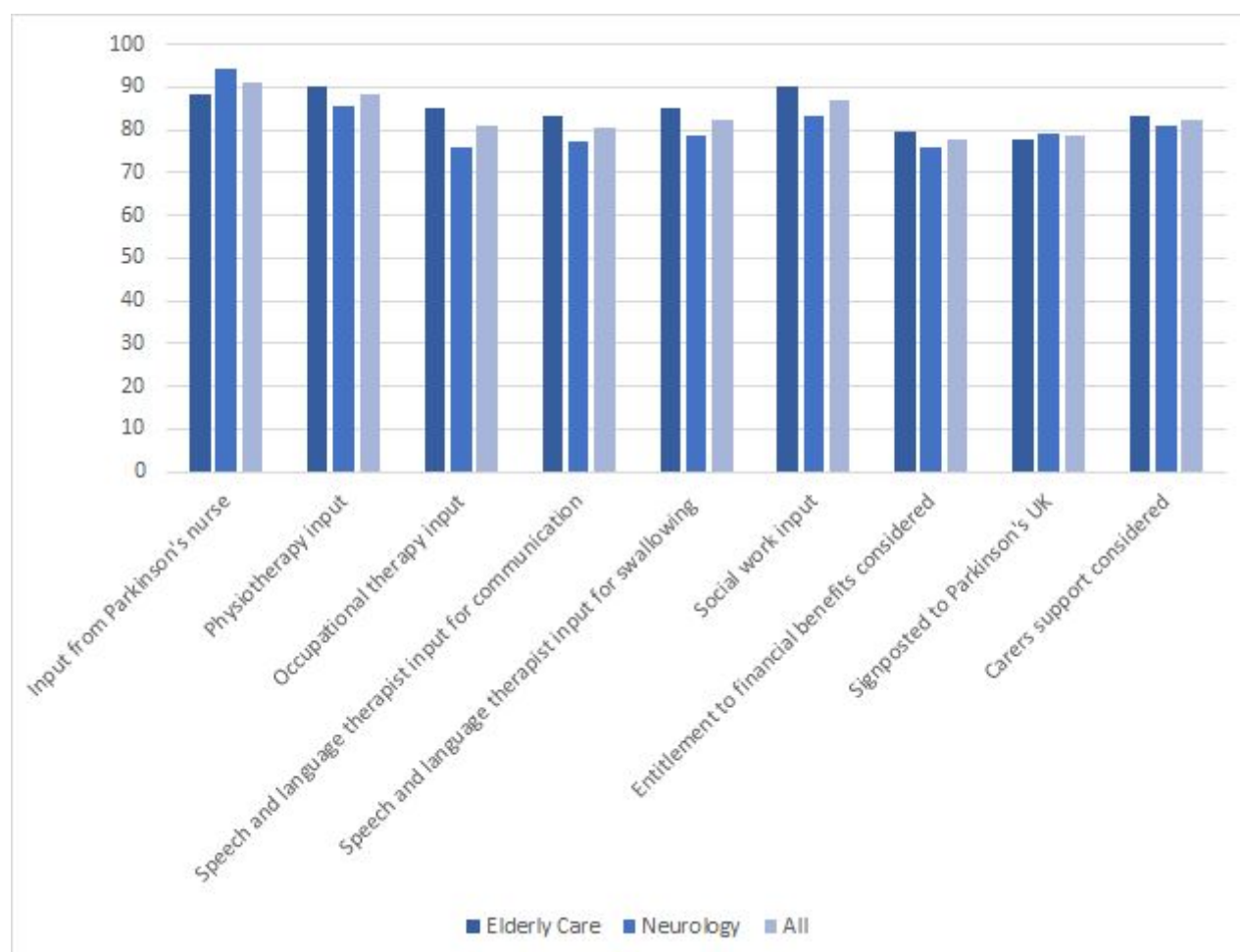
Of those audited people with Parkinson's who are in employment (20.4%), 18.5% had no evidence of enquiry re problems with function at work.

Almost all patients are having falls considered in clinic, with only 5.5% missing out on this key area of enquiry. However the figures show that in 52.4% there is no evidence that fracture risk or osteoporosis has been considered. Given the recently published evidence-based structured approach to assess and improve bone health in this group of patients<sup>3</sup>, we consider this a priority area which we intend to support at a national level. We encourage clinicians to consider joining this national multi-site quality improvement project as a new approach. We would like to evolve from what has previously largely

<sup>3</sup> Parkinsonism and Related Disorders, *Management of fracture risk in Parkinson's: A revised algorithm and focused review of treatments* (2019 Jul;64:181-187.), Henderson EJ, Lyell V2, Bhimjiyani A, Amin J, Kobylecki C, Gregson CL

been a local approach to individual service improvement plans to a more multi-centre model, as we think this will make the process easier and more impactful.

Figure 4: Domain 3 – Education and multidisciplinary involvement during the previous year



The results show that 78.6% of patients and/or carers had been signposted to Parkinson's UK in the last year, or had been previously signposted.

## **Service improvement in Elderly Care and Neurology services resulting from the 2017 audit**

The 2017 Audit highlighted shortcomings in the following areas:

- A multidisciplinary approach to working.
- Recording of blood pressure and weight in Neurology clinics and of pain and saliva in both Elderly Care and Neurology clinics.
- Uptake of Parkinson's-related continuing professional development (CPD) by clinicians.
- Documentation of advice regarding potential impulse control disorders for all dopaminergic therapy.
- Management of bone health.
- Anticipatory care planning.

Services reported implementing the following service improvement measures:

- Plymouth - Delivering Home Based Parkinson's Care. The standard time-locked clinic review was failing to meet the needs of patients and was contributing to staff stress. Through funding from the Health Foundation, a Parkinson's UK service improvement grant and other partners they have developed a new Parkinson's service delivering home-based care, using new technology. Patients will have monitoring of their Parkinson's in their own homes and be able to ask for contact and review at times they need it. Integral to the project is a new way of working for the Parkinson's nurses to ensure they are more supported as part of a larger specialist care team.
- Derby - Mental Health Matters Too. The aim of the project is to demonstrate people with Parkinson's benefit from good mental health care when mental health services are integrated with the Parkinson's Multidisciplinary Team (MDT).
- The Homerton Hospital - Co-designing services. The Homerton Hospital worked with Parkinson's UK to hold a patient focus group to explore patient expectations of their service and what they might be able to do to improve the experience when people come to clinic appointments. The results of the focus group are now being used as part of the wider service redesign of Parkinson's services and the plan is to meet with the group of patients again once this has been implemented to assess if experiences have improved.
- Hull Hospital - new MDT team. Hull Hospital looked at the way they were providing their Parkinson's services and after feedback and discussion with

patients and Commissioners they convened a number of groups to implement a multidisciplinary approach to how they work. The new MDT will now be sharing this work across the Yorkshire and Humber Excellence Network region in 2020.

- The leads of the South East Excellence Network worked with clinicians, introducing them to Quality Improvement principles and PDSA cycles to help them with implementing their Audit action plans. At their meeting in October 2019 each team took away a project to work on and will report back at the next meeting in 2020.

## **Occupational therapy**

### **Aims**

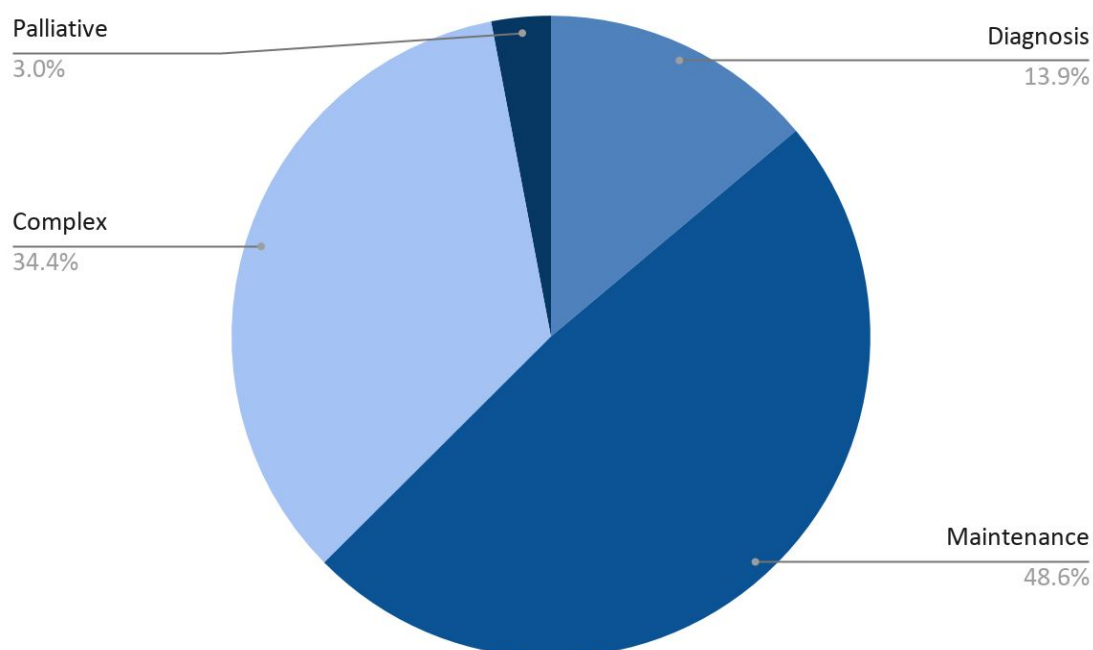
The occupational therapy audit measures whether occupational therapy services are providing quality services for people living with Parkinson's, and examines models of service delivery, referrals, assessment and interventions. It identifies the measures used in assessment and outcomes, the guidance and education available to occupational therapists, and reviews adherence to national guidelines.

### **Demographics**

Occupational therapy services saw 958 people with Parkinson's who were included in the audit. The majority were over 70 years of age (mean age 75.5 years), male (59.6%) and white (92.8%), and the majority of people were living in their own home (93.8%). Of those audited, only 30 people were seen within residential or nursing homes, suggesting that a high proportion of patients who are 'complex' or palliative are managed in the community. It is unclear from the audit data if there are any restrictions in terms of referral source or commissioning pathways for occupational therapists assessing and treating patients in these settings.

The mean length of time between diagnosis and referral for this episode of occupational therapy was six years, and most people are typically still being seen in what is defined as the 'maintenance' phase of the condition, which is consistent with the 2017 audit (46%).

Figure 5: Phase of Parkinson's on referral to occupational therapy



## Service audit

### *Models of service provision*

Only 14.6% of occupational therapy services reported working in an integrated Parkinson's clinic, with occupational therapists typically working in the community seeing patients in their own home or as outpatients in day hospital settings.

Table 10: Setting in which Parkinson's patients are usually seen

Setting in which patients usually seen	Services
Integrated medical and therapy Parkinson's clinic	14.6%
Community rehabilitation service	25.6%
Social services including reablement	1.2%
Outpatient/day hospital	23.2%
Individual's home	26.8%
Other	8.5%
Number of services:	82

Overall, in 2019 58.5% of the occupational therapy services audited specialised in neurological conditions, and 59.8% specialised in the treatment of Parkinson's.



