UK PARKINSON'S
Excellence
Network

2017 UK Parkinson's Audit

Reference report

Contents

Introduction

This report outlines the findings of the 2017 UK Parkinson's Audit. A briefer summary report of the key 2017 audit results and the service improvement work undertaken by services in response to their 2015 audit results is also available, along with an executive summary.

The 2017 audit (the sixth to be completed) represents the largest UK audit of Parkinson's to date. This report refers to PREM results where they relate to the audit data, and also reports on the Patient Reported Experience Measure (PREM) findings.

This report includes some nation-specific data tables. As the number of participating services from Wales, Northern Ireland and in some instances Scotland is low in comparison to England, this needs to be taken into account when there appear to be significant differences in the results. Minor discrepancies in nation-specific data table totals are accounted for by the participation in the audit of services from the Channel Islands and the Isle of Man.

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 (listed in the reference report) 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 is under unprecedented challenge. This makes it more important than ever to look closely at what Parkinson's services are delivering and 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 been 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 audit, with a few exceptions, which allows direct comparison. Details of any changes can be found in the reference report.

In February 2018 the *National NICE quality standard for Parkinson's disease* was published (QS164, National Institute for Health and Care Excellence). The five quality statements

describe high-quality care in priority areas for improvement. This UK-wide audit underpins the NICE quality measure process for the majority of the statements.

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

Design and methods

Elderly Care and Neurology

The audit was designed to examine how patients had been managed and assessed over the previous year rather than on a single visit. For most patients, this captured 2-3 assessments over a year, if the service complied with the NICE guideline requirement for at least 6-12 monthly review.

Definition of a service

A service is defined as that provided by consultants with (or without) a Parkinson's nurse to a geographical area, regardless of who commissions the constituent parts. Clinicians are best placed to decide what constitutes a discrete service. To facilitate benchmarking, each Elderly Care and Neurology submission included a brief service audit to clarify:

- How their service is delivered (purely medical or medical together with Parkinson's nurse)
- The geographical or commissioning areas covered
- The specialty – neurology or elderly care.

Patient sample

The minimum audit sample size was 20 consecutive Parkinson's patients seen during the audit data collection period, which ran from 30 April 2017 to 30 September 2017. A sample of 20 patients per service was chosen to minimise work for clinicians providing input into more than one discrete service, eg a Parkinson's nurse auditing both neurology and elderly care patients, or a consultant who may work with different nurses in different commissioning areas.

Patients were included if the service was responsible for their ongoing management, not if they were seen as a tertiary referral for advice.

Occupational therapy, Physiotherapy and Speech and language therapy

The audit was open to all occupational therapy, physiotherapy, speech and language therapy services and individual therapists working with people with Parkinson's in the United Kingdom.

Patient sample

The minimum audit sample size was 10 consecutive Parkinson's patients seen during the audit data collection period, which ran from 30 April 2015 to 30 September 2015.

Data collection and entry

An audit tool was provided, in the form of an Excel workbook. The tool contained two sections:

- A 'service audit' section consisting of general questions about the service, which needed to be completed only once; and
- A 'patient audit' section, which required the entry of data on individual patients. Each person was documented only once, even if they attend more than once during the data collection period.

Patient Reported Experience Measure (PREM)

All services participating in the audit were invited to participate in the PREM. The PREM took the form of a short paper questionnaire to be distributed to up to 50 consecutive patients between 30 April and 30 September 2017. These patients did not necessarily have to be those included in the main clinical audit.

The questionnaire asked 17 questions about patients' views of their Parkinson's service. If a carer accompanied the patient on their clinic visit, they could assist the patient in completion of the form.

No identifiable information was collected, and the patient sealed their completed questionnaire in an envelope provided. These envelopes were then collected before the patient left the clinic, and all the envelopes were returned to the audit team at Parkinson's UK.

A minimum of 10 questionnaires needed to be returned for a service's data to be included in the data analysis.

Services taking part and patients included

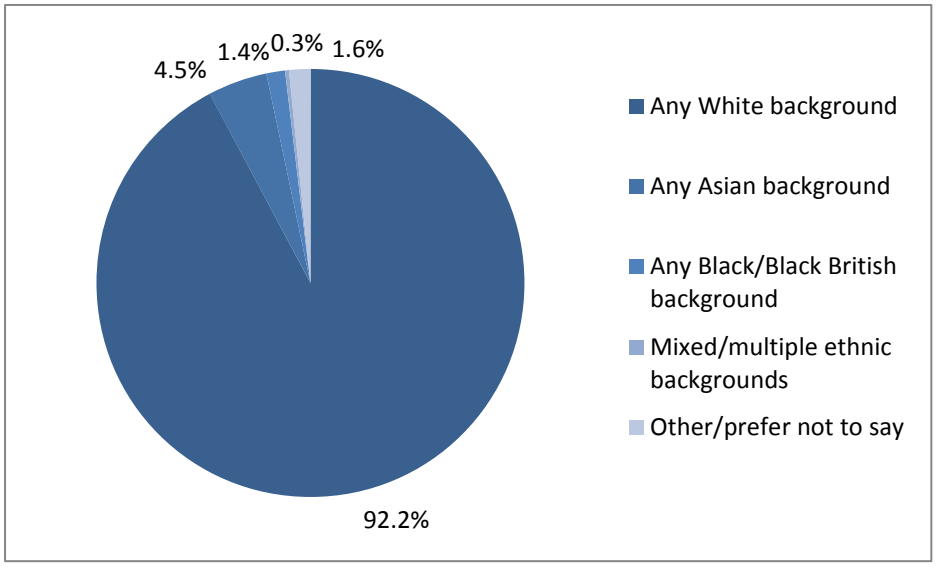
Table 1: Number of each type of service and characteristics of people with Parkinson's included in the audit

	Elderly care		Neurology		Occupational therapy		Physiotherapy		Speech and Language therapy		Total	
Services	138		121		59		95		64		477	
Patients	3397		3046		713		1514		810		9480	
Patient characteristics												
Age (years)												
Mean (SD)	77.0 (8.1)		71.5 (9.9)		75.1 (9.6)		73.8 (9.4)		73.8 (9.6)		74.3 (9.5)	
(range)	(41-98)		(23-96)		(17–95)		(27-97)		(22-96)		(17-98)	
Gender												
		%		%		%		%		%		%
Male	2068	60.9	1848	60.7	441	61.9	946	62.5	579	71.5	5882	62.0
Female	1329	39.1	1198	39.3	272	38.2	568	37.5	231	28.5	3598	38.0
Duration of Parkinson's (years)												
Mean (SD)	5.6 (4.9)		6.1 (5.4)		6.2 (5.9)		5.2 (5.2)		6.0 (5.8)		5.8 (5.3)	
Median	4		5		4		4		4		4	
(range)	(0–38)		(0–42)		(0–32)		(0–35)		(0–37)		(0–42)	
Phase of Parkinson's												
		%		%		%		%		%		%
Diagnosis	400	11.8	372	12.2	113	15.9	255	16.8	85	10.5	1225	12.9
Maintenance	1726	50.8	1587	52.1	328	46.0	806	53.2	484	59.8	4931	52.0
Complex	1172	34.5	981	32.2	259	36.3	434	28.7	223	27.5	3069	32.4
Palliative	99	2.9	106	3.5	13	1.8	19	1.3	18	2.2	255	2.7

Note: minor discrepancies in totals are accounted for by a small amount of missing data

The services taking part are not necessarily the same ones which took part in the audit in 2015, although many are re-auditing their practice this time.

Figure 1: Ethnicity of people with Parkinson's included in the audit



The PREM questionnaire

In addition to the audit data, 6,446 people with Parkinson's and their carers attending 329 (68.9%) 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.

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[1] 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 6,443 people with Parkinson's, who were included in the audit. These patients were aged between 23 and 98 years (mean: 74.4, standard deviation (SD) 9.4 years), and the majority were male (60.8%). Patients seen at Neurology services (mean age: 71.5, SD 9.9 years) tended to be younger than in Elderly Care (mean age: 77.0, SD 8.1 years).

Table 2: Gender of Elderly Care and Neurology patients

Gender	Elderly Care	Neurology	Elderly Care and Neurology
Male	60.9%	60.7%	60.8%
Female	39.1%	39.3%	39.2%
Number:	3397	3046	6443

Mean age at diagnosis was 68.6 years (SD 10.7 years) (Elderly Care: 71.5 SD 9.6; Neurology: 65.4 SD 9.9), and patients audited had a mean Parkinson's duration of 5.8 years (SD 5.2, range 0–49 years). The distribution of phase of Parkinson's was very similar across Elderly Care and Neurology audits (see Figure 2).

[1] Elderly care refers to services provided by a geriatrician.

Figure 2: Patients in each Parkinson's phase (across both Elderly Care and Neurology)

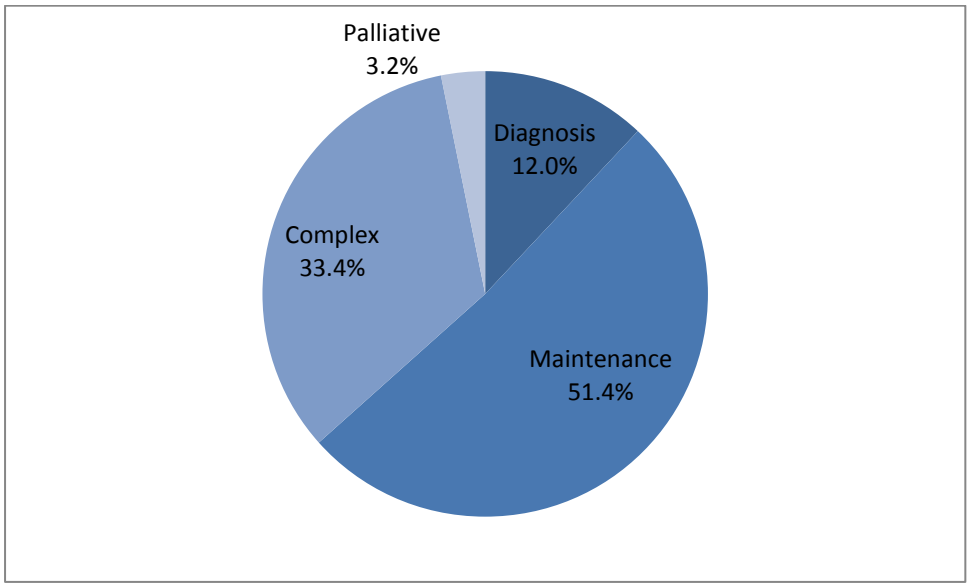


Table 3: Ethnicity of Elderly Care and Neurology patients

Ethnicity	Elderly Care	Neurology	Elderly Care and Neurology
White	95.1%	88.3%	91.9%
Asian/Asian British	2.3%	7.5%	1.4%
Black/Black British	0.7%	2.1%	4.7%
Mixed/multiple ethnic background	0.1%	0.6%	0.3%
Other	1.8%	1.6%	1.7%
Number:	3396	3046	6443

Table 4: Elderly Care and Neurology patients living alone

Patient lives alone	Elderly Care	Neurology	Elderly Care and Neurology
Yes	28.2%	19.3%	24.0%
No	64.8%	75.2%	69.7%
No, at residential home	3.4%	2.5%	3.0%
No, at nursing home	3.6%	3.0%	3.3%
Number:	3397	3045	6442

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

95.6% of audited Elderly Care services see all or most of their patients in specialist clinics compared with 87.6% in the 2015 audit. Neurology services have remained at a similar level to previous audits with 57.9% seeing all or most of their patients in specific clinics (60% in 2012 and 62.8% in 2015). Disappointingly 10.8% of all services still see few or none of their patients in dedicated clinics, although this figure is significantly lower in Elderly Care (2.2%) than in Neurology (20.7%).This figure is similar to 2015 where 11.7% of all services saw few or none of their patients in dedicated clinics.

Table 5: Patients seen within specific Parkinson's/movement disorder clinics
(EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

	EC UK	**N UK**	**ECN UK**	**ECN England**	**ECN Scotland**	**ECN Wales**	**ECN NI**
All patients	65.9%	31.4%	49.8%	46.5%	75%	66.7%	33.3%
Most patients (>75%)	29.7%	26.5%	28.2%	28.4%	25%	33.3%	33.3%
Some patients (25-74%)	2.2%	21.5%	11.2%	12.8%	0	0	11.1%
Few patients (<25%)	1.5%	5.8%	3.5%	4.3%	0	0	0
None	0.7%	14.9%	7.3%	8.1%	0	0	22.2%
Number:	138	121	259	211	24	12	9

b) Integrated clinics

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 only available at 13.5% of all clinics (compared to 12.6% of services audited in 2015). Encouragingly, although this continues to be more common for Elderly Care, a growing number of Neurology services audited provide integrated services (12.4% compared with 5.5% in 2015).The most common model of service provision continues to be a joint or parallel doctor and nurse specialist clinic (58.7% of audited services in 2017, 59% in 2015).

An unchanged and significant proportion of clinics in both Elderly Care and Neurology remain staffed by a doctor alone (27.5% and 28.1% respectively).

Table 6: Most common model of service provision for medical input in each service (EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

	EC UK	**N UK**	**ECN UK**	**ECN England**	**ECN Scotland**	**ECN Wales**	**ECN NI**
Doctor alone	27.5%	28.1%	27.8%	28.9%	25.0%	8.3%	44.4%
Joint/parallel doctor and nurse specialist clinics	58.0%	59.5%	58.7%	57.8%	58.3%	75.0%	44.4%
Integrated clinics	14.5%	12.4%	13.5%	13.3%	16.7%	16.7%	11.1%
Number:	138	121	259	211	24	12	9

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. The maximum and best score after totalling the 3 domain scores is 34 (range 0-34).

Table 7: Mean domain score totals for different models of service provision (standard deviations in brackets)

	Elderly Care	**Neurology**	**Elderly Care and Neurology**
Doctor alone	27.2 (5.3)	24.5 (6.5)	25.9 (6.0)
Joint/parallel doctor and nurse specialist clinics	27.9 (5.2)	27.7 (5.6)	27.8 (5.4)
Integrated clinics	30.3 (3.1)	27.2 (6.9)	29 (5.3)

Using the total domain scores is only a rough surrogate of good practice, but does seem to suggest that 'doctor alone' service provision consistently has a lower score.

Access to a Parkinson's nurse

Similarly to previous audits, the majority of people with Parkinson's (96.1%; 94.1% in 2015) could access a Parkinson's nurse.

Table 8: Access to a Parkinson's nurse in Elderly Care and Neurology services

	EC UK	N UK	ECN UK	ECN England	ECN Scotland	ECN Wales	ECN NI
Yes	96.4%	95.9%	96.1%	95.3%	100%	100%	100%
No	3.6%	4.1%	3.9%	4.7%	0	0	0
Number:	138	121	259	211	24	12	9

87.6% respondents to the PREM reported that they had access to a Parkinson's nurse. 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 respond to the PREM. Alternatively it may suggest that some patients were inadequately informed about how to access a Parkinson's nurse.

Table 9: Main arrangement for contact between consultants and Parkinson's Nurse Specialists

Type of contact	Elderly Care	Neurology	Elderly Care and Neurology
Regular contact in multidisciplinary meeting, joint or parallel clinic	47.8%	31.4%	40.2%
Regular face-to-face contact outside clinic	20.3%	23.1%	21.6%
Regular telephone/email contact with occasional face-to-face contact	21.0%	33.9%	27.0%
Telephone/email contact only	6.5%	6.6%	6.6%
No or rare contact	0.7%	0.8%	0.8%
No Parkinson's nurse specialist	3.6%	4.1%	3.9%
Number:	138	121	259

Availability of written information

Written information about Parkinson's and Parkinson's medication is routinely available all or most of the time at 82.2% of clinics (unchanged since 2015). But written information about Parkinson's is still not routinely available in 7.7% (5.9% in 2015) of outpatient clinics.