It should be noted that the audited therapists indicated that the number of people with Parkinson's make up less than 40% of their caseload, emphasising they have mixed conditions caseloads, with 41.5% not specialising in neurological conditions.

Table 11: Percentage of individuals referred to a service annually with a diagnosis of Parkinson's

Referrals with a diagnosis of Parkinson's	Services
0-19%	36.6%
20-39%	35.4%
40-59%	13.4%
60-79%	3.7%
80-100%	11.0%
Number of services:	82

### ***Accessing Parkinson's-related Continuing Professional Development (CPD)***

Of the 82 occupational therapy services audited, 74 (90.2%) reported having opportunities to undertake Parkinson's related CPD (84.8% in 2017).

Specialist induction was highlighted as an area for improvement from the 2017 audit, so it is reassuring to see there has been a gradual upward trend over the last three audits with 40.2% of services offering new occupational therapists Parkinson's specific induction and support strategies (30.5% in 2017, 23.4% in 2015). However, 26.8% of occupational therapy services still offer no induction, with the remaining 32.9% reporting they offer Parkinson's induction and support within their general competencies.

Support in the form of education and advice is available to those individual occupational therapists working in specialist services from other MDT members. Therapists not working directly in Parkinson's clinics report they can seek this externally from a Parkinson's specialist MDT or nurse. The audit data shown in Table 12 suggests that there has been a downward trend in occupational therapists seeking support from other MDT members. This could correlate to there being a decline in Parkinson's specific specialist services and therapists having a caseload of mixed conditions.

Table 12: Support available to individual occupational therapists working in the service

Support available to individual occupational therapists	Services	
	2017	2019
Can consult any member of the Parkinson's specialist MDT of which they are a member	66.1%	48.8%
Can consult members of a general neurology/elderly care specialist service of which they are a member	8.5%	13.4%
Don't work directly in specialist Parkinson's clinics but access to Parkinson's specialist MDT/Parkinson's nurse specialist	22.0%	30.5%
Don't work directly in a specialist clinic but access to advice from a specialist neurology or elderly care MDT	1.7%	6.1%
No access to more specialised advice	1.7%	1.2%
Number of services:	59	82

### ***Use of standardised assessments and outcome measures***

Within this audit, therapists indicated they use a combination of assessment approaches, with the majority completing face to face interviews with the patient (97.6%), functional assessments (93.9%) and 80.5% of services conducting an MDT assessment.

As in previous audits, occupational therapists use an array of assessments and outcome measures with people living with Parkinson's in clinical practice. This reflects what is stated in the Royal College of Occupational Therapy guideline<sup>4</sup>: "There is currently no comprehensive, standardised, occupational therapy assessment or measurement tool specific to Parkinson's. In daily clinical practice, occupational therapists use a wide range of standardised and in-house assessment formats, with no single uniform assessment currently being used by occupational therapists in the UK".

Standardised assessments were reported to be used by 69.5% of services, a downward trend from 84.7% in the 2017 audit. This could be indicative of more occupational therapy services participating in this year's audit, and reduced specialist neurological services, and may indicate a strain on therapy services, with some occupational therapists citing staffing levels and time limitations as barriers.

The RCOT guideline highlights Parkinson's specific tools which measure activities of daily living and suggests three appropriate measures for use with people living with Parkinson's.

- Canadian Occupational Performance Measure (COPM)
- Assessment of Motor and process skills (AMPS)

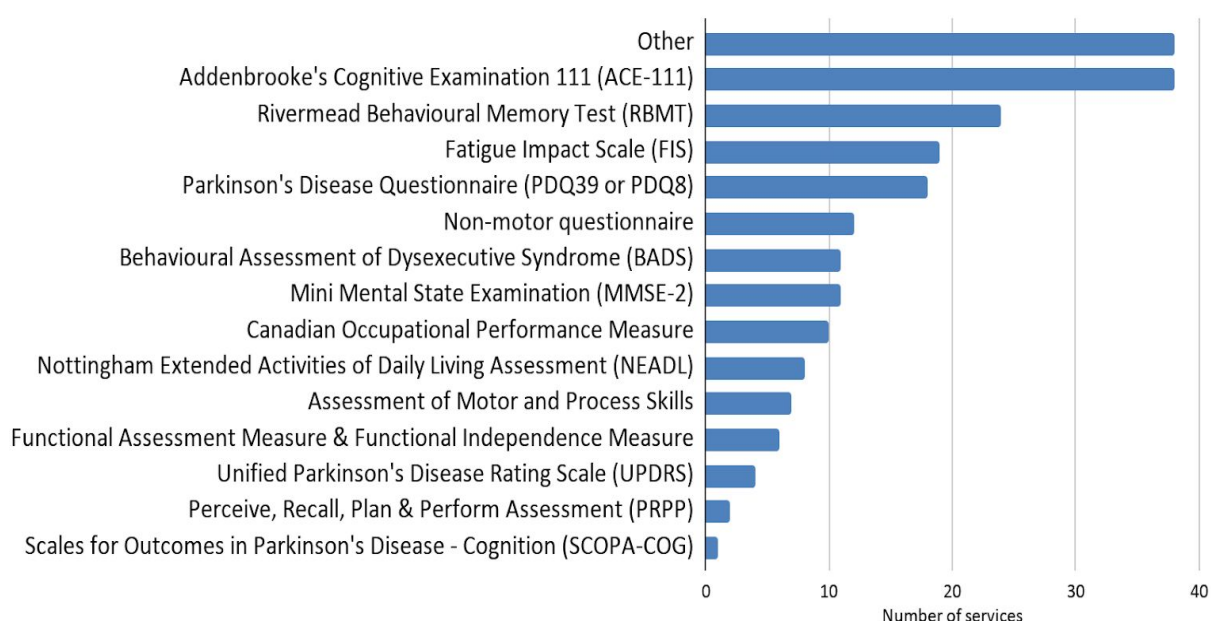
<sup>4</sup> Royal College of Occupational Therapy (2018), *Occupational Therapy for people with Parkinson's*, Ana Aragon and Jill Kings

- Fatigue Impact Scale (FIS)

These were reported in the audit to be used by occupational therapists, with AMPS used by up to 8.5%, COPM 12.2.% and the FIS being used by 23.2% of services.

Other assessments or measures used by therapists fit into the themes of cognition (Montreal Cognitive Assessment, Cognitive Assessment of Minnesota), those focused on goal setting, (Goal Attainment Scaling, Therapy Outcome Measures), mood, fatigue and general health.

Figure 6: Number of occupational therapy services using standardised assessments



## Patient audit

### ***Referral to occupational therapy***

Referrals to occupational therapy continue to be made from a variety of sources, Parkinson's specialist nurses, neurologists, geriatricians, physiotherapists, GP's, social workers and self-referral, with the majority triggered as a result of a medical review (57.2%; 62.3% in 2017). As discussed previously, the highest number of referrals made to occupational therapy is for Parkinson's patients within the maintenance phase, and although this falls below the expectation of NICE guidelines<sup>5</sup>, 91.1% of the referrals were judged by the therapists to be made at an appropriate time.

The quality of essential information recorded on referrals was generally good with 69.3% referrals having this. However of the 958 patients audited 237 referrals lacked

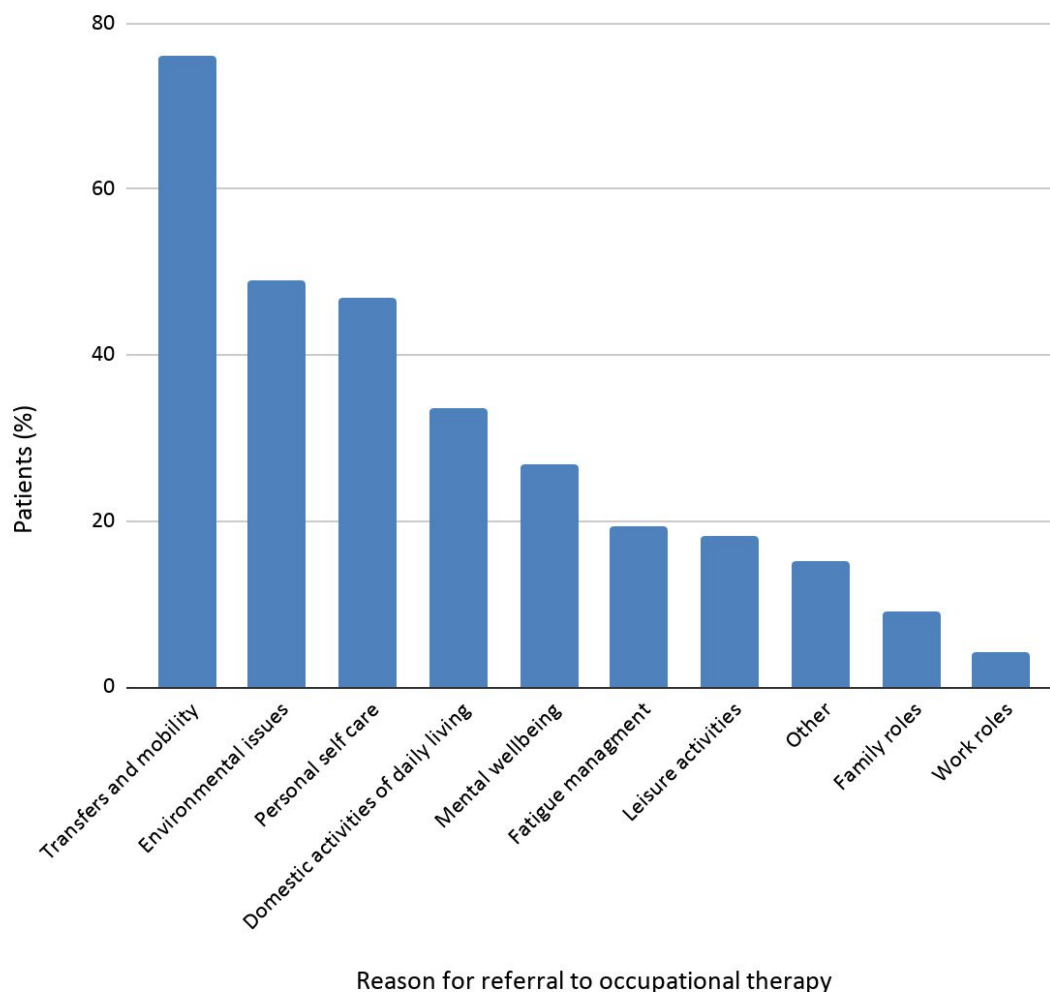
<sup>5</sup> NICE (2017), *Parkinson's Disease in Adults* [NG71]

information and 57 referrals did not have sufficient details documented with comments from therapists advising that referrals lacked past medical history, environmental or social issues, no reason for referral given or vague information such as 'therapy review'. This could be an area for further development to improve service delivery with integrated coordinated communication.

Table 13: Time from diagnosis and occupational therapy referral to this episode

<b>Time between diagnosis and referral</b>	<b>Patients</b>
Less than 1 year	17.6%
1-2 years	15.2%
3-5 years	24.4%
6-10 years	24.8%
11-15 years	10.8%
16-20 years	5.8%
More than 20 years	1.4%
Number of patients:	935

Figure 7: Reasons for referral to occupational therapy



Most patients are seen for individual occupational therapy (68.3%), with 31.7% being seen individually and in a group, the audit indicated none are seen in a group setting only.