This was more evident in doctor alone clinics (16.7%) than joint/parallel doctor and nurse specialist clinics (5.3%) or integrated clinics (0%).

However, providing written information in the clinic may not be enough, as the PREM data suggests only 61.1% of patients feel they are given enough information at diagnosis (66.1% in 2015).

Table 10: Availability of written information in Parkinson's clinic
(EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

	EC UK	N UK	ECN UK	ECN England	ECN Scotland	ECN Wales	ECN NI
All clinics	63.8%	57.0%	60.6%	58.8%	58.3%	91.7%	55.6%
Most clinics (>75%)	23.2%	19.8%	21.6%	21.3%	29.2%	8.3%	33.3%
Some clinics	8.0%	12.4%	10.0%	10.9%	8.3%	0	11.1%
Not routinely available	5.1%	10.7%	7.7%	9.0%	4.2%	0	0
Number:	138	121	259	211	24	12	9

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. Over 90% of Parkinson's nurses have attended specific CPD in the last year.

Table 11: Services where all clinicians have attended CPD specific to movement disorders and all specialist nurses have attended Parkinson's-specific CPD in the last 12 months

	Elderly Care	Neurology	Elderly Care and Neurology
Clinician	86.2%	71.9%	79.5%
Parkinson's nurse	93.5%	88.4%	91.1%

Use of standardised assessments

Table 12: Use of formal Activities of Daily Living tool or checklist during review of people with Parkinson's

Assessment of ADL conducted	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	26.1%	21.5%	23.9%
Most clinics (>75%)	13.0%	18.2%	15.4%
Some clinics	39.9%	34.7%	37.5%
Not routinely available	21.0%	25.6%	23.2%
Number:	138	121	259

Table 13: Use of Parkinson's non-motor symptoms questionnaire or checklist during assessment of people with Parkinson's

Assessment of non-motor symptoms conducted	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	38.4%	29.8%	34.4%
Most clinics (>75%)	25.4%	23.1%	24.3%
Some clinics	20.3%	19.0%	19.7%
Not routinely available	15.9%	28.1%	21.6%
Number:	138	121	259

Table 14: Availability of standardised assessment tools for cognitive function

Standardised assessment for cognition available	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	63.0%	46.3%	55.2%
Most clinics (>75%)	19.6%	22.3%	20.8%
Some clinics	5.8%	13.2%	9.3%
Not routinely available	11.6%	18.2%	14.7%
Number:	138	121	259

Table 15: Availability of standardised assessment tools to assess mood

Standardised assessment of mood available	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	47.8%	28.9%	39.0%
Most clinics (>75%)	17.4%	14.1%	15.8%
Some clinics	21.0%	35.5%	27.8%
Not routinely available	13.8%	21.5%	17.4%
Number:	138	121	259

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. Encouragingly, 98.1% of patients audited in Elderly Care and Neurology services had received a specialist review in the preceding 12 months, maintaining the high percentage seen in the 2015 audit.

Table 16: Review by a specialist (doctor or nurse specialist) within the last year

Review in last year	Elderly Care	Neurology	Elderly Care and Neurology
Yes	98.1%	98.1%	98.1%
No	1.9%	1.9%	1.9%
Number:	3397	3046	6443

Medicines management

In this audit around 95% of people with Parkinson's had their current prescription checked and documented at a clinical review (medicines reconciliation) with both Elderly Care (95.1%; 93.5% in 2015) and Neurology (94.6%; 91.6% in 2015) seeing an increase on the 2015 results.

There was evidence of information about potential side effects of new medication recorded for 86.2% of patients in the audit. This figure was 83.3% in 2015. Concerningly however, the PREM data suggests that only 69.0% of patients (64.1% in 2015) feel they are given enough information when prescribed new medication.

Table 17: Patients given information about potential adverse side effects of new medication (EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

	EC UK	N UK	ECN UK	ECN England	ECN Scotland	ECN Wales	ECN NI
Yes	55.2%	59.3%	57.1%	54.3%	63.9%	73.3%	70.1%
No	9.5%	8.7%	9.1%	9.2%	5.8%	9.9%	17.2%
Not applicable	35.3%	32.1%	33.8%	36.5%	30.4%	16.8%	12.7%
Number:	3397	3046	6443	5206	573	363	221

Monitoring for compulsive behaviours

The 2017 audit results demonstrate that 67.4% of patients on dopaminergic therapy have had a recorded discussion about compulsive behaviours in the preceding year, up from 64.2% in the 2015 cycle. Neurology services are better at documenting this (70% of patients) than Elderly Care (65.2%). Monitoring for compulsive behaviours is particularly pertinent for patients on dopamine agonists, and 19.3% of these patients still appear to have received no advice about potential compulsive behaviours related to their medication. This compares to 22.5% in the previous audit cycle. The audit also shows that for those patients on ergot Dopamine agonists (4.7% of all patients audited) there are low referral rates for echocardiograms (only 26.2%).

Table 18: Evidence recorded that people with Parkinson's taking dopaminergic drugs are monitored for compulsive behaviours
(EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

	EC UK	**N UK**	**ECN UK**	**ECN England**	**ECN Scotland**	**ECN Wales**	**ECN NI**
Yes	56.5%	57.6%	57.0%	54.6%	63.4%	72.5%	62.0%
No	30.1%	24.7%	27.5%	29.1%	25.7%	13.5%	26.2%
Not applicable	13.4%	17.8%	15.4%	16.3%	11.0%	14.1%	11.8%
Number:	3397	3046	6443	5206	573	363	221

Table 19: Evidence recorded that people with Parkinson's taking dopamine agonists are monitored for compulsive behaviours

	Elderly Care	**Neurology**	**Elderly Care and Neurology**
Yes	79.3%	82.0%	80.7%
No	20.7%	18.0%	19.3%
Number:	1233	1295	2528

Table 20: Evidence of patients taking ergot dopamine agonists having an echocardiogram for fibrosis-related adverse effects (only those on ergot dopamine included)

Echocardiogram conducted	**Elderly Care**	**Neurology**	**Elderly Care and Neurology**
Yes	18.2%	33.5%	26.2%
No	81.8%	66.5	73.8%
Number:	143	158	301

Driving and excessive daytime sleepiness

Questioning about excessive daytime sleepiness was recorded in just under three-quarters of cases, as in the 2015 audit (74.6% in Elderly Care; 70.2% in Neurology). Where excessive daytime sleepiness was recorded, its impact on driving was documented in 62.8% of drivers which is an increase from 56.6% in 2015.

Table 21: Evidence of enquiry about excessive daytime sleepiness

Enquiry about excessive daytime sleepiness	Elderly Care	Neurology	Elderly Care and Neurology
Yes	74.6%	70.2%	72.5%
No	25.4%	29.8%	27.5%
Number:	3397	3046	6443

Table 22: 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	63.9%	61.7%	62.8%
No	36.1%	38.3%	37.2%
Number:	809	826	1635

Advance care planning

Of those people who had markers of advanced Parkinson's (21.0%), discussions regarding end-of-life care issues were recorded in only 36.8% (28% in 2015). 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.

Table 23: Markers of advanced disease recorded, eg dementia, increasing frailty, impaired swallowing, nursing home level of care required

Advanced disease markers recorded	Elderly Care	Neurology	Elderly Care and Neurology
Yes	22.7%	19.0%	21.0%
No	77.3%	81.0%	79.0%
Number:	3397	3046	6443

Table 24: Documented discussions about end-of-life care issues/care plans (where there are markers of advanced disease)

End of life care discussion documented	Elderly Care	Neurology	Elderly Care and Neurology
Yes	32.7%	42.3%	36.8%
No	67.3%	57.7%	63.2%
Number:	771	581	1352

Power of Attorney

In only 16.9% of cases (at all phases of Parkinson's) was there evidence that the patient and/or carer had been offered information about, or had set up, a Lasting Power of Attorney (Power of Attorney in Scotland) (Elderly Care 18.4%, Neurology 15.3%). This is a change from the 2015 audit where only those with markers of advanced Parkinson's were asked 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 earlier discussions.

However, 56.1% of patients in the palliative phase had been offered information about, or had set up, a Lasting Power of Attorney (26.3% in 2015).

Table 25: Evidence the patient or carer has been offered information about, or has set up, a lasting power of attorney (power of attorney in Scotland)
(EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

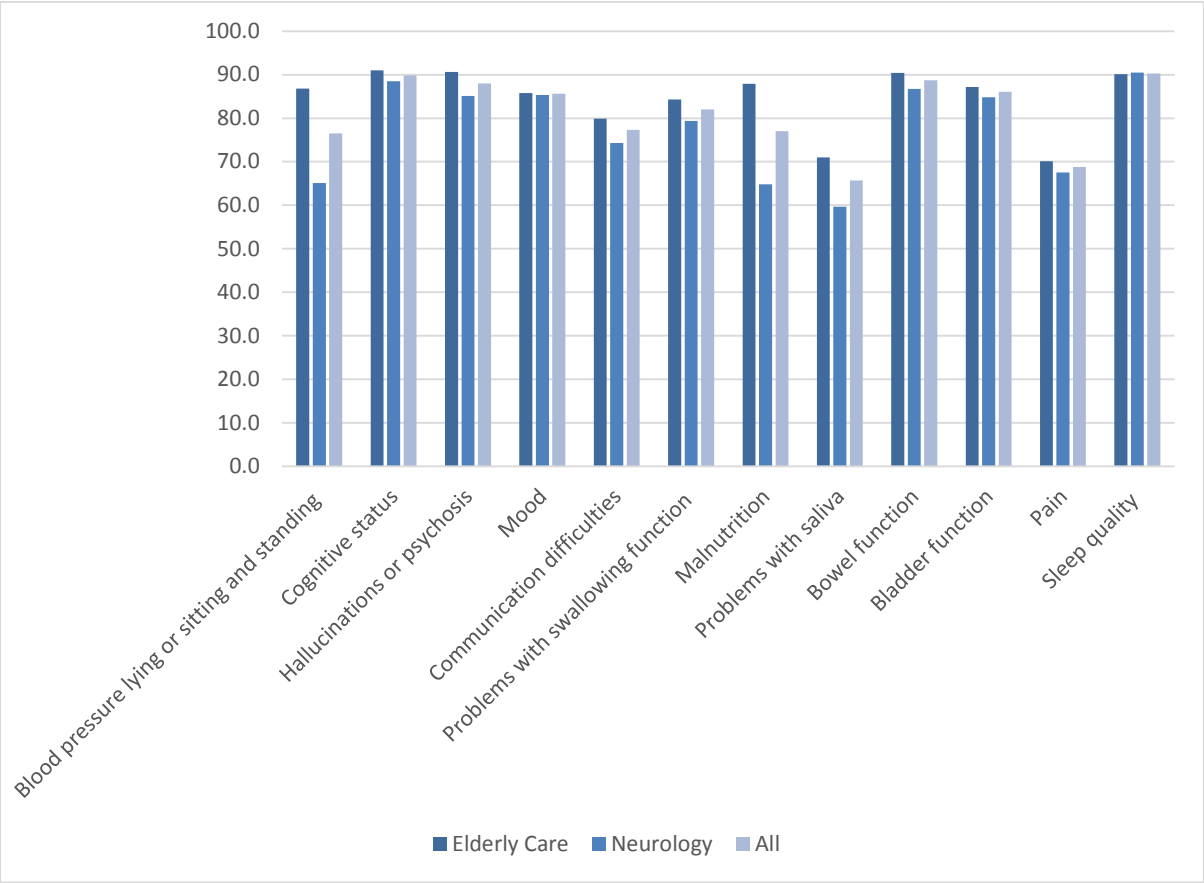
	EC UK	N UK	ECN UK	ECN England	ECN Scotland	ECN Wales	ECN NI
Yes	18.4%	15.3%	16.9%	15.3%	31.6%	28.7%	1.4%
No	81.6%	84.7%	83.1%	84.8%	68.4%	71.4%	98.6%
Number:	3397	3046	6443	5206	573	363	221

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.

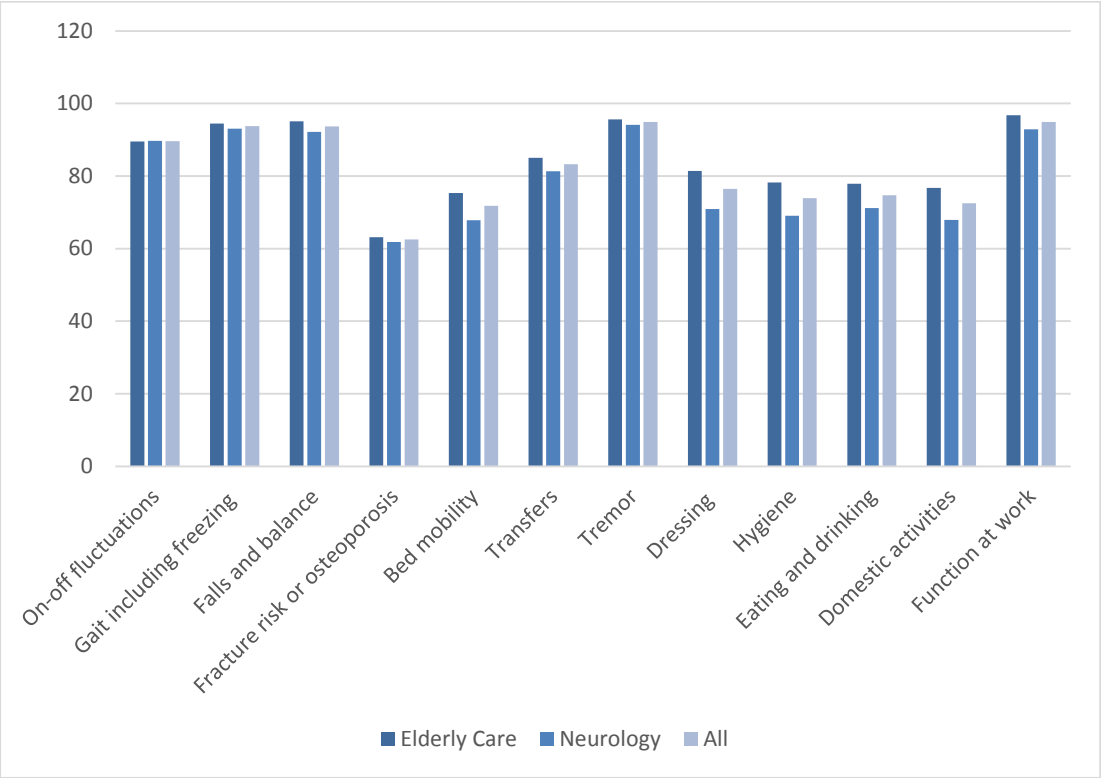
For each element within a domain, total scores were calculated by summing passes (a score of 1) and fails (a score of 0) for each patient. A pass was achieved if the assessment was done. However, a pass was also achieved if an assessment was not done but was considered and not felt to be indicated or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

Figure 3: Domain 1 – Non-motor assessments during the previous year



Blood pressure assessment is better documented in Elderly Care (86.8%) than Neurology clinics (65.1%) though both have improved from 2015 (Elderly Care 85.1%; Neurology 57.2%). The same is true for malnutrition screening where Elderly Care screen 87.9% of patients and Neurology services screen only 64.8%. Again, both have improved from 2015 (Elderly Care 85.1%; Neurology 54%). Assessments of pain and saliva problems were poorly documented by both services in 2015. The services audited in 2017 show modest improvements at 68.8% and 65.7% respectively.