It is encouraging to see that goals are being set in collaboration with patients (64.2%) or led by patients (22.1%) or by their family (2.4%). In a small sample (7.9%) goals were set by the therapist, with only 3.3% of the 'other' audited patients either given advice only or occupational therapy goals were not identified. This is in line with best practice guidance.

### ***Evidence used to inform practice***

There has been no change in occupational therapists relying heavily on clinical experience to guide their practice (97.5%), with only just over half (55.4%) seeking peer support, a reduction on the last audit. (71.0% in 2017)

Worryingly, therapists are utilising Parkinson's specific documents and guidance less, and this is particularly pertinent with the launch of the NICE quality standard (QS164) and RCOT best practice guidance in 2018.

Table 14: Evidence used in occupational therapy to inform clinical practice and choice of intervention for patients.

<b>Evidence used by the audited therapist</b>	<b>Patients</b>
Clinical experience	97.5%
Advice from colleague or supervisor	55.4%
Occupational therapy for people with Parkinson's - best practice guide 2nd edition	57.6%
Information from Parkinson's UK website	49.8%
National Service Framework for Long term Conditions (2005)	37.1%
NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017)	49.7%
Published evidence in a peer reviewed journal	14.7%
Training courses	52.0%
Webinars, social media	10.3%
Other	5.6%
None	1.1%
Number of patients:	958

### ***Occupational therapist Band***

There has been very little change, with over half of people still being initially assessed by a Band 6 occupational therapist (57.5%; 52.6% in 2017). There has been a marginal downward trend in the number of Bands 4, 5 and 7 completing initial assessments and the data shows that 22 of the audited 958 patients were completed by 'other'. It was not specified who conducted this other than that they were not Band 4–8 or social services grade junior/senior, so could be a lower band therapy technician.

The NICE guideline and RCOT Best Practice guidance recommend that assessment is delivered by an occupational therapist with Parkinson's specific experience. With under half of services not being specialist, therapists having mixed caseloads, using clinical experience to inform their practice, we need to be mindful that using unqualified or support staff is not best practice and there may not be the support mechanisms of supervision or CPD in place from therapists with Parkinson's specific knowledge and experience.

## **Service improvement in occupational therapy services resulting from the 2017 audit**

The 2017 Audit highlighted shortcomings in the following areas:

- Specialist induction.
- Use of evidence-based practice rather than reliance on clinical experience and peer support.
- Use of standardised assessments and outcome measures to guide occupation-based intervention.
- Use of outcome measures to support service development

Occupational therapy services reported implementing the following service improvement measures:

- A high percentage of services identified that a key area of improvement for them was ensuring that they were consistently using standardised assessments and outcome measures and ensuring that they were looking at Activities of Daily Living and Non-Motor Symptoms
- In 2017 the acute trust in Leeds introduced a specialist occupational therapist within the outpatient clinic setting and inpatient care to support discharge planning and independence, with the aim of achieving a reduction in length of stay and readmissions. The role was an integral part of the multidisciplinary team, to assess and support people with activities of daily living. The outcomes for patients were really positive and plans are underway to share this work and look at how it can be rolled out across the Trust and how it could be replicated with community or GP settings to try and reach patients before they are admitted to hospital

## **Physiotherapy**

### **Aims**

The physiotherapy audit establishes whether physiotherapy services are currently providing quality services and interventions for people with Parkinson's (taking into account recommendations from evidence-based guidelines and using standardised assessments). It allows for benchmarking of local services against good practice standards and guidance for physiotherapy in Parkinson's, as well as local and national mapping of service provision, patient management and access to continuing professional education.

### **Demographics**

Physiotherapists in 153 services registered for the audit, and reported on 2,099 people with Parkinson's receiving physiotherapy. Patients were aged between 29 and 99 years (mean age 73.7 years) and just 2.9% were living in residential or nursing homes. This raises some questions about access to physiotherapy for people with Parkinson's living in these settings. The majority were male (62.8%) and white (87.8%). Mean age at diagnosis was 68.7 years and audited patients had a mean disease duration of 5.1 years (range 0-33 years).

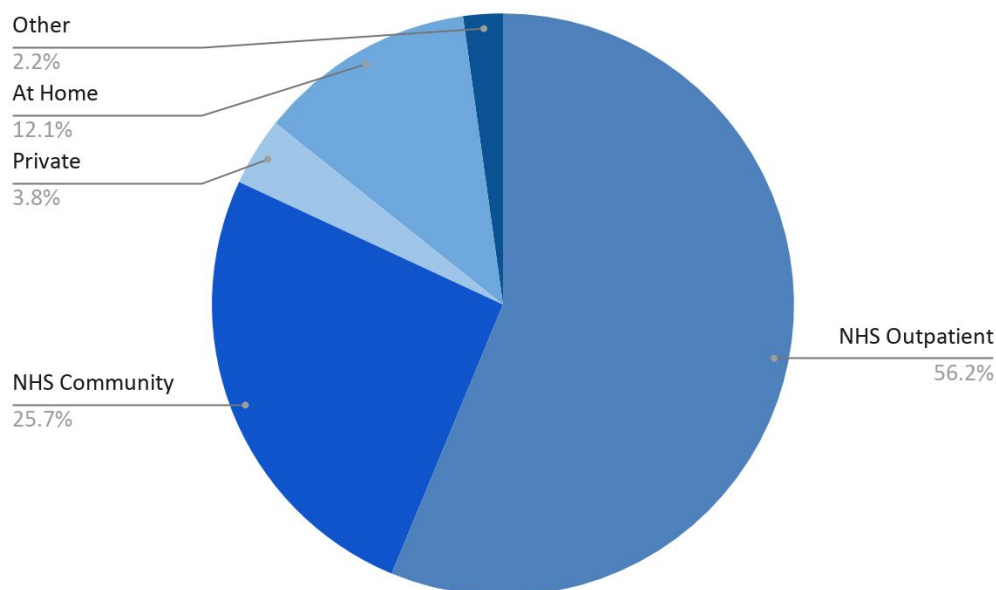
### **Service audit**

#### ***Model of service provision***

Of the 153 physiotherapy services that participated in the audit, only 13.7% reported working in an integrated Parkinson's clinic, but 62.1% (95) offered assessment as part of a multidisciplinary team (MDT). It was reported that 70.6% of the 153 specialised in neurological conditions, with 60.8% specialising in the treatment of Parkinson's. The majority of services (73; 47.7%) were based in the community, within rehabilitation or day hospital teams with only 26 (17.0%) seen in an acute outpatient setting.



Figure 8: The settings in which people with Parkinson's are seen for physiotherapy



The 83 services providing physiotherapy to people with Parkinson's both individually and in groups (54.2%) stated that the groups focused on exercise (75.8%) and patient education (68.6%). This is an upward trend of 14.4% of groups with a focus on exercise since the 2017 audit, suggesting that the importance of exercise for people with Parkinson's is being delivered more frequently by physiotherapists.

### ***Accessing Parkinson's related Continuous Professional Development (CPD) and induction and support strategies***

Although 140 (91.5%) of the 153 services offered access to Parkinson's related CPD at least annually, documented induction and support strategies were not available for new physiotherapists working with individuals with Parkinson's in 65 services (42.5%). This raises concerns about the provision of support for physiotherapists taking up new posts, or those rotating into new specialities, who may not have previous experience in working with people with Parkinson's. The number of physiotherapists not working directly in specialist Parkinson's clinics has increased since the 2017 audit, but services reported that these therapists were able to access support from a Parkinson's MDT or specialist nurse (Table 15). There was a reduction in the number of physiotherapists reporting they can access support from within their own Parkinson's Specialist team, suggesting a reduced number of physiotherapists working in specialist Parkinson's teams over the past 2 years.

It was reported by three (2%) services that individual physiotherapists have no access to support of any kind.

Table 15: Support available to individual physiotherapists working in the service

Support available to individual physiotherapists	Services	
	2017	2019
Can consult any member of the Parkinson's specialist MDT of which they are a member	44.2%	30.1%
Can consult members of a general neurology/elderly care specialist service of which they are a member	14.7%	13.1%
Don't work directly in specialist Parkinson's clinics but access to Parkinson's specialist MDT/Parkinson's nurse specialist	35.8%	48.4%
Don't work directly in a specialist clinic but access to advice from a specialist neurology or elderly care MDT	3.2%	6.5%
No access to more specialised advice	2.1%	2.0%
Number of services:	95	153

## Patient audit

### *Referral to physiotherapy*

Of the 2099 people with Parkinson's, 493 (62.4%) were referred to physiotherapy within two years of diagnosis. This is an improvement from the 2017 audit which reported that 52.0% (253 cases) were referred within those first two years. This is in line with the NICE guideline which suggests considering referral of people in the early stages of Parkinson's to a physiotherapist with experience of Parkinson's for assessment, education and advice, including information about physical activity.

A further 140 (17.7%) were referred within three to five years, but 155 (19.6%) were not referred until they had been diagnosed from between six and 20 years, with a further two individuals (0.3%) more than 20 years.

Table 16 : Physiotherapy - time between diagnosis and referral

Time between diagnosis and referral	Patients
Less than 1 year	34.8%
1-2 years	27.6%
3-5 years	17.7%
6-10 years	13.5%
11-15 years	5.2%
16-20 years	0.9%
More than 20 years	0.3%
Number of patients:	790

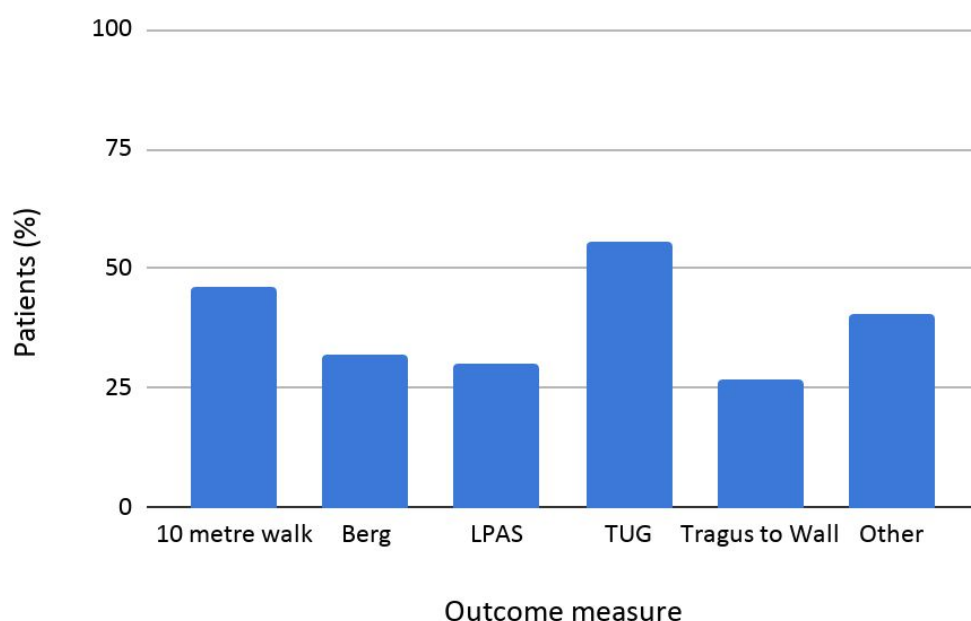
Of these 2099 individuals, 280 were in the diagnosis phase (13.3%), 1225 in maintenance (58.4%), 564 in complex (26.9%) and 30 (1.4%) in palliative. Physiotherapy

had not previously been offered for management of Parkinson's to 1049 (50.0%), and 16 (0.8%) had been offered physiotherapy referral, but had declined.

### ***Use of goal plans and appropriate outcome measures by physiotherapists***

Physiotherapy notes included a goal plan in 2027 (96.6%) of the 2099 cases, but there was a reduction in the number of cases using Parkinson's-specific outcome measures from 85.2% in the 2017 audit to 78.5% in 2019.

Figure 9: Most frequently used physiotherapy outcome measures



In many cases, more than one outcome measure was used and in 670 (40.5%) cases “other” outcome measures (other than the audit suggested list) were used. Many of these were not Parkinson's-specific and in some cases, not physiotherapy-specific. In 94 of the 2099 cases (4.5%) physiotherapists reported that no outcome measures were used although this was fewer than in 2017 (15.4%)

This neither meets the Chartered Society of Physiotherapy (CSP) standards nor the recommendations in the European Physiotherapy Guideline for Parkinson's<sup>6</sup> which states: “Use of measurement tools supports structured, objective and transparent assessment, evaluation and communication. However, this is only the case when appropriate tools are selected and the results well interpreted.” The guideline also includes a table of selection criteria for management tools which suggest that, in order for a scale to be valid, it should measure what it is supposed to measure, has meaning for

<sup>6</sup> Royal Dutch Society for Physical Therapy (KNGF) (2014) *The European Physiotherapy Guideline for Parkinson's Disease*, Keus et al

the person with Parkinson's, and is within the scope of physiotherapy for Parkinson's. In order for it to be a feasible tool, the benefits of using it should outweigh the burden in terms of costs, time, space and effort and that it should be "currently used by (many) physiotherapists)".

NHS England RightCare Toolkit<sup>7</sup> also highlights the importance of using appropriate outcome measures, stating a key area for focus is "consistent use of evidence based standardised assessment and outcomes frameworks". It continues: "...use of standardised assessments across all care settings will facilitate better patient care and ensure that disease progression can be monitored effectively".

Every physiotherapist has free access to these guidelines and those working with people with Parkinson's should be using appropriate outcome measurements.

### ***Physiotherapist Band***

Initial assessments were carried out by a Band 5 in 141 cases (6.7%), Band 6 or 7 physiotherapist in 1787 (85.2%) and 60 (2.9%) were conducted by a Band 8a. A further 54 (2.6%) were seen by grades "other" than Band 4-8b but "other" was not specified. However, in 56 (2.7%) of cases the initial physiotherapy assessment was carried out by a Band 4. The CSP states that "initial assessment is expected to be made by a registered practitioner" who may then delegate ongoing treatment and re-assessment to support staff, such as Band 4. It also states that "In some instances, where a clear protocol has been produced or a specific client group in a particular environment, the support worker may have delegated discretion, alongside limited and defined autonomy for some elements of continual assessment. It is essential that the role and specific activities of the support worker are made explicit, in the design of such protocols"<sup>8</sup>. This raises several questions about initial assessments being carried out by unregistered staff, which is not supported by the NICE guidelines or CSP standards.

### ***Evidence based practice and training***

The European Physiotherapy Guideline for Parkinson's Disease was used to inform clinical practice in 1080 (51.5%) of cases (49.7% in 2017). There was an increase in the total number (39) who reported that none of the guidelines listed in the audit, no advice from colleagues nor personal expertise were used to inform their clinical practice (1.9% in 2019 compared to 0.3% in 2017). In 1107 (52.7%) cases the physiotherapist had attended postgraduate training specific to Parkinson's within the previous 24 months, an increase of 47.1% from 2017, but it is unclear whether the training included a physiotherapy-specific update including the latest evidence-based guidelines, or whether it was a general update about Parkinson's as part of a multidisciplinary conference. In a

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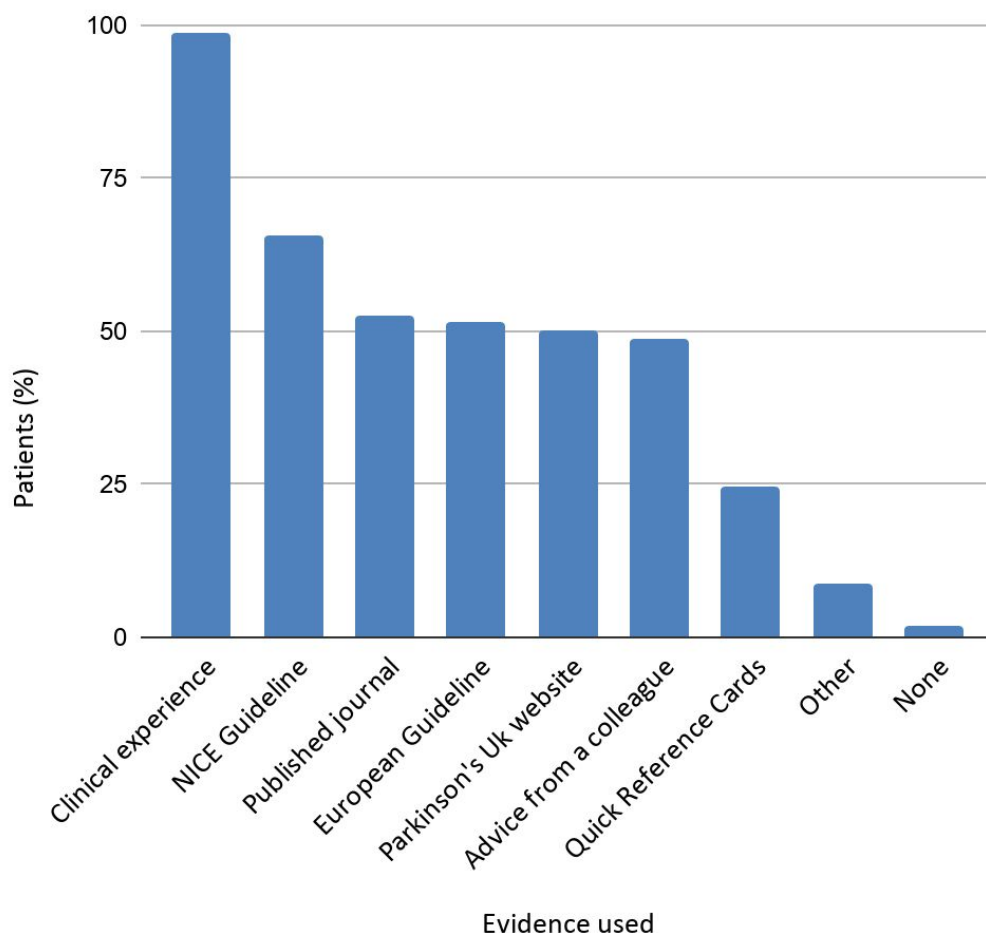
<sup>7</sup> NHS RightCare, Progressive Neurological Conditions Toolkit

<https://www.england.nhs.uk/rightcare/products/pathways/progressive-neurological-conditions-toolkit/>

<sup>8</sup> Chartered Society of Physiotherapy Supervision, Accountability & Delegation – PD126 (April 2017)

total of 992 cases (47.3%) the physiotherapist had not had access to Parkinson's-specific training in the last 24 months and this raises questions and concerns about support for physiotherapist accessing continual professional development (CPD) as well as the impact this can have on overall standards of care from health professionals for people with Parkinson's across the country.

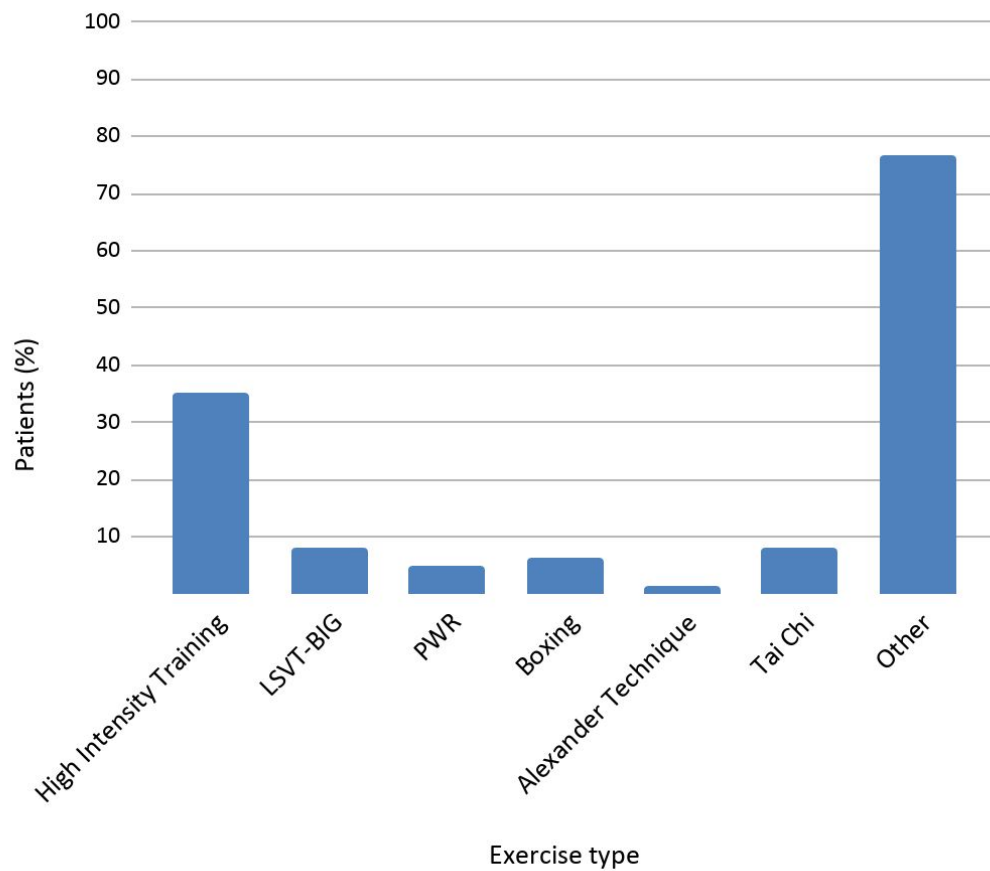
Figure 10: Percentage of physiotherapy patient cases with evidence used to inform clinical practice and guide intervention



## Exercise

Almost all physiotherapists (95.2%) reported offering exercise (advice and/or intervention) to individuals. This was a new question for the 2019 audit, and exercise types were wide-ranging. The most commonly offered was High Intensity Training (HIT).

Figure 11: Percentage of physiotherapy patient cases offered exercise



"Other" included pilates, yoga, individualised exercise programmes tailored to the individuals specific needs, with many focusing on posture, balance, gait and transfers.

## **Service improvement in physiotherapy services resulting from the 2017 audit**

The 2017 Audit highlighted shortcomings in the following areas:

- Use of appropriate outcome measures for people with Parkinson's based on guidelines and best practice.
- Physiotherapists not using outcome measures.
- Provision of induction and support for new physiotherapists working with people with Parkinson's.
- Initial assessment by unregistered therapy support staff (e.g. Band 4).
- Referral to physiotherapy for patients in the diagnosis phase.