Figure 4: Domain 2 – Assessment of motor symptoms and Activities of Daily Living (ADL) during the previous year



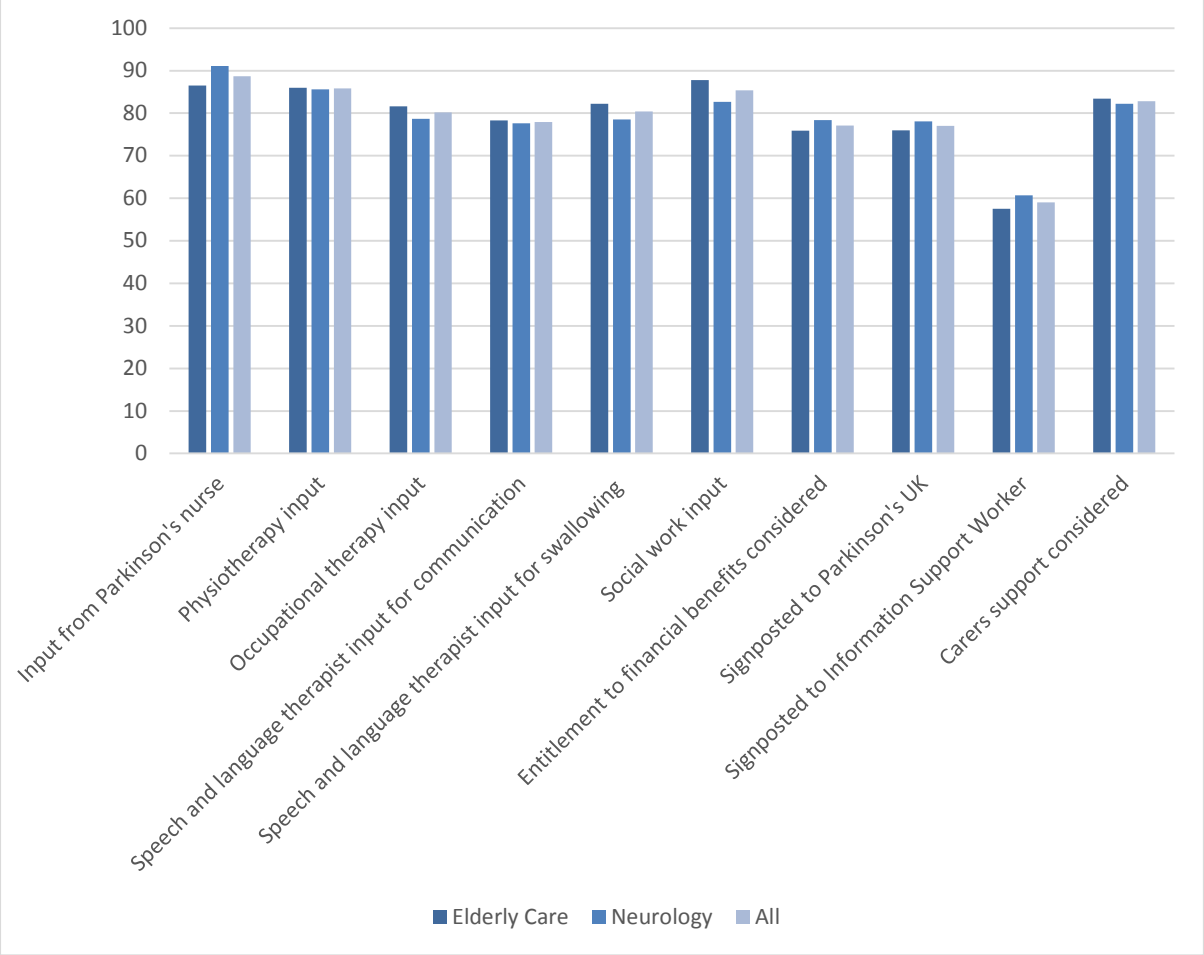
Where there were concerns about falls and/or balance, fracture risk or osteoporosis was documented as a consideration in only 42.9% of people with Parkinson's (45.7% in Elderly Care; 39.5% in Neurology). While these low figures are concerning, it should be noted that they demonstrate some improvement from 2015 (40.6% Elderly Care and 31.4% Neurology)

Please note: the percentages above in the bar chart reflect the total percentage of patients in whom evidence of fracture risk/osteoporosis was considered and includes those in whom the notes document no falls and no concerns re balance, and therefore bone health was not considered.

Table 26: Patients with enquiries re: fracture risk/osteoporosis
(EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

	EC UK	**N UK**	**ECN UK**	**ECN England**	**ECN Scotland**	**ECN Wales**	**ECN NI**
Yes	63.2%	61.8%	62.5%	61.9%	59.3%	75.8%	57.5%
No	36.8%	38.3%	37.5%	38.1%	40.7%	24.2%	42.5%
Number:	3397	3046	6443	5206	573	363	221

Figure 5: Domain 3 – Education and multidisciplinary involvement during the previous year



The results show that 77.0% of patients and/or carers had been signposted to Parkinson's UK in the last year, or had been previously signposted.

Table 27: Patients signposted to Parkinson's UK
(EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

	EC UK	N UK	ECN UK	ECN England	ECN Scotland	ECN Wales	ECN NI
Yes	76%	78.1%	77.0%	75.8%	82.7%	82.4%	74.2%
No	24%	21.9%	23%	24.2%	17.3%	17.6%	25.8%
Number:	3397	3046	6443	5206	573	363	221

Table 28: Signposted to Information Support Worker
(EC = Elderly Care, N = Neurology, ECN = Elderly Care and Neurology)

	EC UK	**N UK**	**ECN UK**	**ECN England**	**ECN Scotland**	**ECN Wales**	**ECN NI**
Yes	57.5%	60.7%	59.0%	58.5%	51.8%	67.5%	64.7%
No	42.5%	39.3%	41.0%	41.5%	48.2%	32.5%	35.3%
Number:	3397	3046	6443	5206	573	363	221

Occupational therapy

Aims

The occupational therapy audit measures the referral to and assessment and management of people with Parkinson's in occupational therapy services. It also aims to describe the models of service delivery used. It identifies the measures used in assessment and outcomes, the guidance and education available to occupational therapists, and adherence to national guidelines.

Demographics

Occupational therapy services saw 713 people with Parkinson's who were included in the audit. The majority were over 70 years of age (mean age 75.1 years), male (61.9%) and white (95.2%). The mean length of time between diagnosis and referral for this episode of occupational therapy was 6.5 years. Typically people seen by occupational therapy services live in their own homes (93.0%).

Table 29: Gender of occupational therapy patients

Gender	Patients
Male	61.9%
Female	38.2%
Number:	713

Table 30: Ethnicity of occupational therapy patients

Ethnicity	Patients
White	95.2%
Asian/Asian British	3.0%
Black/Black British	0.8%
Mixed/multiple ethnic background	0.1%
Other	0.8%
Number:	713

Figure 6: Phase of Parkinson's on referral to occupational therapy

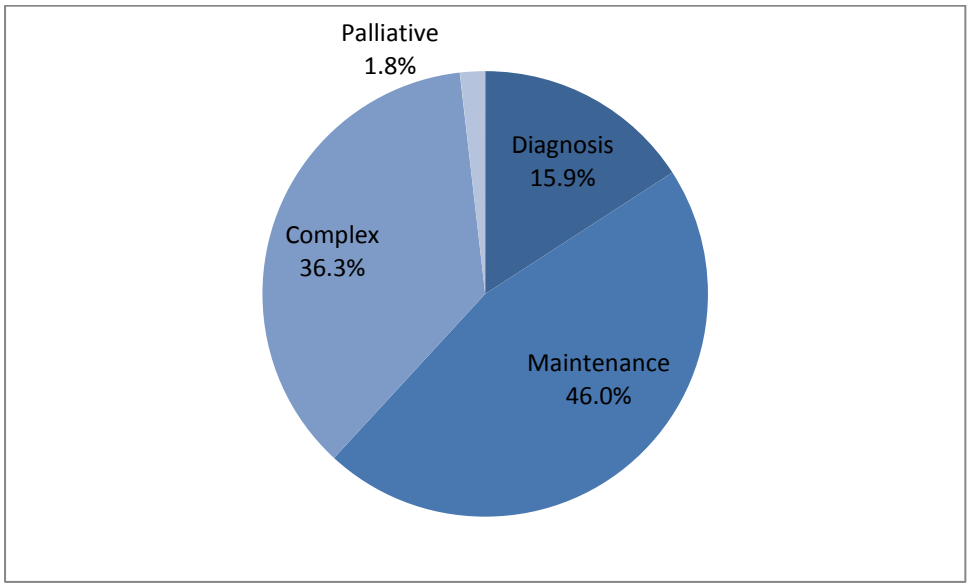


Table 31: Phase of Parkinson's on referral to occupational therapy

Parkinson's phase	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Diagnosis	15.9%	15.4%	25.4%	8.8%	9.5%
Maintenance	46.0%	42.0%	55.9%	45.6%	66.7%
Complex	36.3%	40.4%	18.6%	43.9%	19.1%
Palliative	1.8%	2.2%	0	1.8%	4.8%
Number:	713	495	118	57	21

Table 32: Settings in which occupational therapy patients live

Home setting	Patients
Own home	93.0%
Residential care home	2.5%
Nursing home	1.8%
Other	2.7%
Number:	713

Table 33: Health settings in which occupational therapy patients are seen

Health setting	Patients
NHS – inpatient	7.6%
NHS – outpatient	35.5%
NHS – community	19.9%
At home	32.7%
Other	4.4%
Number:	713

Service audit

Models of service provision

Only 10.2% of occupational therapy services reported working in an integrated Parkinson's clinic. The majority of occupational therapy services (71.2%; 63.8% in 2015) were based in the community, within rehabilitation, reablement or day hospital teams.

Overall, 69.5% of the occupational therapy services audited specialise in neurological conditions, with 72.4% specialising in the treatment of Parkinson's.

Table 34: Services specialising in treatment of people with neurological conditions

Service specialises in neurological conditions	Services
Yes	69.5%
No	30.5%
Number:	59

Table 35: Services specialising in treatment of people with Parkinson's

Service specialises in Parkinson's treatment	Services
Yes	72.4%
No	27.6%
Number:	58

Table 36: Settings in which people with Parkinson's are normally seen

	Services UK	Services England	Services Scotland	Services Wales	Services NI
Integrated medical and therapy Parkinson's clinic	10.2%	9.1%	12.5%	25.0%	0
Inpatient acute service	3.4%	4.6%	0	0	0
Inpatient rehabilitation service	1.7%	0	0	0	50.%
Community rehabilitation service	37.3%	38.6%	12.5%	50.0%	50.%
Social services, including reablement	1.7%	2.3%	0	0	0
Outpatient/day hospital	33.9%	31.8%	75.0%	0	0
Other	11.9%	13.6%	0	25.0%	0
Number:	59	44	8	4	2

Table 37: Percentage of people referred to the service annually with a diagnosis of Parkinson's

Referred	Services
0–19%	28.8%
20–39%	33.9%
40–59%	11.9%
60–79%	5.1%
80–100%	20.3%
Number:	59

Table 38: How patients with Parkinson's are usually seen

How patients seen	Services
Individually	64.4%
In a group setting	1.7%
Both individually and in groups	33.9%
Number:	59

Table 39: Locations in which services provide interventions

Location of interventions	Services
Community setting	13.6%
Day hospital/centre	32.2%
Individual's home	45.8%

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

Of the occupational therapists audited, 84.8% reported having opportunities to undertake Parkinson's-related CPD (91.5% in 2015).

Support (e.g. education, advice) was available to individual therapists through their specialist multidisciplinary team by 66.1% of occupational therapists (78.7% in 2015).

Specific induction and support strategies for working with people with Parkinson's were available to new staff in 30.5% of occupational therapy services (an increase on the 23.4% reported in 2015) and 37.3% included Parkinson's within their general competencies, a similar percentage to 2015.

Table 40: Access to Parkinson's-related CPD at least yearly

Access to yearly CPD	Services UK	Services England	Services Scotland	Services Wales	Services NI
Yes	84.8%	88.6%	87.5%	75.0%	0
No	15.3%	11.4%	12.5%	25.0%	100%
Number:	59	44	8	4	2

Table 41: Documented induction and support strategies for new occupational therapists working with people with Parkinson's

Induction and support strategies available	Services
Yes, specifically in relation to patients with Parkinson's	30.5%
Yes, as part of more general competencies	37.3%
No	32.2%
Number:	59

Table 42: Support (eg education and advice) available to individual therapists in the service

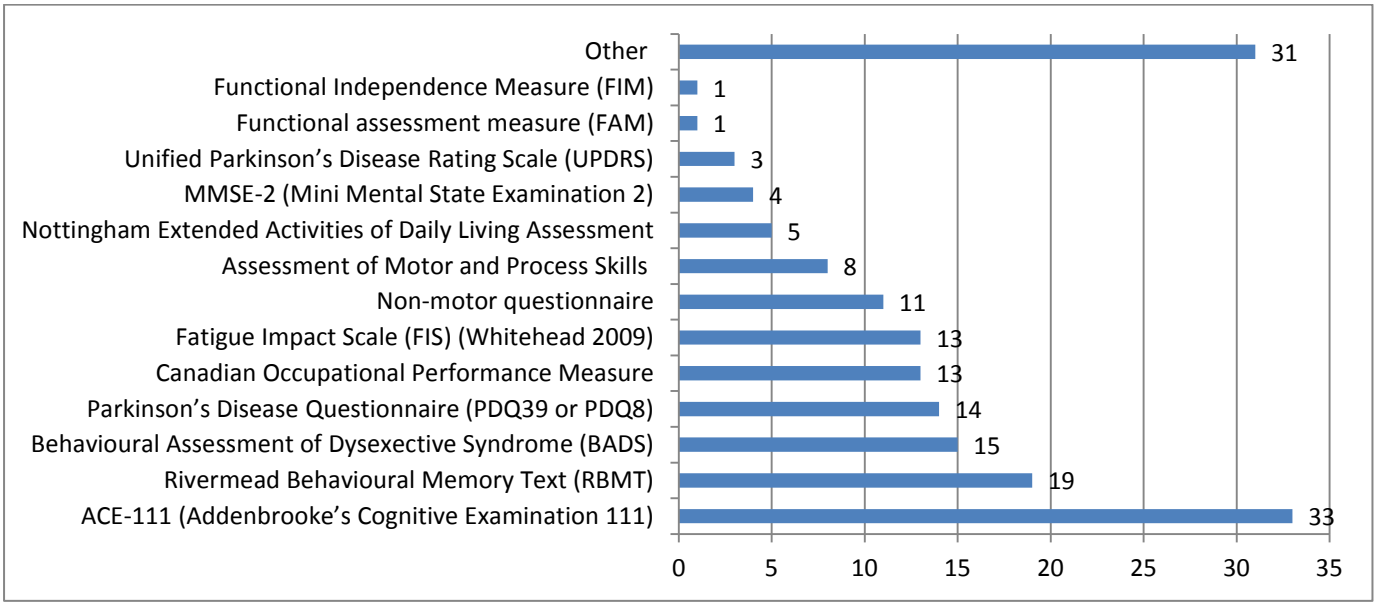
Support available	Services
Consult any member of the Parkinson's specialist movement disorder team (MDT) of which they are a member	66.1%
Consult members of a general Neurology/Elderly Care specialist service of which they are a member	8.5%
Doesn't work directly in specialist Parkinson's clinics, but has access to Parkinson's specialist multidisciplinary team/Parkinson's nurse	22.0%
Doesn't work directly in a specialist clinic, but has access to advice from a specialist Neurology or Elderly Care multidisciplinary team	1.7%
No access to more specialist advice	1.7%
Number:	59

Use of standardised assessments and outcome measures

Occupational therapy services are using a wide range of standardised assessments. 84.7% of services used a least one of the listed standardised assessments (i.e. not 'other') with people with Parkinson's (an increase from 55.3% in 2015). 'Other' assessments used included assessments of mood, cognition, falls and general health.