Physiotherapy services reported implementing the following service improvement measures:

- The Queen Elizabeth University Hospital (QEUII) and Gartnavel General Hospital (GGH) were awarded a service improvement grant to look at three key areas: improving the care of people with Parkinson's across the hospital including increased support to ward therapists, improved access to specialist physiotherapy at the point of diagnosis and improved adherence to exercise by providing an integrated physiotherapy review service at both sites. Whilst in the early stages, this project is already showing some positive results in feedback from staff and patients.
- A number of services recognised the lack of induction and support for new staff as part of their service improvement plan following their participation in the 2017 Audit. Lancashire Care NHS Trust will be designing and implementing an induction pack.
- In Newcastle there was a focus on very bespoke areas of care for people who were undergoing DBS procedures. One vital element that was missing from the service was input to physiotherapy pre- and post-operatively. Following positive results for a small group of patients the team are now looking for funding to continue and expand the service.
- A number of services were able to demonstrate the need for additional dedicated Parkinson's physiotherapy posts.

## Speech and language therapy

### Aims

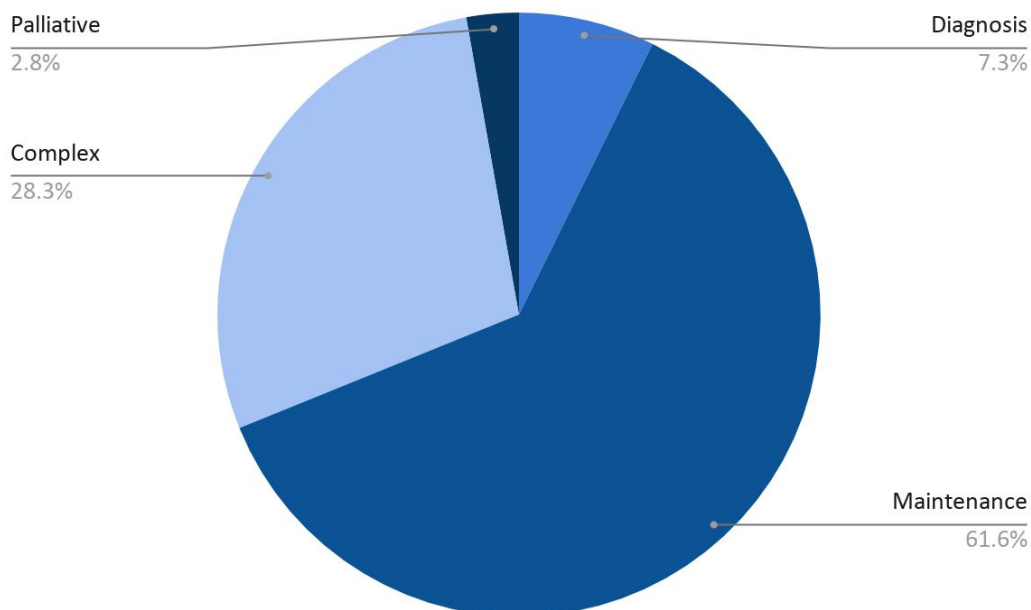
The speech and language therapy audit intended to examine the models of service delivery including timings and source of referral, nature of concerns patients are seen for, the types of assessment and interventions used, information giving and support and whether practice adheres to national guidelines. It also examined the seniority of staff, their experience and their ongoing professional development in Parkinson's.

### Demographics

Speech and language therapists in 79 services (64 in 2017) registered for the audit reported on 1022 people with Parkinson's (810 in 2017). Patients were aged between 34 and 95 years (mean 73.7 years), the majority were male (67.1%) and living in their own home (89.5%). Audited patients had a mean Parkinson's duration of 6.6 years (range 0-36 years).

While the NICE guideline recommends referring patients to speech and language therapy in the early phase of the condition for assessment, education and advice, most patients continue to be seen in the maintenance phase (61.5% 2019, 60.7% 2017). As in 2017 far fewer patients were seen in the complex (28.3% 2019, 17.3% 2017) and palliative phase (2.8% 2019, 1.2% 2017).

Figure 12: Phase of Parkinson's on this referral to speech and language therapy





## Service audit

### *Model of service provision*

Most people with Parkinson's continue to be seen within general adult acquired speech and language disorder services (86.2% 2019, 90.6% 2017).

The number of services taking part in the audit that specialise in neurological conditions remains largely unchanged (72.2% 2019, 71.9% 2017), although there was a slight upward trend in services specialising in the treatment of Parkinson's (54.4% 2019, 50.0% 2017). Only nine speech and language therapy services saw patients with Parkinson's in a specialist Parkinson's clinic (11.4% 2019, 4.7% 2017). This number remains low.

The number of services taking part in the audit for whom approximately 80-100% of referrals annually are for patients with Parkinson's was 7.6% (6.3% 2017) whilst services for whom 60-79% of referrals are for patients with Parkinson's was 8.9% (7.9% 2017). It may be that more patients with Parkinson's are being referred to speech and language therapy services or that increased numbers of specialised services are taking part in the audit.

Overall, most patients continue to be treated by therapists for whom Parkinson's is part of a mixed caseload and not a specialised service.

Table 17: Percentage of individuals referred to a service annually with a diagnosis of Parkinson's

Individuals referred annually with a diagnosis of Parkinson's	Services	
	2017	2019
0-19%	59.4%	57.0%
20-39%	23.4%	24.1%
40-59%	7.8%	10.1%
60-79%	1.6%	1.3%
80-100%	6.3%	7.6%
Missing	1.6%	0%
Number of services:	64	79

### *Accessing Parkinson's-related Continuing Professional Development (CPD)*

2019 saw the launch of the UK Parkinson's Excellence Network's learning pathway for therapists making it easier to access Parkinson's specific learning. Indeed, there was an upward trend in services reporting having opportunities to undertake Parkinson's-related CPD this year (87.3% 2019, 81.3% 2017).

Unfortunately, the number of services providing specific induction and support strategies for staff new to working with people with Parkinson's remains low (19.0% 2019, 17.2% 2017) with around half of services including Parkinson's within more general competencies (50.6% 2019, 62.5% 2017). Having Parkinson's specific induction strategies is essential in supporting therapists to offer high quality care. This is especially true given that most therapists see people with Parkinson's as part of a generalist caseload. It is of concern that more services audited (30.4% 2019, 20.3% 2017) reported having no induction and support strategies for new therapists. A working party has been established by the UK Parkinson's Excellence Network to create a best practice guideline for speech and language therapy which may act as a key driver for improvement in this area.

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

As in previous years almost all speech and language therapy services offered a full service for communication difficulties (98.7% 2019, 93.8% 2017), for swallowing (97.5% 2019, 93.8% 2017) and drooling (93.7% 2019, 90.6% 2017).

Whilst some services remain unable to provide Lee Silverman Voice Treatment (LSVT) to all potentially eligible people with Parkinson's (7.6%), for the first time the LSVT programme was offered in full by over half of services (55.7% 2019). This continues to increase with each audit cycle (43.8% 2017, 34.9% 2015). There was also a corresponding decrease in the number of services offering similar alternatives to LSVT (17.7% 2019, 28.1% 2017). This might reflect a greater number of LSVT trained therapists or an increase in services that provide LSVT taking part in the audit.

### **Patient audit**

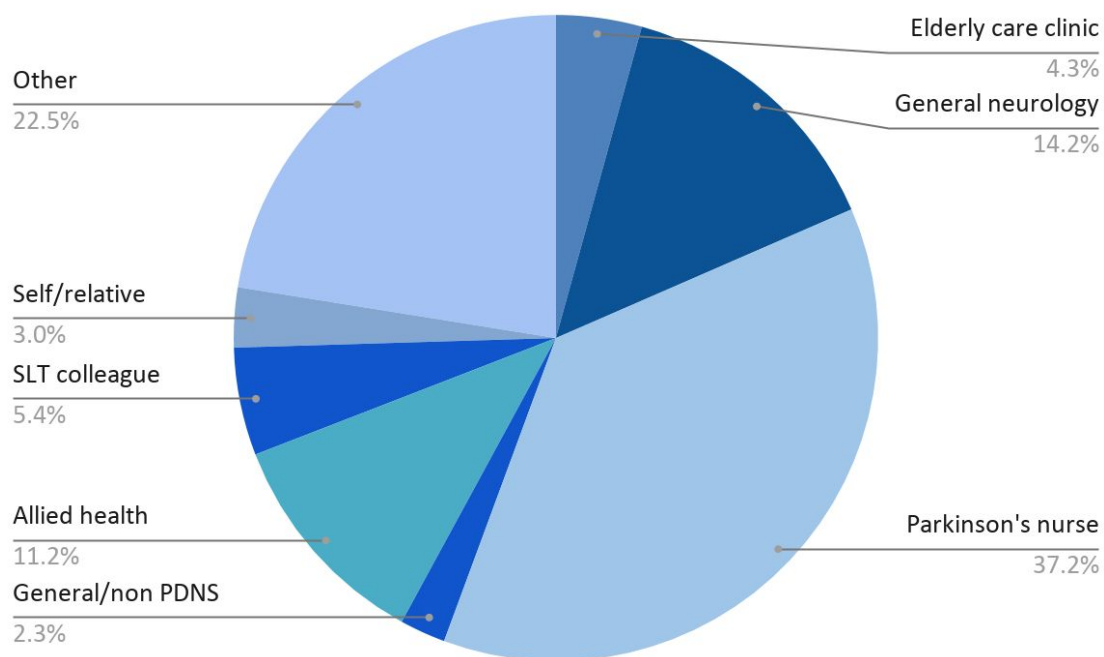
#### ***Referral to speech and language therapy***

Most patients continue to be seen within target wait times (84.1% 2019, 86.8% 2017). As in other areas of health and social care an ageing population and a rise in the number of people living with Parkinson's are likely to increase pressures on speech and language services. Robust systems need to be in place to ensure patients continue to be seen in a timely manner and the reduction in patients being seen within target wait times does not become a trend.

Patients were referred primarily for specific opinions regarding speech (70.8%) and swallowing (53.5%) with far fewer referred for assessment of drooling (11.1%), language (8.0%) and cognition (2.8%). Some patients will have been referred for and have had assessments in multiple domains.

As seen in Figure 13, most referrals to speech and language therapy continue to originate from Parkinson's Disease nurse specialists (37.2% 2019, 32.7% 2017). There is then an on-going need for services to make strong links with their nurse specialist colleagues, but also for services to raise awareness of referral pathways amongst the wider healthcare community. Many referrals continue to come from 'other' sources (22.5 % 2019, 21.0% 2017) and this would benefit from more careful consideration in the next audit.

Figure 13: Source of referral to speech and language therapy services



### ***Content of assessment***

75.4% and 59.4% of patients had a recorded communication assessment and a recorded swallowing assessment respectively at initial consultation (94.0% and 98.9% respectively of eligible cases).

Most patients were seen for communication assessment in a one to one context (93.0% 2019, 87.1% 2017) with the therapist considering the impact of Parkinson's on the patient's communication (87.4%), communication participation (83.9% 2019, 85.0% 2017) as well as the patients communication strengths and needs in both their current and likely environment (79.6%). Only 61.6% of assessments considered the impact of the patient's communication changes on the partner or carer. Engaging communication partners is essential in promoting shared decision making, in achieving functional improvements with therapy and reducing carer burden/stress.

As in previous years speech assessment focused primarily on loudness (94.4% 2019, 62.9% 2017) as well as phonation including voice quality (83.5% 2019) and articulation and speech rate (76.8% 2019). Whilst the Dutch guidelines<sup>9</sup> note that people with Parkinson's should be explicitly asked about difficulties with word finding and conversations, only 40% of patients had observations of or patient reported word finding difficulties recorded. Just 7.7% of these amounted to a formal or informal word finding assessment.

As seen in Table 18 the measurement of intelligibility was at 82.1% in 2019 (78.0% 2017), the use of standardised intelligibility assessments was at 14.4% in 2019 (10.3% 2017). This was a key area for improvement from the 2017 audit and remains so. Intelligibility assessment is a vital part of the perceptual assessment of motor speech disorders as it usually forms one of the primary outcome measures on which treatment is based. A robust baseline pre and post treatment is therefore essential and recommended in the RCSLT Clinical Guidelines<sup>10</sup> (2005). With 24.1% of patients seen for an initial assessment only, services should consider what outcome measures are used and how these are being recorded for such patients.

Table 18: Intelligibility assessed (in individuals not seen for swallow only)

Intelligibility assessed	Patients	
	2017	2019
Standardised diagnostic intelligibility test completed and score given	10.3%	14.4%
Informal assessment, non-standardised/subsection of other test completed and score given	33.3%	23.6%
Informal assessment (e.g. rating scale) completed	34.4%	44.1%
No assessment/results documented but justification given	10.4%	8.7%
No assessment/results but no justification given	11.7%	9.2%
Number of patients	634	771

Despite being recommended in the Dutch Guidelines and in the RCSLT Clinical Guidelines (2005) only 21.3% of communication assessments included an audio/video recording of the patient (24.6% 2017). Both can be useful tools for providing feedback given that patients with Parkinson's are known to overestimate their loudness and speech intelligibility in conversation, but not when listening to recordings (Dutch Guidelines).

Again, despite being recommended in the Dutch Guidelines, in 68.8% of patients audited there was no documentation of whether the patient was seen during an 'on' or 'off' phase

<sup>9</sup> ParkinsonNet *Guideline for speech-language therapy in Parkinson's disease* (2011), Kalf J G, de Swart B J M, Bonnier M

<sup>10</sup> Royal College of Speech and Language Therapy *Clinical Guidelines* (2005)

at the time of assessment. This is essential as swallowing and communication abilities may vary in line with timings of medication and will therefore have a direct impact on assessment outcomes and resulting therapy/management plans.

### ***Care planning***

There was a clear plan of management based on assessment outcomes documented for 94.9% of patients (90.4% in 2017). This remains an area of strength in speech and language therapy services.

### ***Content of therapy***

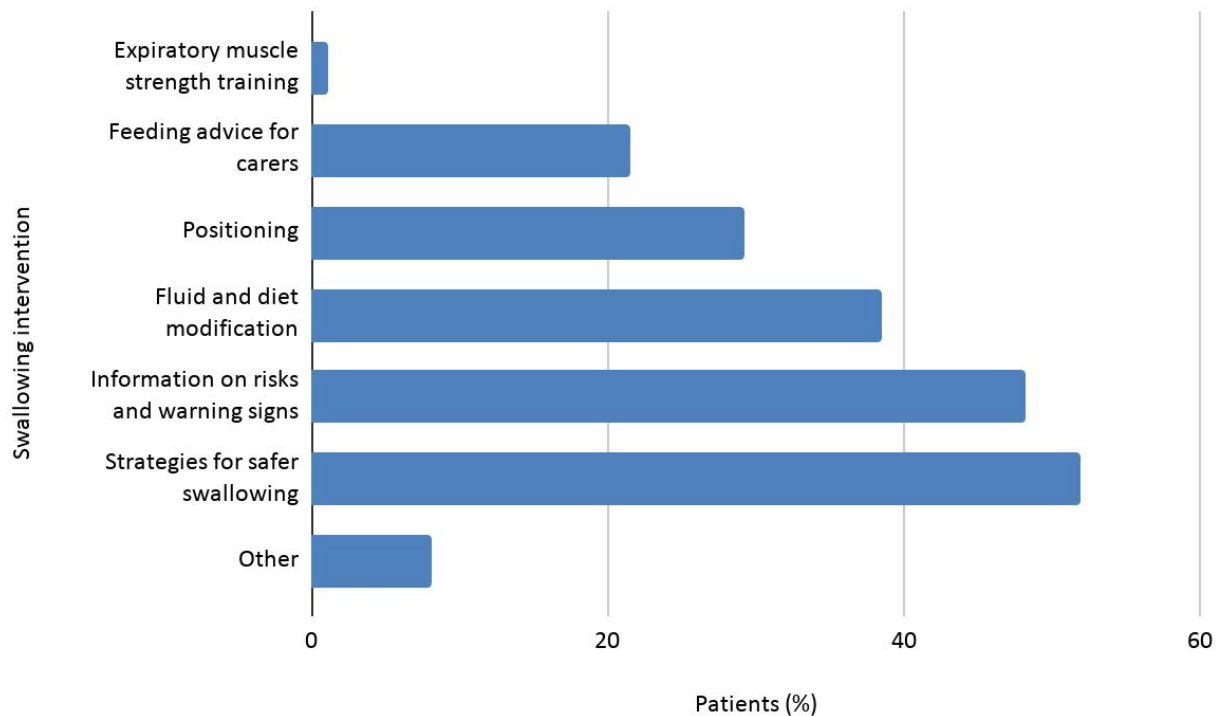
Therapy for communication continues to focus primarily on improving vocal loudness (67.5% 2019, 62.9% 2017) and optimising intelligibility (60.4% 2019, 58.0% 2017). As seen in Table 3, this year there was less emphasis on patient and carer education/advice. Whilst some slight progress has been made, there needs to be continued focus on generalising improvements outside of the clinic setting. This is essential in ensuring that therapy has a direct impact on the daily life of the patient.

Table 19: Percentage of patient with interventions targeting features outside of direct speech/voice work

<b>Interventions outside direct speech/voice work</b>	<b>Patients</b>	
	<b>2017</b>	<b>2019</b>
Patient education/advice	80.2%	70.5%
Managing patient participation	46.3%	52.7%
Managing patient impact	42.1%	52.2%
Managing generalisation outside clinic	47.6%	52.4%
Carer education/advice	46.2%	38.1%
Managing carer impact	11.1%	14.4%
Number of patients	810	1022

Swallowing interventions are inconsistent (see Figure 14). Furthermore, despite being recommended in the NICE guidelines, the number of patients being offered Expiratory Muscle Strength Training (EMST) remains extremely low at just 1.1%. Studies have demonstrated EMST to reduce penetration-aspiration scores, improve cough effectiveness and enhance voice quality through enhanced breath support. Good outcomes may be maintained if the self-administered programme is continued.

Figure 14: Swallowing interventions offered to patients with Parkinson's



### **Information giving**

For those patients referred to speech and language therapy in the complex or palliative stage of disease there was evidence of anticipatory care planning in the past 12 months for 45.3% of patients in which it was indicated.

Information sharing is an important part of anticipatory care planning and in previous years of the audit this has been an area of strength in speech and language therapy. This year this has improved further still. In almost all cases (98.2%) results and the rationale for resulting actions (e.g. review period, intervention plans) were explained to the patient and/or carer, rising from 91.1% in 2017. Furthermore, both verbal and written information were provided to the patient and carer in most cases (92.5%).

### **Speech and language therapist Band**

Most patients continue to see therapists whose caseload includes less than approximately 20% of people with Parkinson's a year and are Band 6 or 7 (75.7% 2019, 70.5% in 2017, see Table 20). This is consistent with working with a varied caseload and a team with a mixed skillset. The NICE guideline requires that patients are assessed by a therapist experienced in working with Parkinson's. This means that working within a

mixed caseload clinicians need access to training and supervision to ensure that they have the knowledge and skills to provide high quality, evidence-based assessment and treatment to people with Parkinson's. This should include opportunities to keep up to date and regular supervision

Table 20: NHS Band of the therapist assessing the patient

<b>Band of therapist assessing patient</b>	<b>Patients</b>
Band 5	17.1%
Band 6	45.5%
Band 7	30.2%
Band 8a	6.0%
Band 8b	1.2%
Number of patients:	1022

## **Service improvement in speech and language therapy services resulting from the 2017 audit**

The 2017 Audit highlighted shortcomings in the following areas:

- Patients continue to be referred in the maintenance phase rather than in the early phase as recommended by NICE.
- Inconsistent use of appropriate standardised assessments for people with Parkinson's that are based on best practice.
- Test results, on which management plans or reports are based, are not fully documented.
- Parkinson's-specific induction for therapists new to working with Parkinson's.

Speech and Language therapy services reported implementing the following service improvement measures:

- Most patients were referred in the maintenance stage of the disease and by Parkinson's Disease nurse specialists.
  - Services recognised the need to improve or develop pathways to ensure that patients were being referred at the time of diagnosis as well as in later stages of the disease.
  - For example, one service in East Lancashire spent time promoting a new referral pathway across the whole area including to GPs, Parkinson's nurse specialists and other therapy teams.
  - It will be interesting to hear more about the impact of such initiatives on referral figures including whether more patients with Parkinson's are being referred and earlier in the disease course. These figures alongside other resources such as the 2017 NICE guidelines are likely to be valuable in supporting service development.
- Most patients were seen by therapists as part of generalist caseloads and without Parkinson's specific induction procedures in place for therapists new to Parkinson's.
  - One group of therapists recognised the importance of sharing expertise, tools and resources and established a regional group across Yorkshire and Humber who meet on a regular basis.



- Furthermore, there has been an increase in the number of therapists taking up the opportunity to apply for Educational Bursaries to undertake LSVT training.
- The launch of the UK Parkinson's Excellence Network best practice guidelines for speech and language therapy which are currently in development may serve as a key driver for further change in this area and others.

## Patient Reported Experience Measure (PREM) questionnaire

### Aims

The PREM questionnaire gathered views from people with Parkinson's and their carers about their Parkinson's service. Of the 580 services that submitted clinical data to the audit, 77.7% also took part in the PREM. This provided responses from 8,247 people with Parkinson's and their carers.

### Demographics

The majority of PREM questionnaires (78.3%) were completed by a person with Parkinson's rather than a carer. The majority of respondents were male (61.7%) and white (94.6%). Only 2.9% of respondents lived in a care home, and 20.8% lived alone. The demographics of the respondents to the PREM questionnaire were comparable to those seen in the audit data.

### Findings

#### *Frequency of review by consultant or Parkinson's nurse*

The majority of respondents (80.3%) felt that the number of reviews carried out by their Parkinson's nurse met their needs, but there was a small but significant decrease in percentage of who felt this was true for their Parkinson's specialist doctor, 79.4% compared with 82.5% in 2017. This could reflect the findings in the patient audit of the significant reduction in frequency of review appointments.