From the audit data it is unclear, when the standardised assessments are completed, whether they are repeated as outcome measures, and how they are used to guide patient treatment and service development. This makes it difficult to ascertain which measures best reflect meaningful changes in occupational performance.

Figure 7: Number of occupational therapy services using standardised assessments/ outcome measures



Evidence used to inform practice

Table 43: Evidence used in occupational therapy to inform clinical practice and guide choice of intervention for patients

Type of evidence	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Clinical experience	95.7%	97.2%	98.3%	73.7%	100%
Advice from colleague or supervisor	71.0%	73.3%	57.6%	79.0%	81.0%
Recommendations given in *Occupational therapy for people with Parkinson's: best practice guidelines*	75.6%	86.1%	47.5%	63.2%	81.0%
Information from Parkinson's UK website	62.3%	67.7%	50.9%	50.9%	71.4%
NICE – Parkinson's disease NG71 (2017)	55.4%	55.4%	67.7%	24.6%	45.6%
Training courses	54.7%	54.7%	60.2%	44.9%	31.6%
NSF LTNC (2005)	47.4%	47.4%	61.0%	14.4%	10.5%
Published evidence in a peer-reviewed journal	29.3%	29.3%	36.8%	12.7%	3.5%
Webinars, social media	12.6%	12.6%	15.6%	9.3%	1.8%
None	0.4%	0.4%	0.2%	0	1.8%
Other	1.8%	1.8%	2.4%	0.9	0

Occupational therapists rely heavily on clinical experience and peer support to guide practice. This is supported through the use of practical guidance in preference to more evidence-based documents such as the NICE guideline for Parkinson's.

Patient audit

Referral to occupational therapy

Referrals to occupational therapy are made by a wide variety of professionals including neurologists, geriatricians, Parkinson's nurses, physiotherapists, GPs and social care workers (as well as self-referral) with the majority triggered as a result of a medical review (62.3%; 59.6% in 2015). Referred patients had a range of condition durations.

Table 44: Source of referral to occupational therapy

Source of referral	Patients
Parkinson's nurse	27.9%
Geriatrician	18.8%
Neurologist	12.3%
Physiotherapist	10.1%
GP	5.1%
Self Referral	4.2%
Social Care Worker	2.6%
Other	19.1%
Unknown	0.1%
Number:	693

Table 45: Time from diagnosis and occupational therapy referral to this episode

Duration of Parkinson's	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Less than 1 year	7.0%	6.8%	8.9%	8.7%	4.8%
1-2 years	24.1%	22.4%	32.7%	39.1%	4.8%
3-5 years	24.5%	24.8%	26.7%	19.6%	19.1%
6-10 years	22.6%	23.2%	21.8%	8.7%	23.8%
11-15 years	12.6%	14.1%	4.0%	10.9%	28.6%
16-20 years	5.6%	6%	3.0%	8.7%	4.8%
More than 20 years	3.6%	2.7%	3.0%	4.4%	14.3%
Number	673	483	101	46	21

Overall 70.3% of referrals had most of the information required for assessment and intervention.

Table 46: Information essential for occupational therapy assessment and intervention available on referral

Information available on referral	Patients
Yes, most of it	70.3%
Yes, some of it	23.1%
No	6.6%
Number:	713

The majority of referrals were judged to have been made at the appropriate time (89.9%).

Table 47: Patient referred at an appropriate time according to the occupational therapist

Referral at appropriate time	Patients
Yes	89.9%
No	7.7%
Don't know	2.4%
Number:	713

Table 48: Referrals triggered as a result of medical review

Referral triggered by medical review	Patients
Yes	62.3%
No	35.5%
Unknown	2.2%
Number:	713

Table 49: Outcomes reported back to referrer

Reports made	Patients
Yes	59.5%
No	10.1%
No, but will be at the conclusion of this intervention	30.4%
Number:	713

Intervention strategies

Table 50: Needs addressed through occupational therapy - reasons for referral

	Patients
Transfers and mobility	74.1%
Personal self-care activities	44.3%
Environmental issues	39.4%
Domestic activities of daily living	28.9%
Mental wellbeing	27.4%
Leisure activities	13.9%
Management of fatigue	12.6%
Family roles	7.2%
Work roles	3.1%
Other	14.2%

The main needs addressed by occupational therapists were transfers and mobility, followed by personal self-care activities. However, a range of needs and occupational performance areas were addressed through occupational therapy intervention, and it is important to note that the areas most frequently addressed are not necessarily the ones of greatest importance to the individual with Parkinson's.

Table 51: Interventions used for initiating and maintaining movement

Intervention strategies used	**Patients UK**	**Patients England**	**Patients Scotland**	**Patients Wales**	**Patients NI**
Promoting occupational performance abilities through trial of intrinsic cueing techniques	22.4%	24.0%	14.4%	35.1%	14.3%
Promoting functional abilities through trial of extrinsic cueing techniques	32.3%	29.9%	46.6%	33.3%	23.8%
Promoting functional ability throughout a typical day, taking account of medication	46.7%	42.6%	50.0%	75.4%	71.4%
Promoting functional ability throughout a typical day taking into account fatigue	48.7%	50.5%	38.1%	49.1%	85.7%
None of the above treatment strategies applicable	23.4%	25.5%	13.6%	19.3%	4.8%

Table 52: Interventions used for engagement, motivation, learning and carry-over

Intervention strategies used	Patients
Promoting mental wellbeing	48.3%
Promoting new learning	37.9%
None of the treatment strategies applicable	33.8%
Number:	713

Table 53: Interventions that included assessment of environmental adaptations/assistive technology

Assessment	Patients
Small aids and adaptations	69.0%
Wheelchair and seating	17.8%
Major adaptations	10.5%
Assistive technology	9.7%
Other	6.5%
None of the treatment strategies applicable	21.7%
Number:	713

Table 54: Services to which referrals were made to support community rehabilitation and social support

Referrals made	Patients
Social services OT	14.7%
Social worker/carers	13.2%
Other allied health professionals	31.8%
Respite care	1.7%
Voluntary work	8.6%
Access to work	0.3%
Other	13.5%
None of the treatment strategies applicable	47.0%
Number:	713

Table 55: Advice and guidance provided to support patient's self-management

Information provided	Patients
Work advice and resources	3.9%
Specific ADL techniques	64.8%
Cognitive strategies	26.8%
Fatigue management	30.6%
Relaxation/stress management	19.1%
None of the treatment strategies applicable	18.2%
Number:	713

Table 56: Information and support provided for family and carers

Information provided	Patients
Optimising function	50.8%
Safe moving and handling	38.0%
Support services	26.7%
Managing changes in mood, cognition or behaviour	19.1%
Other	3.2%
None of the treatment strategies applicable	29.0%
Number:	713

Table 57: Support provided to enable choice and control

Support provided	Patients
Positive attitude/emotional set	37.9%
Developing self awareness/adjustment to limitations	51.5%
Increasing confidence	56.5%
Explore new occupations	7.0%
Other	1.7%
None of the treatment strategies applicable	20.8%
Number:	713

Occupational therapist Band

Table 58: NHS Band of the therapist assessing the patient

	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Band 4	4.4%	4.0%	8.5%	0	0
Band 5	15.2%	15.6%	3.4%	3.5%	19.1%
Band 6	52.6%	49.3%	82.2%	50.9%	23.8%
Band 7	27.2%	30.1%	5.9%	45.6%	57.1%
Band 8a	0.7%	1.0%	0	0	0
Number:	713	495	118	57	21

Half of people seen were assessed by a Band 6 occupational therapsist. These therapists will generally have at least two years experience. The level of experience of the Band 4 occupational therapy technicians is unclear. What assessments they were undertaking is also unclear.

Physiotherapy

Aims

The physiotherapy audit intended to establish whether physiotherapy services are currently providing quality services for people with Parkinson's (taking into account recommendations from evidence-based guidelines and using standardised assessments). It allows 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 the 95 services registered for the audit reported on 1,514 people with Parkinson's receiving physiotherapy. Patients were aged between 27 and 97 years (mean age73.8 years) and just 3.0% 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 (62.5%) and white (92.9%). Mean age at diagnosis was 68.7 years and audited patients had a mean Parkinson's duration of 5.2 years (range 0–35 years).

Table 59: Gender of Physiotherapy patients

Gender	Patients
Male	62.5%
Female	37.5%
Number:	1514

Table 60: Ethnicity of Physiotherapy patients

Ethnicity	Patients
White	92.9%
Asian/Asian British	4.6%
Black/Black British	1.2%
Mixed/multiple ethnic background	0.5%
Other	0.9%
Number:	1514

Table 61: Settings in which Physiotherapy patients live

Home setting	Patients
Own home	95.4%
Residential care home	1.9%
Nursing home	1.1%
Other	1.7%
Number:	1514

Table 62: Health settings in which Physiotherapy patients are seen

Healthcare setting	Patients
NHS – inpatient	5.1%
NHS – outpatient	66.5%
NHS – community	17.2%
At home	7.8%
Other	3.4%
Number:	1514

Figure 8: Phase of Parkinson's on referral to physiotherapy

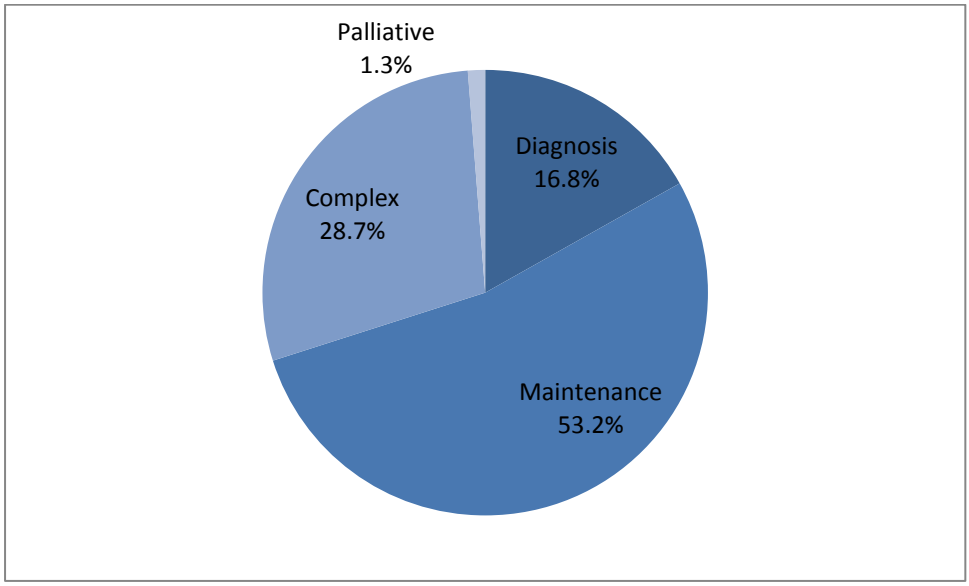


Table 63: Phase of Parkinson's on referral to physiotherapy

Parkinson's phase	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Diagnosis	16.8%	16.8%	19.8%	21.7%	4.2%
Maintenance	53.2%	54.9%	52.3%	54.4%	36.1%
Complex	28.7%	27.4%	27.9%	17.4%	56.9%
Palliative	1.3%	0.8%	0	6.5%	2.8%
Number:	1514	1229	86	92	72

Table 64: How patients with Parkinson's are usually seen

How patients seen	Services
Individually	39.0%
Individually and in groups	61.0%
Number:	95

Service Audit

Model of service provision

Only 13.7% of physiotherapy services reported working in an integrated Parkinson's clinic but 56.8% of services offered assessment as part of a multidisciplinary team. The majority of services (59.0%) were based in the community, within rehabilitation or day hospital teams.

Table 65: Settings in which people with Parkinson's are normally seen

	Services UK	Services England	Services Scotland	Services Wales	Services NI
Integrated medical and therapy Parkinson's clinic	13.7%	14.3%	20.0%	20.0%	0
Inpatient acute service	3.2%	2.6%	0	0	16.7%
Inpatient rehabilitation service	2.1%	1.3%	0	0	16.7%
Acute outpatient rehabilitation	20.0%	18.2%	40.0%	20.0%	16.7%
Community rehabilitation service	39.0%	45.5%	0	20.0%	16.7%
Social services	0	0	0	0	0
Other	22.1%	18.2%	40.0%	40.0%	33.3%
Number:	95	77	5	5	6

72.6% of the physiotherapy services audited specialise in neurological conditions, with 64.2% specialising in the treatment of Parkinson's. This is an encouraging increase in the number of services specialising in Parkinson's since 2015 (57.8%). But the overall percentage of physiotherapists working in integrated Parkinson's services is disappointingly low.

Table 66: Physiotherapy services specialising in the treatment of neurological conditions and Parkinson's

Service specialisation	Yes	No
Specialise in treatment of neurological conditions	72.6%	27.4%
Specialise in treatment of Parkinson's	64.2%	35.8%

Table 67: Percentage of people referred to the service annually with a diagnosis of Parkinson's

Percentage referred	Services
0–19%	35.8%
20–39%	37.9%
40–59%	13.7%
60–79%	5.3%
80–100%	7.4%
Number:	95

Accessing Parkinson's-related continuing professional development (CPD)

Although 89.5% of services offered access to Parkinson's-related CPD (88% in 2015), induction and support strategies were not available for new physiotherapists working with people with Parkinson's in 49.5% of services (39.8% in 2015). Two services reported no access to specialised advice and support for individual therapists. It is encouraging that such a high number of therapists can access Parkinson's-related CPD, and that this is an increase since 2015. However, the lack of induction and support services is an area of concern as it shows, over the last two years, a significant decrease of availability for new physiotherapists who may have little or no knowledge of intervention for Parkinson's. Although it is imperative that individual services aim to provide necessary inductions and support for staff, this is also an area that could be improved by provision of support, online training and signposting to resources and guidelines. For example, information and support available, through the UK Parkinson's Excellence Network.

Table 68: Support available to individual physiotherapists (2015 results in brackets)

Type of support	Services
Can consult any member of the Parkinson's specialist MDT of which they are a member	44.2%
Can consult members of a general neurology/elderly care specialist service of which they are a member	14.7%
Don't work directly in specialist Parkinson's clinics but access to Parkinson's specialist MDT/Parkinson's nurse	35.8%
Don't work directly in a specialist clinic but access to advice from a specialist neurology or elderly care MDT	3.2%
No access to more specialised advice	2.1%
Number:	95

Table 69: Access to Parkinson's-related CPD at least yearly

Access to CPD yearly	Services UK	Services England	Services Scotland	Services Wales	Services NI
Yes	89.5%	89.6%	100%	60%	100%
No	10.5%	10.4%	0	40%	0
Number:	95	77	5	5	6

Table 70: Documented induction and support strategies for new physiotherapists working with people with Parkinson's

Induction and support strategies	Services
Yes	50.5%
No	49.5%
Number:	95

Table 71: Assessments offered to patients with Parkinson's

Assessment	Services
MDT assessment	56.8%
Physiotherapy assessment	81.1%
Other	7.4%
Number:	95

Table 72: Needs addressed by group work

Needs addressed	Services
Education	49.5%
Exercise	59.0%
No group work	36.8%
Other	12.6%
Number:	95

Evidence used to inform practice

The *European physiotherapy guideline for Parkinson's disease* was used to inform clinical practice in the care of 49.7% of patients (43% in 2015). In five patient cases, no evidence was used. Over the past two years, this European guideline has been highlighted and promoted as evidence-based guidance for physiotherapists working with people with Parkinson's, so it is disappointing that the percentage of physiotherapists using the guideline has only increased by just under 7%, and that half of all audited physiotherapists are not using them.