#### *Quality of services provided within a Parkinson's service*

Figure 15: Quality of service offered by Parkinson's doctor (7557 respondents)

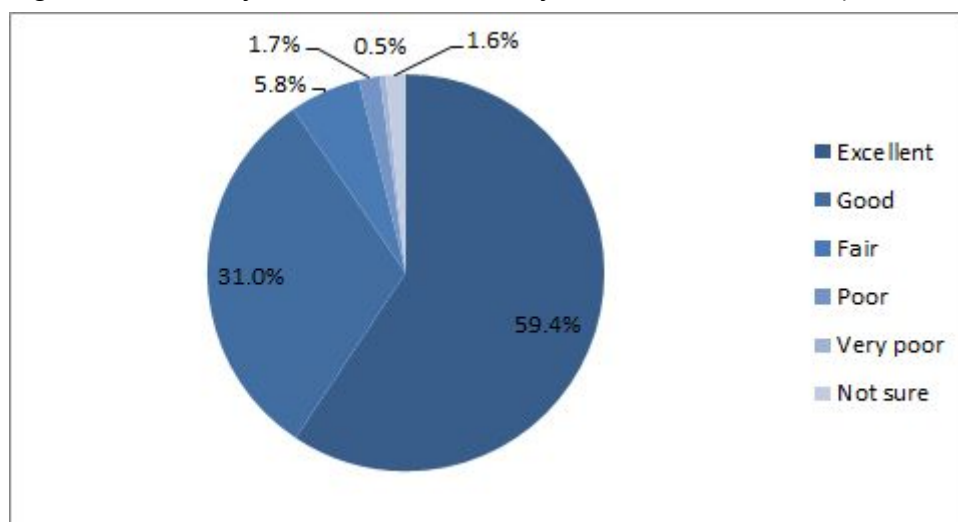


Figure 16: Quality of service offered by Parkinson's nurse (7165 respondents)

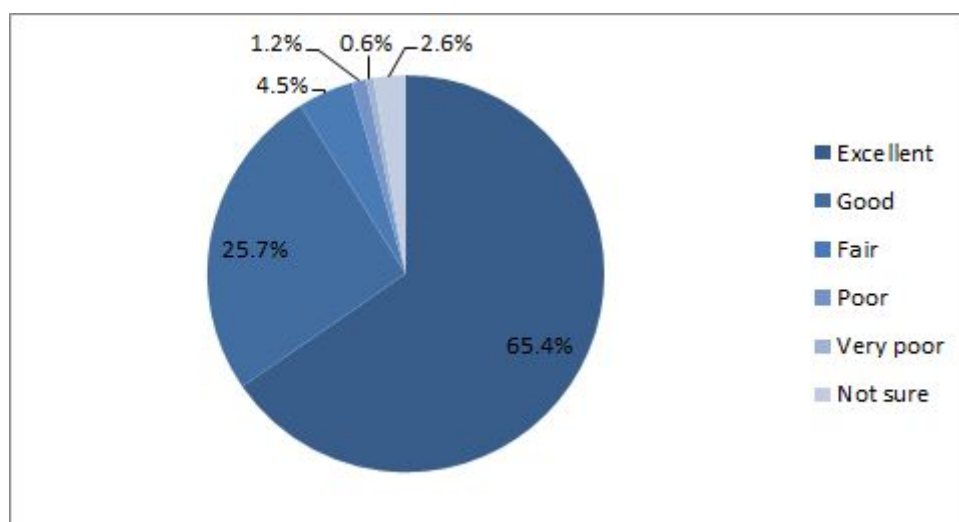


Figure 17: Quality of service offered by occupational therapists (3471 respondents)

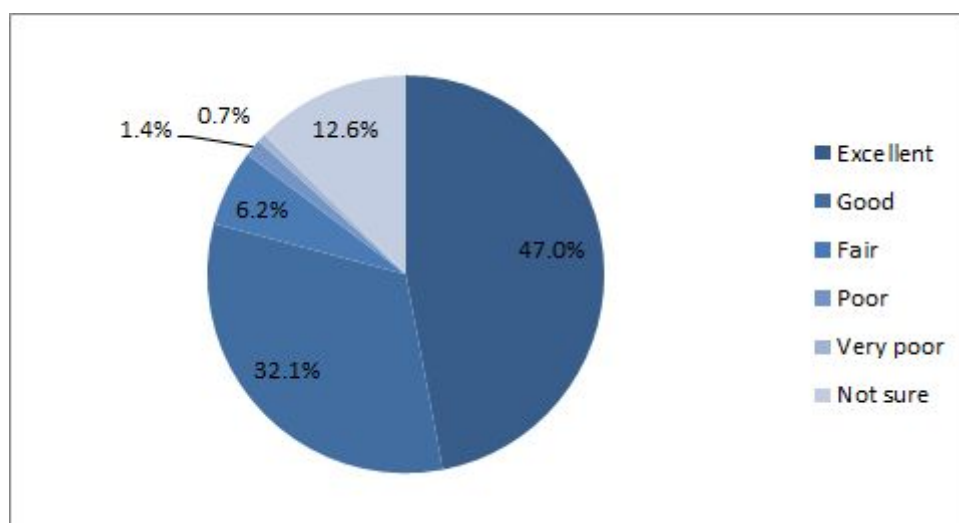


Figure 18: Quality of service offered by physiotherapists (4434 respondents)

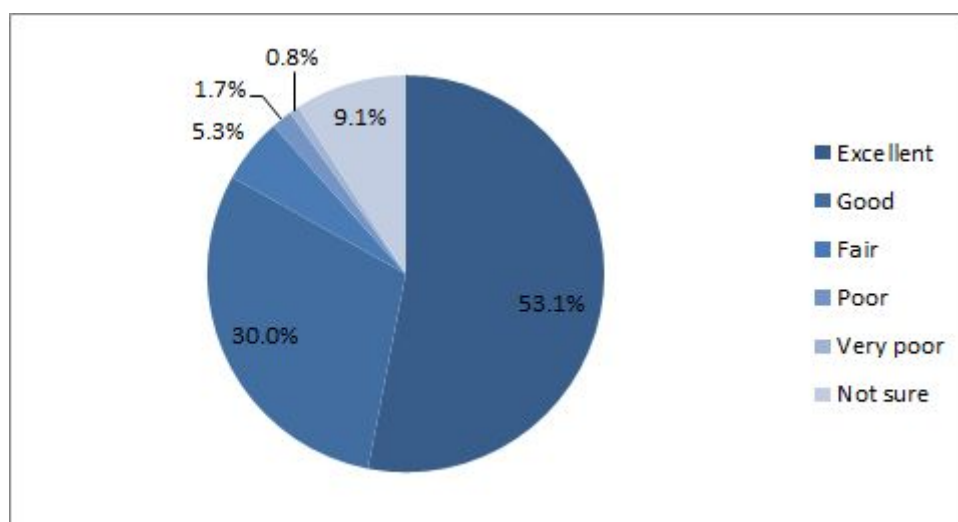
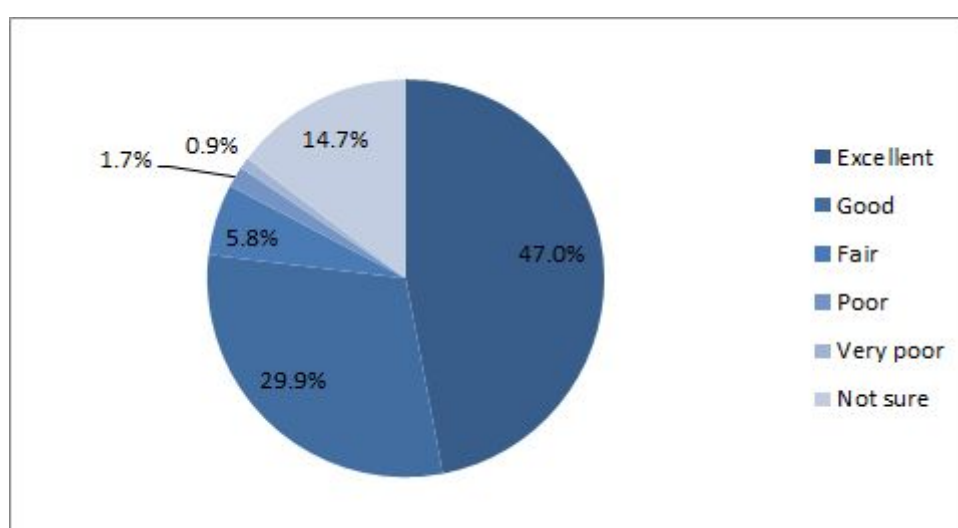


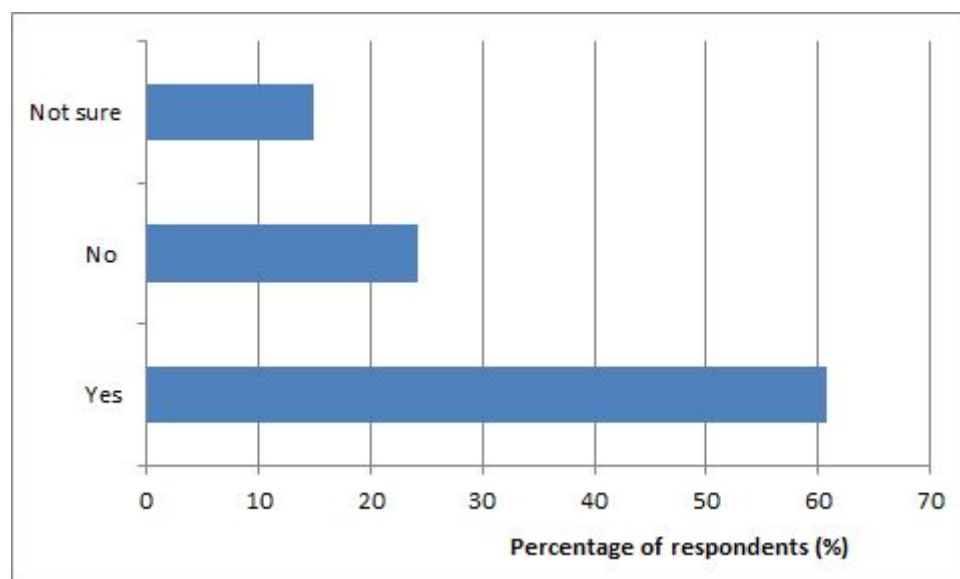
Figure 19: Quality of service offered by speech and language therapists (2975 respondents)



### ***Provision of information about Parkinson's at diagnosis***

Although the majority of respondents (60.7% of those who answered) said they had received enough information about Parkinson's at diagnosis, there was still a substantial number who had not received enough information or were not sure if they had.

Figure 20: Percentage of people with Parkinson's who received enough information about Parkinson's at diagnosis (8080 respondents)



About new medication: 31.3% felt that they were not given enough information, or were not sure if they had been given enough information. This included information about potential side effects, when starting new medications. This is a small but significant decline from the 2017 audit findings.

### ***Advice given to drivers about contacting the DVLA and their car insurance company***

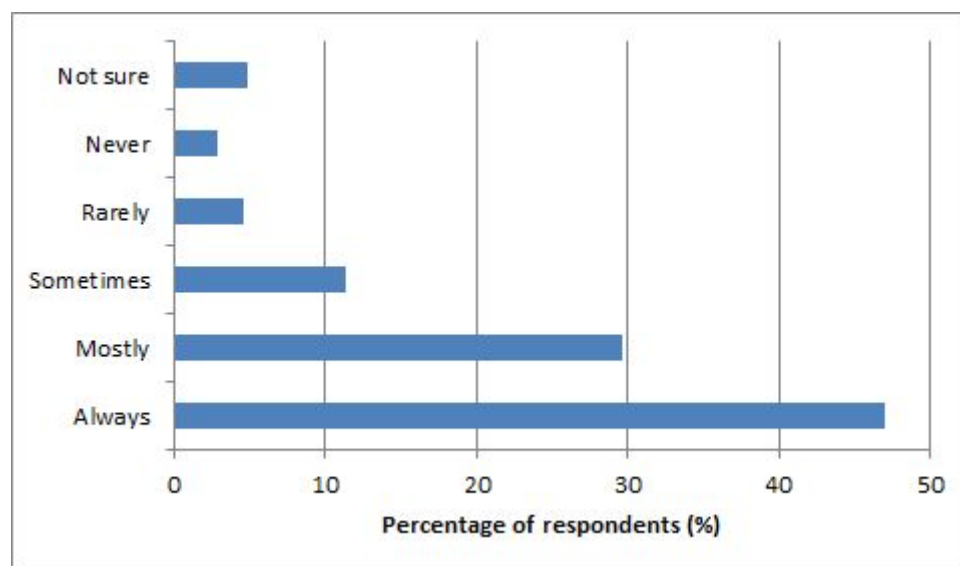
Of people with Parkinson's who were drivers, and who answered this question, 82% had been given information about contacting the DVLA and their insurance company. This is similar to the 83.9% finding in 2017.

### ***Medicines management in hospital***

In the last year, 23.2% of respondents had been admitted to hospital. Getting medication on time can be a problem when a person with Parkinson's goes to hospital. When someone with Parkinson's and motor fluctuations doesn't get their medication at the time prescribed for them their symptoms can become uncontrolled. This increases their care needs considerably. Not receiving medication on time contributes to a 73% increase in the length of hospital stay for a person with Parkinson's compared with people of similar age without Parkinson's. It may also lead to further health problems.<sup>11</sup>

<sup>11</sup> Parkinsonism and Related Disorders, *Measuring the burden and mortality of hospitalisation in Parkinson's disease: A cross-sectional analysis of the English Hospital Episodes Statistics database 2009-2013*. (2015 May;21(5):449-54), Low V, Ben-Shlomo Y, Coward E, Fletcher S, Walker R, Clarke CE

Figure 21: Percentage of people with Parkinson's who received their Parkinson's medication on time while in hospital (1773 respondents)



Of those who did not always receive their medication on time, 41% said this had a negative or significantly negative effect, 33.8% were unsure if it had any effect, 21.5% said it had no effect and 3.7% said it had a positive effect.

In some cases, hospitals will allow a patient to self-medicate, which ensures they take their medication on time, every time. 57.3% of our respondents wanted to manage and take their own medication, which they had brought from home and 36.7% were able to. However, 50.1% were unable to self-medicate, and 13.3% were not sure if they were able to.

### ***Enquiry into balance and falls***

76.3% of people who responded to this question reported raising concerns about balance and falls, or being asked if they had any concerns about them. This is encouraging.

### ***Enquiry into constipation***

This common non-motor symptom of Parkinson's, occurring in up to two thirds of all people with Parkinson's, was only raised as a concern and/or asked about in 43.4% of respondents. This is a significant decrease from 60.5% in the 2017 audit.

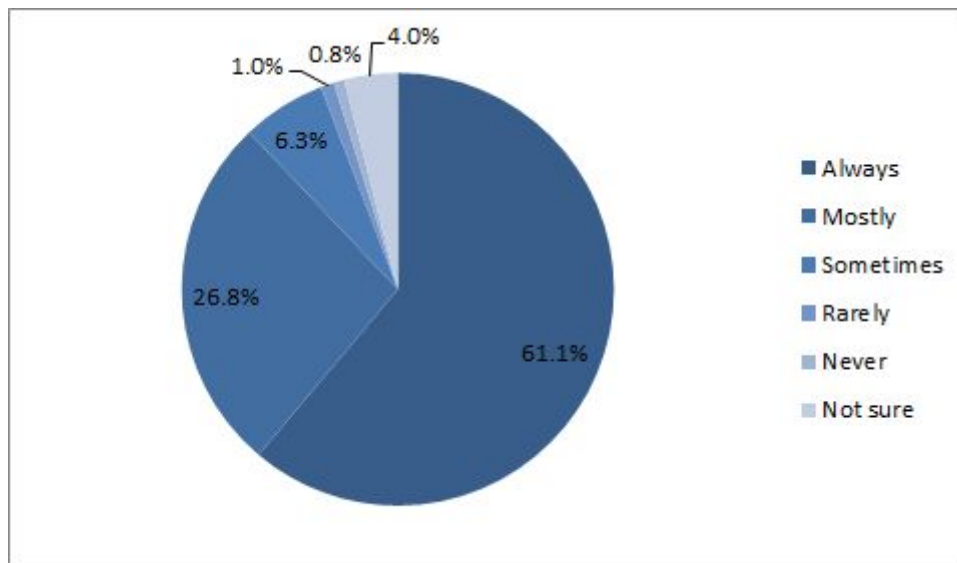
### ***Accessing Parkinson's UK support services***

25.6% reported that their service had not given them information on how to access Parkinson's UK support services, or they were not sure if they had.

### ***Overall service quality***

The majority of respondents reported that their service was already good (60.1%) with another 27% saying their service was improving. 11.2% felt that their service needed to improve but was staying the same, and 1.6% reported that their service was getting worse.

Figure 22: Percentage of people with Parkinson's who feel listened to by their Parkinson's service (8051 respondents)



## **Actions indicated by the audit findings**

It is very encouraging to note the significant progress that has been made to improve the quality of care delivered to people with Parkinson's and their carers. There is still work to be done however across all specialities in the following areas:

### **Specialised multidisciplinary working**

Statement 3 of the NICE Parkinson's Disease quality standard states that adults with Parkinson's are referred to physiotherapy, occupational therapy or speech and language therapy if they have problems with balance, motor function, ADLs, communication, swallowing or saliva. The audit highlights that the majority of services have access to these therapies, but that patients are not consistently being referred.

### **Standardised practices**

The recording of non-motor symptoms in clinics remains poor. This could be improved through use of, for example, the non-motor questionnaire. Many clinics have, as standard practice, a clinic nurse who checks weight and an erect and supine blood pressure. This means that patients are being regularly assessed for malnutrition as well as orthostatic hypotension.

Bone health assessment is suboptimal in many services, and we particularly encourage these services to take part in this key priority area for quality improvement work, which will be supported as a multi-centre activity by the Excellence Network.

Use of standardised guidance, assessments and outcome measures rather than reliance on clinical experience and peer support in occupational therapy, physiotherapy and speech and language therapy should be the norm. For example health professionals should use the *Best practice guideline for occupational therapy*, the *European physiotherapy guideline for Parkinson's*, and the *Dutch Guidelines for Speech-language therapy in Parkinson's disease*.

All patients should be able to access the Lee Silverman Voice treatment.

### **Communication and information sharing**

Information regarding diagnosis and new medication should be available at all clinics. Information regarding Parkinson's UK support and services should also be available, as should information regarding lasting Power of Attorney.

### **Medicines management**

In-patient medicines management continues to leave room for improvement, according to the PREM results, with less than half of patients consistently getting their medication on



time. In response to statement 4 of the NICE Parkinson's disease quality standard it is advised that all hospitals consider having a local Parkinson's guideline incorporating a recommendation that levodopa be administered within 30 minutes of prescribed time.

At outpatient clinics patients should be asked about the development of any side effects pertaining to their medication including impulse control disorders and daytime somnolence associated with driving. These should be clearly documented.

### **Supporting the workforce**

To enable good quality care to be delivered to patients and their carers the workforce providing this care has to be adequately supported and educated. Across all three therapies provision of induction and support for new starts working with people with Parkinson's has been highlighted as a key improvement area for national work. In addition attendance at specialist meetings about Parkinson's is desirable as part of the portfolio of CPD for movement disorder specialists, occupational therapists, physiotherapists and speech and language therapists.

These areas are not mutually exclusive, but rather encompass the key themed areas for improvement work with the aim of further driving up the quality of care delivered to people with Parkinson's and their carers.

## Conclusion

This largest ever audit of Parkinson's services provides a powerful set of data for the UK Parkinson's Excellence Network to use as we continue to drive up the overall quality of Parkinson's services across the UK. The significant uplift in the numbers of services taking part in the 2019 audit is a reflection of the investment into audit development and of the commitment and dedication from all of the professionals involved.

In a challenging NHS environment, it's vital that we continue to work to close gaps in services and in many cases, focusing on simple adjustments will enable more standardised, evidence based care that can improve life for people affected by the condition. Thank you to everyone who has been involved.

This set of audit results demonstrates where service improvement plans delivered developments in practice and services and offers learning and inspiration for others taking their next step in the improvement cycle. The Excellence Network continues to provide a whole range of support, tools, data and training to support services taking their next step in the improvement cycle. For the first time ever we are investing into a UK wide multicentred service improvement approach and we are confident that this will ultimately support many more people affected by the condition.

Together we can continue to drive up standards of care and make sure that everyone affected by Parkinson's has access to the high quality multidisciplinary service that they deserve.

Katherine Crawford  
Director of Services  
Parkinson's UK  
January 2020

## **Acknowledgements**

The work of the following groups and individuals was central to the successful running of the 2019 UK Parkinson's Audit

### **Governance Board**

Dr Anne-Louise Cunningham – Clinical Lead

Dr Donald Grosset – Clinical Director, Parkinson's Excellence Network

Dr Richard Walker - Clinical Lead: Medicine, Parkinson's Excellence Network

Fiona Lindop – Clinical Steering Group representative

Lisa Brown, Alison Leake, Annette Hand – Parkinson's nurse representatives

Val Buxton – Director of Strategic Intelligence and Excellence, Parkinson's UK (to Dec 2019)

Daiga Heisters – Head of UK Parkinson's Excellence Network, Parkinson's UK (to Nov 2019)

Katherine Crawford - Director of Services, Parkinson's UK

Katherine French - Service Improvement Programme Manager, Parkinson's UK

Cathal Doyle – Head of Strategic Intelligence, Parkinson's UK

Kim Davis – Audit Manager, Parkinson's UK

Sigita Stankeviciute - Data and Analytics Adviser, Parkinson's UK

Elaine Evans – Person with Parkinson's

### **Reporting Group**

Membership as per Governance Board with the addition of:

James Martin - Speech and language therapy

Laura Hartley - Occupational therapy

**The UK Parkinson's Excellence Network is the driving force for improving Parkinson's care, connecting and equipping professionals to provide the services people affected by the condition want to see.**

The tools, education and data it provides are crucial for better services and professional development.

The network links key professionals and people affected by Parkinson's, bringing new opportunities to learn from each other and work together for change.

**[parkinsons.org.uk/excellencenetwork](https://parkinsons.org.uk/excellencenetwork)**