Figure 9: Evidence used to inform physiotherapists' practice and to guide intervention

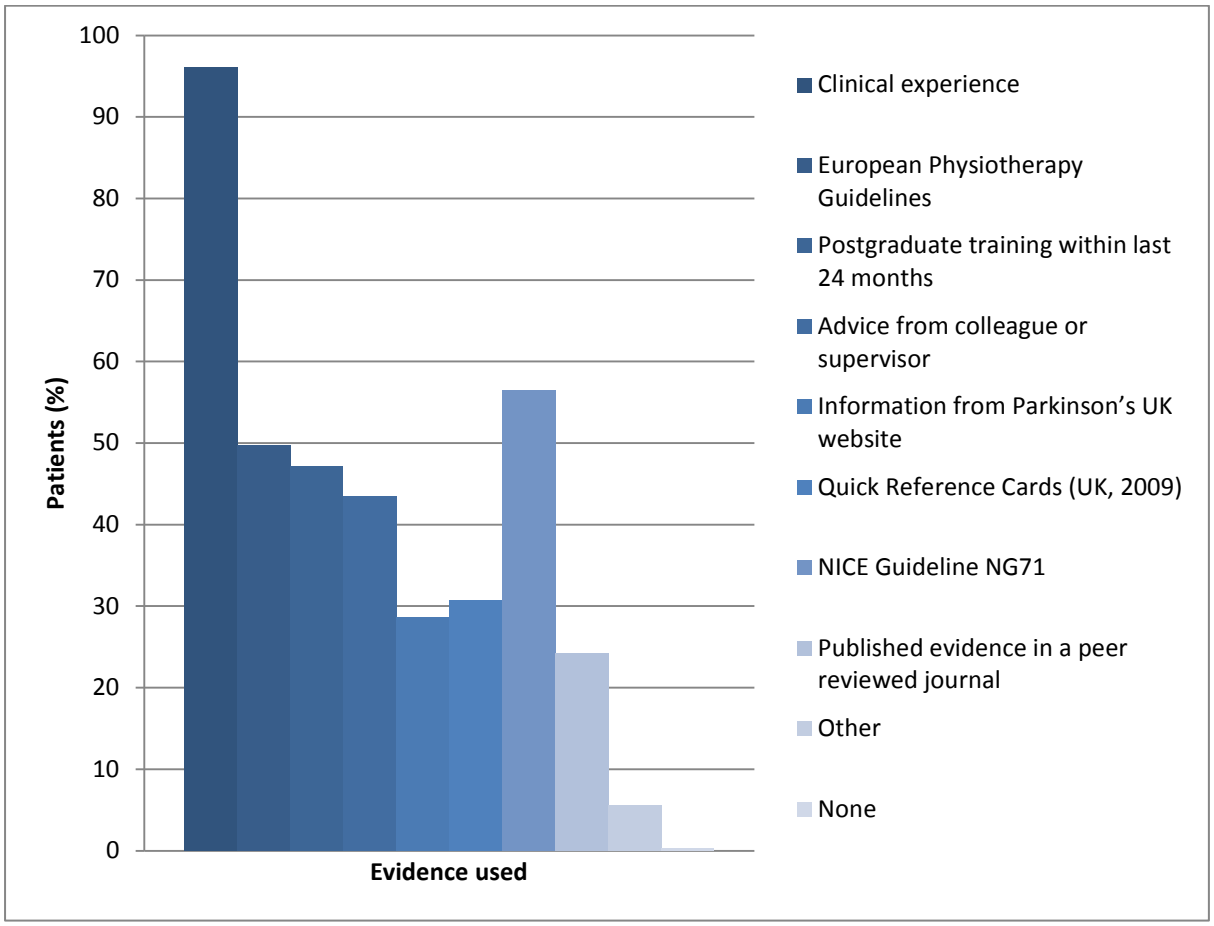


Table 73: Evidence used in physiotherapy to inform clinical practice and guide choice of intervention for patients

Type of evidence	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Clinical experience	96.0%	96.0%	94.2%	98.9%	95.8%
Advice from colleague or supervisor	43.5%	44.5%	30.2%	58.7%	31.9%
European Physiotherapy Guideline for Parkinson's Disease (2013)	49.7%	48.1%	69.8%	48.9%	48.6%
Quick Reference Cards (UK, 2009)	30.7%	32.1%	29.1%	29.4%	12.5%
Information from Parkinson's UK website	41.1%	42.2%	17.4%	51.1%	36.1%
NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017)	56.5%	57.9%	29.1%	76.1%	58.3%
Published evidence in a peer reviewed journal (read within last 12 months)	24.2%	25.3%	26.7%	31.5%	2.8%
Postgraduate training within last 24 months	47.1%	43.6%	52.3%	76.1%	59.7%
Other	5.6%	4.5%	26.7%	4.4%	1.4%
None	0.3%	0.41%	0	0	0

Patient audit

Referral to physiotherapy

A referral within two years of diagnosis was reported in 52.0% of patients (49.3% in 2015). This is an encouraging trend, but interestingly, the number of patients referred in the diagnosis phase of Parkinson's was only 16.8%. *The NICE guideline for Parkinson's disease in adults* (NG71, National Institute for Health and Care Excellence, July 2017) recommends physiotherapy is offered early so that people can be encouraged to exercise and remain active, even when problems arise. There is much evidence to suggest that exercise can have a positive impact on symptoms, and it is important to encourage this from the outset. The Parkinson's exercise framework encourages exercise from diagnosis onwards. (https://www.parkinsons.org.uk/professionals/resources/exercise-framework-professionals)

Table 74: Time between diagnosis and first physiotherapy referral letter (if the person had previous physiotherapy) and first referral letter to this episode (if current physiotherapy episode is the first)

Time between diagnosis and referral	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Less than 1 year	29.3%	28.7%	31.2%	35.7%	23.8%
1–2 years	28.8%	30.2%	27.9%	26.2%	15.9%
3–5 years	18.4%	19.1%	14.8%	17.9%	12.7%
6–10 years	14.2%	13.3%	18.0%	17.9%	19.1%
11–15 years	6.3%	5.8%	6.6%	2.4%	17.5%
16–20 years	2.3%	2.2%	1.6%	0	9.5%
More than 20 years	0.8%	0.8%	0	0	1.6%
Number:	1333	1094	61	84	63

36.3% of patients included in the audit had previously had physiotherapy for Parkinson's.

Table 75: Routine or urgent referrals

Referral type	Patients
Urgent	8.8%
Routine	90.2%
Unknown	1.1%
Number:	1514

Table 76: Referrals that meet local standards for time between referral and initial assessment

Local standard met	Patients
Yes	75.8%
No	16.3%
No local standard	7.9%
Number:	1514

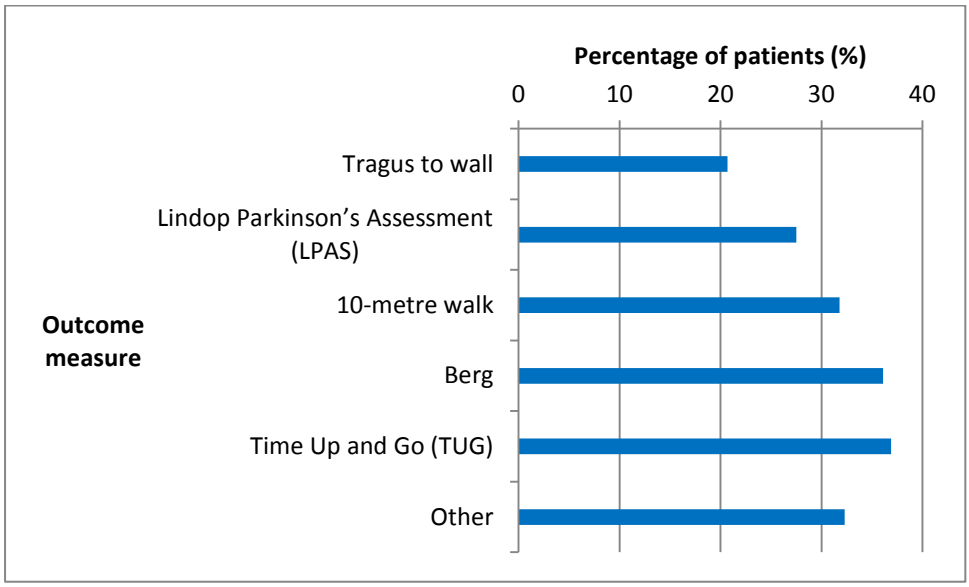
Table 77: Outcomes reported back to referrer

Reports made	Patients
Yes	51.8%
No	10.8%
No but will be done at end of this intervention	37.5%
Number:	1514

Use of appropriate outcome measures by physiotherapists

Outcome measures were reported as being used in 85.2% of patients (84.9% in 2015).

Figure 10: Most frequently used physiotherapy outcome measures



The audit data collection tool included outcome measures recommended in the *European physiotherapy guideline for Parkinson's disease*. For many patients, multiple outcome measures were used and in 32.3% of cases, use of 'other' outcome measures not on the suggested list were reported. Some of these were not specific to physiotherapy (a list is included in the reference report) and several others were not recognised outcome measures at all. Unfortunately, for 14.8% of people with Parkinson's the physiotherapist

reported using no outcome measures. This finding is similar to the 2015 audit (15.4%) and reflects the continuing poor practice of some professionals, which has an impact on patient outcomes.

Table 78: Physiotherapy notes included a goal plan

Goal plan included	Patients
Yes	95.3%
No	4.7%
Number:	1514

Table 79: Outcome measures used

Outcome measures used	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Yes	85.2%	84.6%	83.7%	91.3%	91.7%
No	14.8%	15.4%	16.3%	8.7%	8.3%
Number:	1514	1229	86	92	72

Physiotherapist Band

The majority of patients in the audit were assessed by a Band 6 or 7 physiotherapist. The Chartered Society of Physiotherapy *Supervision, Accountability & Delegation* – PD126, April 2017 document 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".

In 21 of the audit cases (1.4%) a Band 4 carried out the assessment, and in another 27 (1.8%) assessment was carried out by someone ‘other’ than Band 4-8b. It may be that a therapist with a band higher than 8c saw the patient, or that it was a Band 3 or lower. This raises several questions about initial assessments being carried out by unregistered staff, which is not supported by the *NICE guideline*, *NICE quality standards* or the Chartered Society of Physiotherapy standard.

Table 80: NHS band of the therapist assessing the patient

	Patients UK	Patients England	Patients Scotland	Patients Wales	Patients NI
Band 4	1.4%	1.7%	0	0	0
Band 5	11.5%	12.9%	4.7%	3.3%	6.9%
Band 6	44.3%	45.4%	51.2%	32.6%	43.1%
Band 7	38.6%	36.1%	40.7%	64.1%	31.9%
Band 8a	2.4%	2.0%	0	0	16.7%
Band 8b	0.1%	0.2%	0	0	0
Band 8c	0%	0	0	0	0
Other	1.8%	1.9%	3.5%	0	1.4%
Number:	1514	1229	86	92	72

The majority of physiotherapists had a caseload in which people with Parkinson's made up less than 40% of total. This reflects the mixed-conditions caseloads that many physiotherapists are required to manage. *The Parkinson's NICE guideline* recommends the following. "Consider referring people who are in the early stages of Parkinson's disease to a physiotherapist with experience of Parkinson's disease for assessment, education and advice, including information about physical activity." It is important that the physiotherapist has a good understanding of Parkinson's in order to offer appropriate assessment, advice and any required intervention.

Table 81: Percentage of people seen by the audited physiotherapist in a year who have Parkinson's

	Patients
0-19%	24.0%
20-39%	40.1%
40-59%	24.6%
60-79%	2.4%
80-99%	2.7%
100%	1.2%
Unknown	5.0%
Number:	1514

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 64 services registered for the audit reported on 810 people with Parkinson's. Patients were aged between 22 and 96 years (mean: 73.8 years) and the majority were male (71.5%) and living in their own home (90.6%). Audited patients had a mean Parkinson's duration of 6.0 years (range 0–37 years). While the NICE guideline recommends referring patients to speech and language therapy services in the early phase of the condition for assessment for education and advice, the majority of patients continue to be seen in the maintenance phase (59.8%). This is consistent with the 2015 audit (57.9%).

Table 82: Gender of speech and language therapy patients

Gender	Patients
Male	71.5%
Female	28.5%
Number:	810

Table 83: Ethnicity of speech and language therapy patients

Ethnicity	Patients
White	91.6%
Asian/Asian British	4.1%
Black/Black British	1.9%
Mixed/multiple ethnic background	0.3%
Other	2.2%
Number:	810

Figure 11: Phase of Parkinson's on referral to speech and language therapy

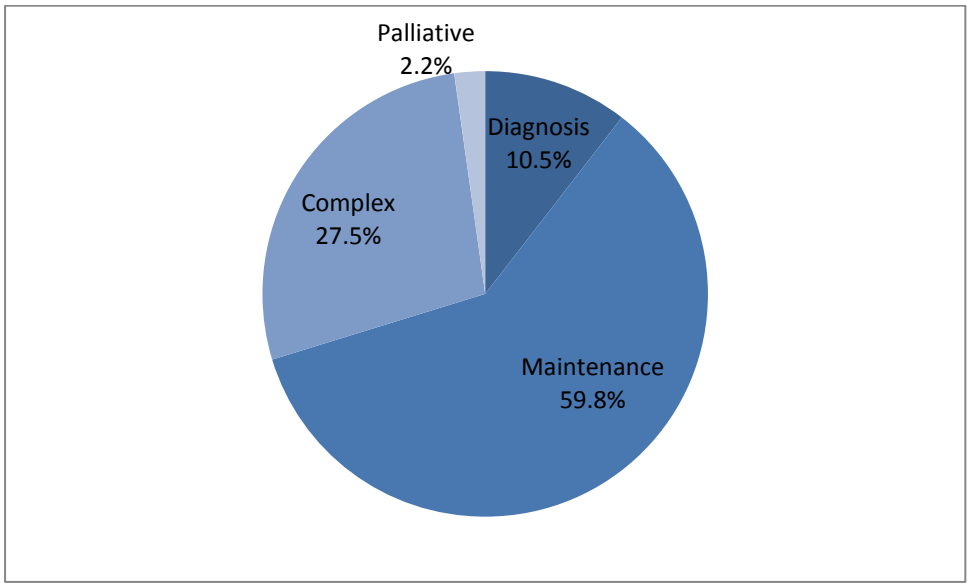


Table 84: Phase of Parkinson's on referral to speech and language therapy

Parkinson's phase	Patients UK	Patients England	Patients Scotland	Patients Wales
Diagnosis	10.5%	9.7%	18.2%	5.4%
Maintenance	59.8%	58.1%	52.0%	80.7%
Complex	27.5%	29.2%	28.6%	14.0%
Palliative	2.2%	3.0%	1.3%	0
Number:	810	534	154	93

Table 85: Settings in which speech and language therapy patients live

Home setting	Patients
Own home	90.6%
Residential care home	3.1%
Nursing home	4.6%
Other	1.7%
Number:	810

Table 86: Health settings in which speech and language therapy patients were seen

Healthcare setting	Patients
NHS – inpatient	4.3%
NHS – outpatient	47.8%
NHS – community	19.0%
At home	26.1%
Other	2.8%
Number:	810

Service audit

Model of service provision

The majority of speech and language therapy input (75.0% 2017; 76.3% in 2015) was offered to people with Parkinson's within general adult acquired speech and language disorder services. Only three speech and language therapy services saw people with Parkinson's in a specialist Parkinson's clinic. (4.7% 2017; 7.9% 2015). As with 2015, for the majority of services (60.3% 2017; 61.9% 2015) Parkinson's constitutes less than 20% of referrals.

Table 87: Settings in which patients with Parkinson's are usually seen

	Patients UK	Patients England	Patients Scotland	Patients Wales
In a specialist clinic for patients with Parkinson's	4.7%	4.4%	0	14.3%
In more general specialist neurology clinics	1.6%	2.2%	0	0
In an elderly/older person's clinic	3.1%	2.2%	10.0%	0
In SLT adult/acquired disorders service mainly based in a hospital	18.8%	15.6%	30.0%	28.6%
In SLT adult/acquired disorders service mainly based in a community clinic	23.4%	17.8%	30.0%	42.9%
In SLT adult/acquired disorders service mainly domiciliary based	32.8%	44.4%	10.0%	0
In generalist SLT service mainly based in a hospital	7.8%	4.4%	10.0%	14.3%
In generalist SLT service mainly based in a community clinic	6.3%	8.9%	0	0
In generalist SLT service mainly domiciliary based	1.6%	0	10.0%	0
Number:	64	45	10	7

However, 71.9% of these services specialise in neurological conditions (76.2% in 2015), with 50.0% specialising in the treatment of Parkinson's within their service provision (47.6% in 2015).

Table 88: Services specialising in treatment of people with neurological conditions

Specialising in neurological conditions	Services
Yes	71.9%
No	28.1%
Number:	64

Table 89: Services specialising in treatment of people with Parkinson's

Specialising in Parkinson's	Services
Yes	50.0%
No	50.0%
Number:	64

People with Parkinson's were mostly seen in either outpatient/community clinics (66.8%; 64.6% in 2015) or their homes (26.1%; 28.4% in 2015).

Most patients were being treated by therapists for whom Parkinson's is only a part of a mixed caseload and not a specialised service.

Table 90: Source of referrals

Referral source	Patients
Elderly Care clinic	7.8%
General Neurology clinic	13.8%
Parkinson's nurse	32.7%
General/non-Parkinson's nurse	6.2%
Allied health professions colleague	9.8%
Speech and language therapy colleague	5.6%
Self/relative	3.2%
Other	21.0%
Number:	810

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

Of the audit services, 81.3% reported having opportunities to undertake Parkinson's-related CPD at least yearly (79.4% in 2015). This remains stable.

Table 91: Access to Parkinson's-related CPD at least yearly

Access to CPD yearly	Services UK	Services England	Services Scotland	Services Wales
Yes	81.3%	84.4%	90.0%	71.4%
No	18.8%	15.6%	10.0%	28.6%
Number:	64	45	10	7

Note: no speech and language therapy services from Northern Ireland participated in the 2017 audit

Specific induction and support strategies for working with people with Parkinson's was given to new staff in 17.2% of speech and language therapy services, a slight increase on the 14.3% reported in 2015. 62.5% of responding services included Parkinson's within their general competencies (50.8% in 2015). While this reflects a slight improvement on 2015 this is an area for further development. Services should consider how new staff are inducted into working with people with Parkinson's to ensure consistency of service between

therapists. This is especially true where therapists are only seeing people with Parkinson's as part of a generalist caseload.

Table 92: Documented induction and support strategies for new therapists

Induction and support strategies	Services
Yes, specifically in relation to patients with Parkinson's	17.2%
Yes, as part of more general competencies	62.5%
No	20.3%
Number:	64

Table 93: Speech and language therapy assistants involved in the delivery of care

Involvement of assistants	Services
Always	6.3%
Sometimes	34.4%
Never	59.4%
Number:	64

Access to services

The majority of speech and language services offered a full service for communication changes (93.8% 2017; 90.5% in 2015), for swallowing (93.8%) and drooling (90.6%).

Table 94: Speech and language therapy available for all people with Parkinson's for issues with communication, irrespective of Parkinson's phase at referral

Service offered for communication issues	Services
Full service, all referrals seen	93.8%
Not full service, some patients not seen depending on their stage of Parkinson's	-
Not full service, restricted by number of hours assigned (eg patients can receive only 10 hours before discharge/re-referral/placed on review)	4.7%
Not full service, some patients not seen depending on postcode/area	3.1%
Not full service, some patients not seen depending on service (eg Neurology versus Elderly Care)	-
Not full service, some patients not seen depending on issue (eg communication versus swallowing)	1.6%
Not full service, some patients not seen depending on prioritization in speech and language therapy Parkinson's service	1.6%
Not full service, some patients not seen depending on prioritization in overall speech and language therapy service	1.6%
Number:	64

Table 95: Speech and language therapy available for people with Parkinson's for eating/swallowing issues irrespective of Parkinson's phase at referral

Service available for eating, swallowing and drooling	Services
Full service, all referrals seen	3.8%
Not full service, some patients not seen depending on stage of their Parkinson's	-
Not full service, restricted by number of hours assigned (eg patients can receive only 10 hours before discharge/re-referral/placed on review)	3.1%
Not full service, some patients not seen depending on postcode/area	1.6%
Not full service, some patients not seen depending on service (eg Neurology versus Elderly Care)	-
Not full service, some patients not seen depending on issue (eg communication versus swallowing)	-
Not full service, some patients not seen depending on prioritization in speech and language therapy Parkinson's service	1.6%
Not full service, some patients not seen depending on prioritization in overall speech and language therapy service	3.1%
Number:	64

Table 96: Speech and language therapy available for people with Parkinson's for drooling issues irrespective of Parkinson's phase at referral

Service available for eating, swallowing and drooling	Services
Full service, all referrals seen	90.6%
Not full service, some patients not seen depending on stage of their Parkinson's	1.6%
Not full service, restricted by number of hours assigned (eg patients can receive only 10 hours before discharge/re-referral/placed on review)	4.7%
Not full service, some patients not seen depending on postcode/area	1.6%
Not full service, some patients not seen depending on service (eg Neurology versus Elderly Care)	-
Not full service, some patients not seen depending on issue (eg communication versus swallowing)	-
Not full service, some patients not seen depending on prioritization in speech and language therapy Parkinson's service	1.6%
Not full service, some patients not seen depending on prioritization in overall speech and language therapy service	3.1%
Number:	64

The Lee Silverman Voice Treatment (LSVT) programme was offered in full by 43.8% of services, an increase on 34.9% in 2015. It was not available to all potentially eligible people with Parkinson's in 7.8% of services (17.5% in 2015). A similar alternative programme to LSVT was offered by 28.1% of services. These findings show LSVT is increasingly available to people with Parkinson's and services can offer it to more people. But still less than half of patients in the audit had access to the full LSVT programme.

Table 97: Services offering Lee Silverman Voice Treatment (LSVT) for people with Parkinson's who meet inclusion criteria

LSVT treatment availability	Services
Full LSVT service offered as required	43.8%
Variant(s) of LSVT offered	28.1%
LSVT not offered due to no service delivery decision	12.5%
LSVT not offered due to lack of LSVT trained speech and language therapist	7.8%
Not all eligible candidates able to receive full service	7.8%
Number:	64

Table 98: Services with equipment available to those requiring assistive technology (Augmentative and Alternative Communication, AAC) to support independent living

AAC available	Services
Yes, it is part of the service	39.1%
Yes, full access via other AAC service	18.8%
Restricted AAC service due to financial restrictions	20.3%
Restricted AAC service due to equipment range	12.5%
Only able to access AAC if patient meets complex technology specialist referral criteria applicable within relevant devolved government	9.4%
Number:	64

Reviews

Only 14.1% (12.7% 2015) of speech and language therapy services offered regular 6-12 month reviews.

Table 99: Review policies in speech and language therapy services

Review policy	Services
All patients in speech and language therapy service routinely reviewed every 6–12 months	14.1%
Some patients reviewed at request of wider MDT/Parkinson's nurse	21.9%
Some patients reviewed according to local prioritisation	3.1%
Patients are not automatically reviewed	18.8%
No fixed time set for review	20.3%
Patients are discharged after a set number of treatment sessions/episodes of care	21.9%
Number:	64

Table 100: Communication measures specifically stipulated to be carried out at initial assessment and each review point

Initial communication assessment	Services
Standardised assessments of all speech/voice and language variables	6.3%
Selective range of formal speech/voice and/or language assessments	26.6%
Informal disease-specific assessment proforma	17.2%
No specific assessments stipulated	50.0%
Number:	64

Table 101: Swallowing measures specifically stipulated to be carried out at initial assessment and each review point

Initial swallowing assessment	Services
Standardised assessments of swallowing	12.5%
Selective range of formal assessments	18.8%
Informal disease-specific assessment proforma	17.2%
No specific assessments stipulated	51.6%
Number:	64

Table 102: Saliva management included in the speech and language therapy assessment and treatment plan if required

Saliva management	Services
Yes	98.4%
No	1.6%
Number:	64

Patient audit

Table 103: Patients experiencing first episode of care within any speech and language therapy service

First episode of speech and language therapy care	Patients
Yes	63.3%
No	34.6%
Not known	2.1%
Number:	810

Table 104: Description of current episode of care

Current episode of care	Patients
Initial assessments only	24.2%
Review appointment only	14.2%
Group treatment only	5.1%
Individual treatment only	40.9%
Group and individual treatment	11.1%
Other	4.6%
Number:	810

Referral to speech and language therapy

Table 105: Time between diagnosis and first referral letter to speech and language therapy (years)

	Patients UK	Patients England	Patients Scotland	Patients Wales
Less than 1 year	6.4%	5.0%	10.1%	10.0%
1-2 years	31.2%	30.1%	37.2%	26.7%
3-5 years	25.9%	26.2%	22.3%	31.1%
6-10 years	22.3%	23.0%	20.3%	23.3%
11-15 years	7.2%	7.4%	6.1%	5.6%
16-20 years	4.7%	5.6%	2.7%	2.2%
More than 20 years	2.3%	2.8%	1.4%	1.1%
Number:	767	501	148	90

The majority of patients were seen in a timely manner (86.8%). Patients were referred for specific opinion on an aspect of their communication and/or swallowing (77.5% 2017; 79.0% 2015). 60.3% of all patients audited received a full communication assessment and 57.5% of all patients audited received a full swallow assessment. There is an overlap in these percentages as a number of patients will have required both a communication and swallowing assessment.

Table 106: Referrals that meet target time between referral and first speech and language therapy appointment

Target met	Patients
Yes	86.6%
No, and no reason documented	8.6%
No, but reason documented (eg clinician leave)	4.6%
Number:	810

Table 107: Target met for waiting time between speech and language therapy intention-to-treat decision and first appointment

Target met	Patients
Yes	67.3%
No, there was no intention to treat	5.3%
No and no reason documented	2.7%
No, but reason documented (eg failed appointment)	2.2%
Service does not have prescribed target time	22.5%
Number:	810

Table 108: Reason for referral to the audited service

Referral reason	Patients
General assessment opinion	9.0%
Specific assessment opinion: breathing, voice, speech, swallowing, drooling or other	77.5%
Treatment	13.3%
Unknown	0.1%
Number:	810

Table 109: Full communication assessment carried out on first referral

Communication assessed	Patients
Yes	60.3%
No reference to assessments documented	5.3%
No, but reasons why assessment was inappropriate documented	10.1%
No, referred for swallow assessment only	24.3%
Number:	810

Table 110: Full swallowing assessment carried out on first referral

Swallowing assessed	Patients
Yes	57.5%
No reference to assessments documented	1.6%
No, but reasons why assessment was not appropriate documented	12.0%
No, referred for communication assessment only	28.9%
Number:	810

Table 111: Communication assessment carried out at each review

Communication assessment at review	Patients
Yes	40.7%
No reference to assessments documented	4.4%
No, but reasons why assessment was inappropriate documented	7.9%
Initial assessment only at this stage	26.2%
No, referred for swallow assessment only	20.7%
Number:	810

Table 112: Swallowing assessment carried out at each review

Swallowing assessment at review	Patients
Yes	30.0%
No reference to assessments documented	3.0%
No, but reasons why assessment was inappropriate documented	11.5%
Initial assessment only at this stage	24.2%
No, referred for communication assessment only	31.4%
Number:	810

Table 113: Audio or video recording made at initial assessment and follow-up appointments, and recording available (where not referred for swallow only)

Recording made	Patients
Yes and available	16.4%
Yes, but not available	8.2%
No, Trust or Board governance rules do not permit acquisition or storage of digital data	17.2%
No, client did not consent	0.3%
No	57.9%
Number:	634

Content of assessment

For patients referred for communication assessments, the assessment mainly focussed on speaking (96.6% 2017; 97.9% 2015).

Table 114: Tasks/contents covered by assessment (where not referred for swallowing only)

Task covered	Patients
Speaking	96.6%
Reading	36.9%
Writing	8.3%
One-to-one	87.1%
Group	27.6%
Number:	626

The majority of assessments occurred within a one to one context (87.1%). In less than half of patients all speech subsystems were assessed across stimulated and unstimulated conditions (38.6%). As in 2015, the main focus for assessment was loudness (92.2% 2017; 94.1% 2015).

Table 115: Assessment results available for all speech subsystems in initial assessment and all review appointments (in individuals not seen for swallow only)

	Patients UK
Subsystems assessed in both stimulated and unstimulated conditions	38.6%
Restricted range of subsystems and/or conditions assessed, justification documented	24.6%
Restricted range of subsystems and/or conditions assessed, no justification documented	21.1%
No assessments documented, but with justification documented	9.5%
No assessments and with no justification documented	6.2%
Number:	634

Table 116: Assessment results available for all speech subsystems in initial assessment and all review appointments (all patients)

	Patients UK	**Patients England**	**Patients Scotland**	**Patients Wales**
Yes, subsystems assessed in both stimulated and unstimulated conditions	30.3%	26.8%	46.8%	25.8%
Restricted range of subsystems and/or conditions assessed, justification documented	19.3%	19.3%	16.2%	25.8%
Restricted range of subsystems and/or conditions assessed, justification not documented	16.6%	17.4%	11.0%	22.6%
No assessments documented, but with justification documented	7.4%	5.8%	12.3%	3.2%
No assessments and with no justification documented	4.8%	5.2%	3.3%	2.2%
Seen for swallowing only	21.6%	25.5%	10.4%	20.4%
Number:	809	534	154	93

85.0% of people with Parkinson's were assessed on communication participation (83.7% 2015) and 88.0% (84.9% 2015) how Parkinson's impacted on communication participation

(excluding those seen for swallowing issues only). These are key outcome measures so it is positive that they continue to be assessed consistently.

The area of assessment that continues to show no change is the standardised assessment of intelligibility (10.3% 2017; 10.5% 2015). Intelligibility assessment is a key part of the perceptual assessment of motor speech disorders as it usually forms one of the key outcome measures for treatment. Therefore, a robust baseline pre and post treatment is essential and recommended in the RCSLT clinical guidelines (2005). While there has been no change in people with Parkinson's receiving a standardised assessment, there is an increase in measurement of intelligibility overall (67.7% 2017; 53.7% 2015). This is positive, but standardised or evidence-based measures of intelligibility should be considered as a key outcome measure for treatment.

Table 117: Intelligibility assessed (in individuals not seen for swallow only)

Evaluation of intelligibility	Patients
Standardised diagnostic intelligibility test completed and score given	10.3%
Informal assessment, non-standardised tool/subsection of other test completed and score given	33.3%
Informal assessment (e.g. rating scale) completed	34.4%
No assessment/results documented but justification given	10.4%
No assessment documented and no justification given	11.7%
Number:	634

The full details of test scores and their interpretations regarding communication strengths and needs were documented in just under two thirds of patients audited (59.9% 2017; 53.5% 2015).

Table 118: Assessment includes communication participation (where not referred for swallow only)

Communication participation assessed	Patients
Yes	85.0%
No	15.5%
Number:	634

Table 119: Assessment includes the impact of Parkinson's on communication (where not referred for swallow only)

Impact on communication assessed	Patients
Yes	88.0%
No	12.0%
Number:	634

Table 120: Assessment includes the impact of communication changes on partner/carer (where not referred for swallow only)

Impact of communication changes assessed	Patients
Yes	64.0%
No	24.9%
No carer	11.0%
Number:	634

Table 121: Onward referrals (eg ENT, video fluoroscopy) made where recommended in notes

Onward referrals	Patients
Yes	24.8%
None, reasons documented	2.1%
None, reasons not documented	1.1%
No onward referrals recommended	72.0%
Number:	810

Care planning

Although full test scores and their interpretations are not always fully documented, there was a plan of management detailed in the notes of 90.4% (89.9% 2015) of patients. This remains a consistent area of strength but would be enhanced by full analysis of test results on which to base planning and outcome measurement.

Table 122: Clear plan of management based on assessment outcomes

Plan of management based on assessment outcomes	Patients
All plans detailed in notes	90.4%
Some restricted plans documented	8.8%
No plans documented	0.8%
Number:	634

Content of therapy

Direct therapy for communication focused mainly on vocal loudness (62.9%) and strategies to improve intelligibility (58%) supported by patient education and advice (80.2%).

Table 123: Targets of intervention

Intervention target	Patients
Pitch	26.3%
Prosody	18.5%
Improvement of vocal loudness	62.9%
Strategies to optimise Intelligibility	57.9%
Patient seen for swallow only	29.6%
Number:	809

There was less emphasis on the non-direct aspects of treatment, such as generalisation of skills, participation and carer support. These are key aspects of intervention to ensure that therapy outcomes have a direct benefit to the person with Parkinson's in their daily lives.

Table 124: Percentage of patients with interventions targeting features outside of direct speech/voice work

	Patients
Patient education/advice	80.2%
Managing patient participation	46.3%
Managing patient impact	42.1%
Managing generalisation outside clinic	47.5%
Carer education/advice	46.2%
Managing career impact	11.1%

Table 125: Prophylactic and anticipative interventions used, not just symptomatic

Prophylactic and anticipative interventions used	Patients
Yes, education/planning for upcoming issues included	75.2%
No, no prophylactic component indicated	24.8%
Number:	810

Table 126: Indication of preparation during an earlier phase for patients in later stages

Preparation for later stages	Patients
Yes	15.6%
No	4.7%
Not referred in early stages	14.8%
Patient not in later stages	64.9%
Number:	810

Information giving

For both communication and swallowing, results and the rationale for resulting actions (e.g. review period, intervention plans) were explained to the patient and/or carer in 91.1% of cases. The therapist provided education and advice to 92.6% of patients to help them make informed decisions about their future care and treatment. Intervention was also prophylactic and anticipatory in three quarters of cases. This appears to be a strength in speech and language therapy service delivery, where anticipatory planning is important (particularly in management of swallowing).

Table 127: Assessment results and rationale for subsequent action (eg review period, intervention plans) conveyed and explained to patient and/or carer

Results and action explained	Patients
Explanation of causal/maintaining factors for patient and carer documented	91.1%
No explanation made/documented, but justification documented	3.1%
No explanation made/documented and no justification documented	5.8%
Number:	810

Table 128: Information about communication and/or swallowing supplied by the therapist to the client to help make informed decisions about care and treatment

Information supplied	Patients
Intervention specifically included education and advice on self-management, and was documented	92.6%
No explanation made/documented, but justification documented	2.6%
No explanation made/documented and no justification documented	4.8%
Number:	810

Table 129: Reports made back to referrer or other key people at the conclusion of intervention (or interim reports where treatment lasts longer)

Reports made	Patients
Yes	77.0%
No	23.0%
Number:	810

Table 130: Referral letters to other agencies include relevant history

Relevant history included	Patients
Yes	24.6%
No	75.4%
Number:	810

Table 131: Referral letters to other agencies include questions the referrer wishes to have answered

Questions included	Patients
Yes	20.6%
No	79.4%
Number:	810

Table 132: Referral letters to other agencies include type of referral requested (eg single consultation for advice or initiation of treatment)

Type of referral included	Patients
Yes	23.3%
No	76.7%
Number:	810

Speech and Language therapist Band

The majority of patients are seeing therapists who see less than 20% of people with Parkinson's a year (42.1% 2015) and are Band 6 or 7. 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 even 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 133: NHS Band of the therapist assessing the patient

	Patients UK	Patients England	Patients Scotland	Patients Wales
Band 5	18.5%	20.4%	9.7%	23.7%
Band 6	36.2%	35.4%	37.0%	26.9%
Band 7	34.3%	36.3%	24.7%	46.2%
Band 8a	9.0%	5.8%	26.6%	1.1%
Band 8b	2.0%	2.1%	2.0%	2.2%
Number:	810	534	154	93

Table 134: Percentage of individuals referred to a service annually with a diagnosis of Parkinson's

	Services
0-19%	59.4%
20-39%	23.4%
40-59%	7.8%
60-79%	1.6%
80-100%	6.3%
Total	98.4%
Missing	1.6%
Number:	64

Table 135: Sources of information informing clinical practise around the management of Parkinson's

	Patients UK	**Patients England**	**Patients Scotland**	**Patients Wales**
Own clinical experience	98.6%	98.1%	100%	100%
Advice from colleagues	87.8%	86.9%	90.9%	98.9%
RCSLT Clinical Guidelines (CQ Live)	83.3%	85.2%	81.2%	87.1%
RCSLT Communication Quality Live	54.8%	48.1%	79.2%	58.1%
2017 NICE Guideline	79.1%	83.0%	68.2%	85.0%
National Service Framework LTNC	48.3%	58.2%	37.0%	23.7%
Published evidence in peer reviewed journal	66.7%	65.0%	75.3%	72.0%
None	0.5%	0.2%	2.0%	0
Other	14.3%	9.4%	22.1%	25.8%

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 477 services that submitted clinical data to the audit, 56.4% also took part in the PREM. This provided responses from 6,446 people with Parkinson's and their carers.

Demographics

The majority of PREM questionnaires (75.6%) were completed by a person with Parkinson's rather than a carer. The majority of respondents were male (60.8%) and white (92.6%).

Table 136: Ethnicity of people with Parkinson's represented in the PREM

Ethnicity	
White	92.6%
Asian/Asian British	3.3%
Black/Black British	1.1%
Mixed/multiple ethnic background	0.3%
Other ethnic group/prefer not to say	0.5%
No data	2.3%
Number:	6446

Only 3.1% of respondents lived in a care home, and 19.2% lived alone.

Table 137: Living arrangements

Living arrangements	
Live with husband/wife/partner	70.5%
Live with family/friends	5.9%
Live on their own	19.2%
Live in care home	3.1%
Other	0.7%
No data	0.6%
Number:	6446

The duration of Parkinson's ranged from less than a year to over 20 years.

Table 138: Duration of Parkinson's

Parkinson's duration	
Less than 2 years	20.5%
2-10 years	59.2%
11–20 years	16.5%
Over 20 years	2.7%
Not answered	1.0%
Number:	6446

The demographics of the respondents to the PREM questionnaire were comparable to those seen in the audit data.

Table 139: Age of people with Parkinson's represented in the PREM

Age	
20–29	0.1%
30–39	0.3%
40–49	1.4%
50–59	6.0%
60–69	21.2%
70–79	43.7%
80–89	25.1%
Over 90	1.8%
Not answered	0.5%
Number:	6446

Table 140: Duration of attendance at current Parkinson's service

Duration of service attendance	
Less than 1 year	15.2%
1–2 years	21.5%
3–5 years	26.7%
Over 5 years	32.9%
Not answered	3.8%
Number:	6446

Findings

Frequency of review by consultant or Parkinson's nurse

The majority of respondents (82.5%) felt that the number of reviews carried out by their consultant met their needs, while 81.6% felt this was true for their Parkinson's nurse. Some

respondents felt that they weren't reviewed enough by either their consultant (14.1%) or Parkinson's nurse (11.8%).

Table 141: Number of face-to-face or telephone reviews by consultant meets needs

Meets needs (consultant)	
Yes	74.6%
No - less than needed	12.7%
No – more than needed	1.6%
No access	1.6%
Not answered	9.5%
Number:	6446

Table 142: Number of face-to-face or telephone reviews by Parkinson's nurse meets needs

Meets needs (Parkinson's nurse)	
Yes	67.7%
No - less than needed	9.8%
No – more than needed	1.4%
No access	4.0%
Not answered	17.0%
Number:	6446

Accessing services

Table 143: Access to Parkinson's nurse

Parkinson's Nurse access	
Yes	83.5%
No – but have tried	3.4%
No – don't need it	3.2%
Not sure	5.1%
No data	4.7%
Number:	6446

Table 144: Access to occupational therapy

Occupational therapy access	
Yes	38.8%
No – but have tried	3.4%
No – don't need it	20.6%
Not sure	11.9%
No data	25.4%
Number:	6446

Table 145: Access to physiotherapy

Physiotherapy access	
Yes	50.1%
No – but have tried	3.8%
No – don't need it	14.9%
Not sure	10.0%
No data	21.3%
Number:	6446

Table 146: Access to speech and language therapy

Speech and language therapy access	
Yes	32.4%
No – but have tried	3.2%
No – don't need it	27.5%
Not sure	10.2%
No data	26.6%
Number:	6446

Contacting Parkinson's service between reviews

Table 147: Access to Parkinson's nurse between scheduled reviews

Parkinson's Nurse access between reviews	
Yes	77.8%
No	4.6%
Not needed	3.7%
Not sure	6.3%
No data	7.6%
Number:	6446

Table 148: Access to occupational therapy between scheduled reviews

Occupational therapy access between reviews	
Yes	26.9%
No	6.9%
Not needed	17.6%
Not sure	13.7%
No data	35.0%
Number:	6446

Table 149: Access to physiotherapy between scheduled reviews

Physiotherapy access between reviews	
Yes	35.1%
No	7.0%
Not needed	13.4%
Not sure	14.0%
No data	30.6%
Number:	6446

Table 150: Access to speech and language therapy between scheduled reviews

Speech and language therapy access between reviews	
Yes	22.0%
No	6.1%
Not needed	22.6%
Not sure	13.5%
No data	35.8%
Number:	6446

Quality of services provided within a Parkinson's service

Figure 12: Quality of service offered by consultant/doctor

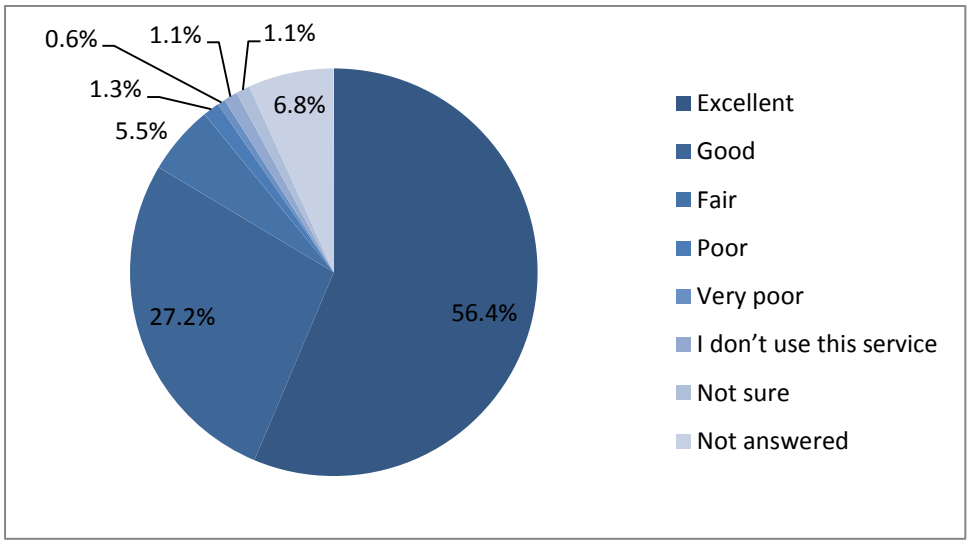


Figure 13: Quality of service offered by Parkinson's nurse

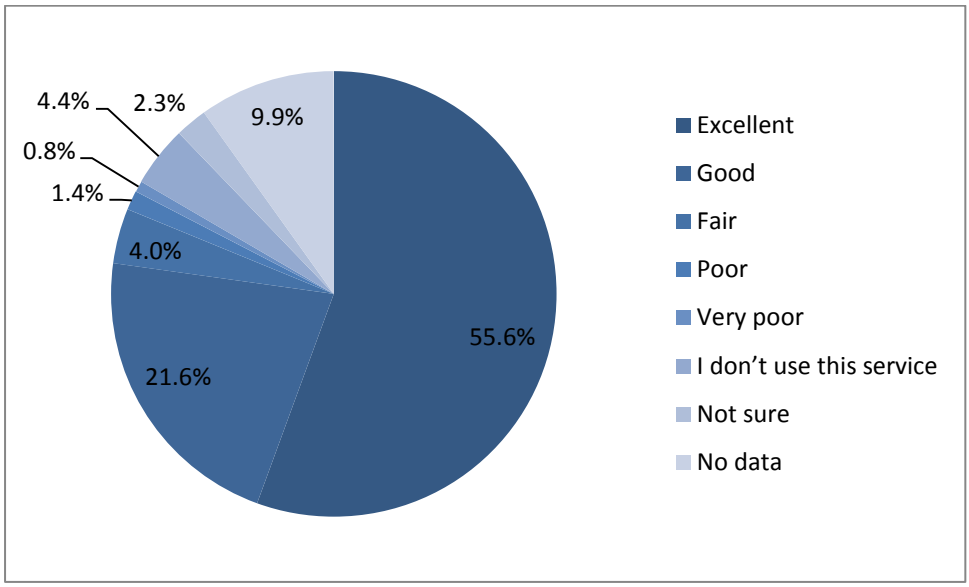


Figure 14: Quality of service offered by occupational therapists

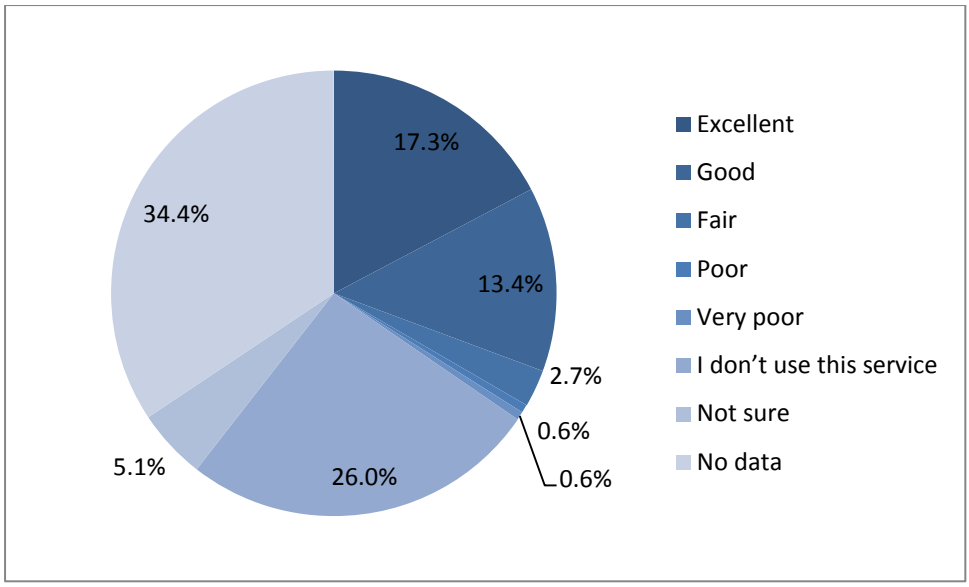


Figure 15: Quality of service offered by physiotherapists

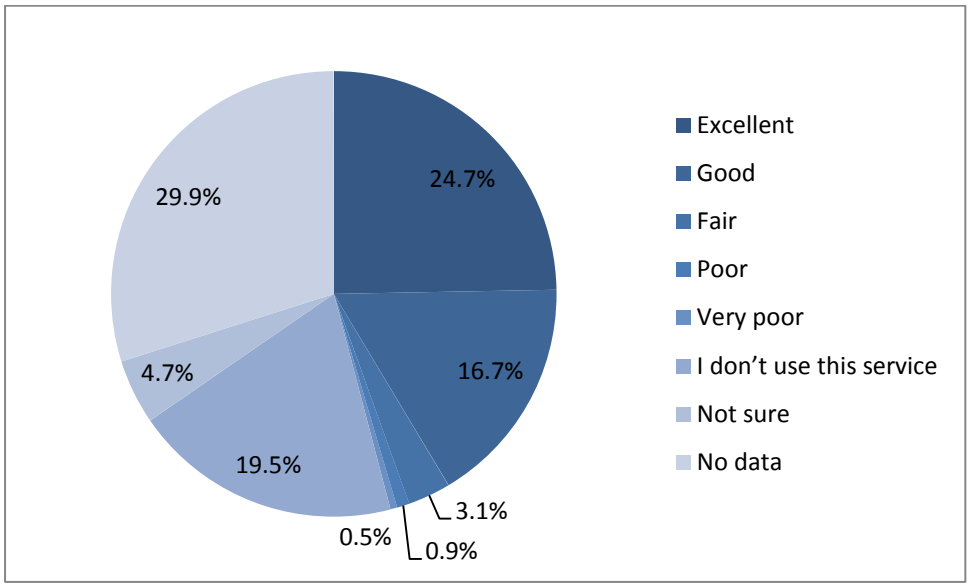
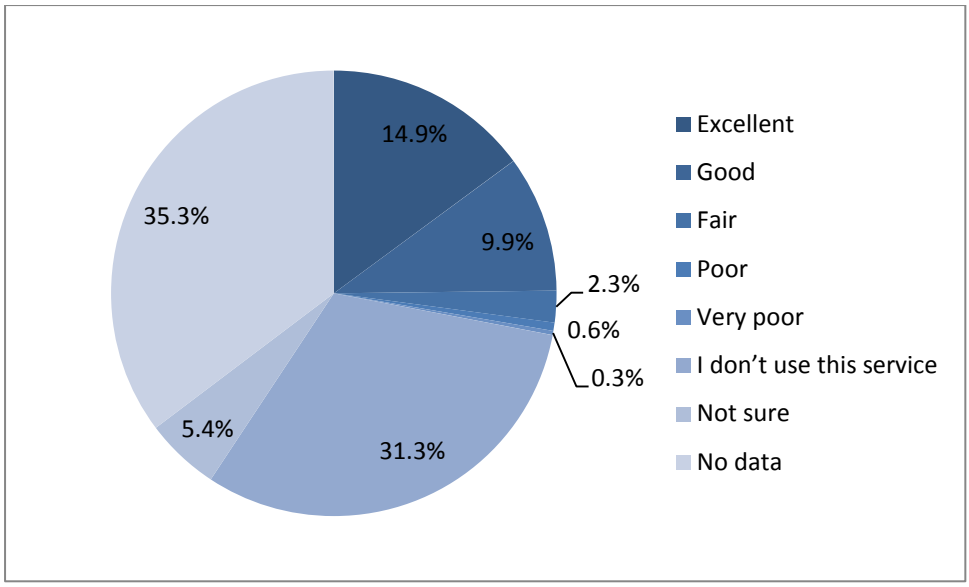


Figure 16: Quality of service offered by speech and language therapists



Provision of information

Although the majority of respondents (61.1% of those who answered) said they had received enough information about Parkinson's at diagnosis, there was still a significant number who had not received enough information or were not sure if they had.

Figure 17: Percentage of people with Parkinson's who received enough information about Parkinson's at diagnosis

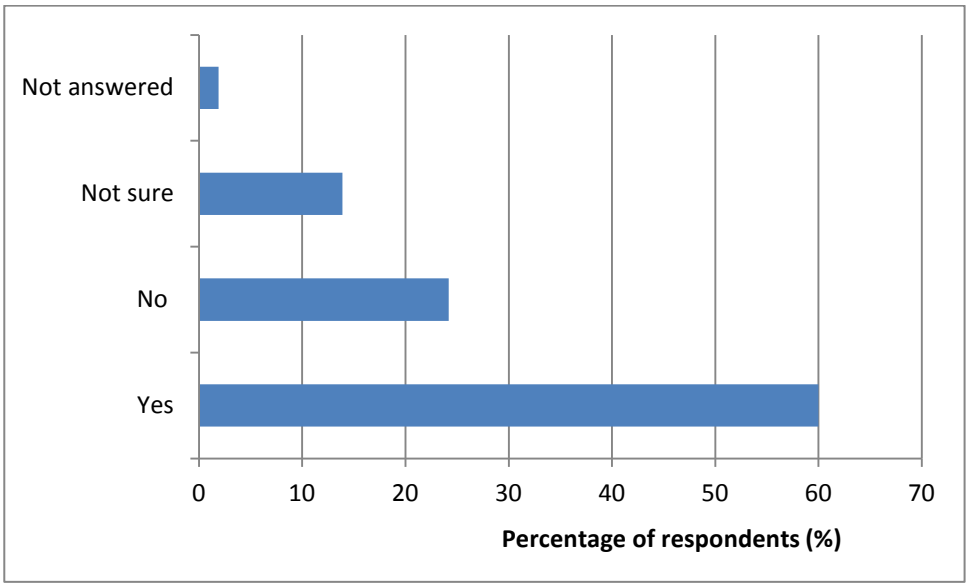


Table 151: People with Parkinson's who received enough information about Parkinson's at diagnosis

Enough information received at diagnosis	
Yes	60.0%
No	24.2%
Not sure	13.9%
Not answered	1.9%
Number:	6446

38.1% 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.

Table 152: People with Parkinson's given enough information about new medication, including potential side effects

Enough information provided about new medication	
Yes	67.7%
No	15.1%
Not sure	12.4%
No new medication started	2.9%
Not answered	1.9%
Number:	6446

Table 153: Services providing information about the role of social work for people with Parkinson's and their carers

Information provided about social work	
Yes	42.5%
No	22.2%
Not sure	18.3%
Not answered	16.9%
Number:	6446

Table 154: Services providing information about support for carers

Information provided about carer support	
Yes	30.9%
No	26.9%
Not sure	20.8%
Not answered	21.3%
Number:	6446

Table 155: Services providing information about how to take part in clinical trials

Information provided about taking part in clinical trials	
Yes	22.4%
No	37.4%
Not sure	20.2%
Not answered	20.0%
Number:	6446

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, 16.1% had either not been given information about contacting the DVLA or their insurance company, or were not sure whether they had. This is an improvement on the 26.5% who responded this way in 2015.

Table 156: Drivers given verbal and/or written advice about contacting the DVLA (or DVA) and car insurance company

Advice given	
Yes	46.0%
No	7.1%
Not sure	1.7%
Not a driver	36.0%
Not answered	9.2%
Number:	6446

Medicines management in hospital

In the last year, 22.9% 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 doesn't get their medication at the time prescribed for them their symptoms 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.

Figure 18: Percentage of people with Parkinson's who received their Parkinson's medication on time while in hospital

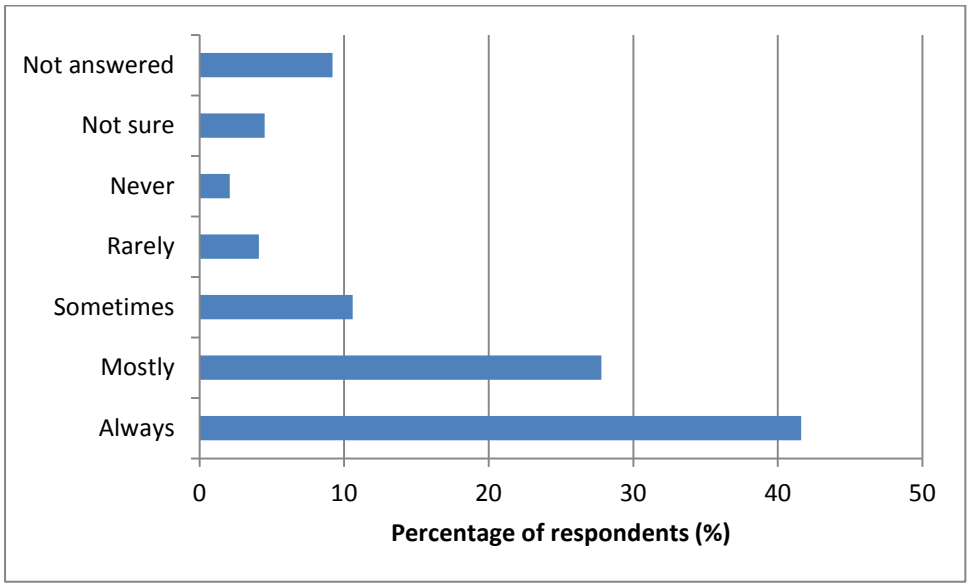


Table 157: Percentage of people with Parkinson's who received their Parkinson's medication on time while in hospital

Medication on time	
Always	41.6%
Mostly	27.8%
Sometimes	10.6%
Rarely	4.1%
Never	2.1%
Not sure	4.5%
Not answered	9.2%
Number:	1456

Table 158: Effect experienced after receiving Parkinson's medication late while in hospital

Effect experienced	
Significant negative effect	10.0%
Negative effect	15.3%
No effect	11.1%
Positive effect	2.1%
Not sure	19.6%
Not answered	41.9%
Number:	1456

In some cases, hospitals will allow a patient to self-medicate, which ensures they take their medication on time, every time. 58.5% of our respondents wanted to manage and take their own medication, which they had brought from home and 34.5% were able to. However, 50.8% were unable to self-medicate and 14.7% were not sure if they were able to.

Table 159: Percentage of people with Parkinson's in hospital who wanted to managed and take their own Parkinson's medication brought from home

Wanted to self-medicate	
Yes	51.2%
No	36.3%
Not answered	12.6%
Number:	1456

Table 160: Percentage of people with Parkinson's who were able to manage and take their own Parkinson's medication in hospital

Able to self-medicate	
Yes	30.1%
No	44.2%
Not sure	12.8%
Not answered	12.8%
Number:	1456

Enquiry into symptoms

Table 161: Concerns raised or asked about concerns regarding symptoms

	Concerns raised	**No data**
Balance and falls	75.8%	24.2%
Mood and memory (e.g. anxiety, depression)	64.4%	35.6%
Speech, swallowing or salivary (drooling) problems	63.2%	36.8%
Bladder problems	57.4%	42.6%
Bowel problems (constipation)	60.5%	39.5%
Sleep	63.9%	36.1%
Uncontrollable movements (e.g. tremor, dyskinesia)	65.4%	34.6%

75.8% 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.

Accessing Parkinson's UK support services

25.8% 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.

Table 162: Services providing information about how to access Parkinson's UK support services

Information provided about Parkinson's UK	
Yes	69.6%
No	13.1%
Not sure	11.1%
Not answered	6.2%
Number:	6446

Overall service quality

Figure 19: Percentage of people with Parkinson's who feel listened to by their Parkinson's service

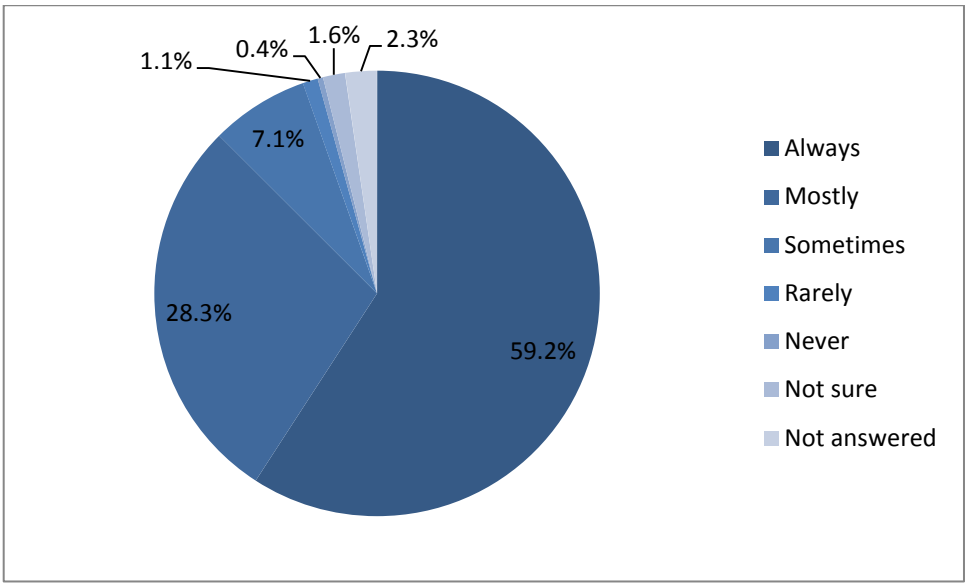


Table 163: Percentage of people with Parkinson's who feel listened to by their Parkinson's service

Feel listened to	
Always	59.2%
Mostly	28.3%
Sometimes	7.1%
Rarely	1.1%
Never	0.4%
Not sure	1.6%
Not answered	2.3%

Figure 20: Percentage of people with Parkinson's who feel their Parkinson's service involved them in decisions about their care

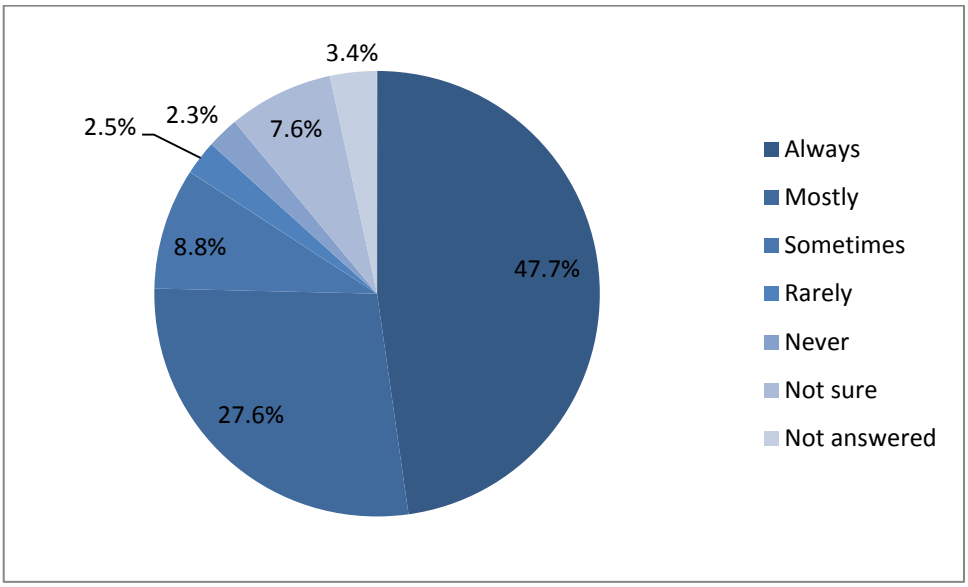


Table 164: Percentage of people with Parkinson's who feel their service involves them in decisions about their care

Involved in decisions	
Always	47.7%
Mostly	27.6%
Sometimes	8.8%
Rarely	2.5%
Never	2.3%
Not sure	7.6%
Not answered	3.4%
Number:	6446

Table 165: Percentage of people with Parkinson's who feel treated as an individual, taking into account unique concerns and cultural needs (which may include other conditions they have if relevant)

Treated as a whole person	
Always	60.6%
Mostly	25.2%
Sometimes	4.0%
Rarely	1.2%
Never	0.4%
Not sure	3.0%
Not answered	5.6%
Number:	6446

The majority of respondents reported that their service was already good (61.5%) with another 26.5% saying their service was improving. 10.6% felt that their service needed to improve but was staying the same, and 1.4% reported that their service was getting worse.

Table 166: Percentage of people with Parkinson's who feel their service is improving or getting worse

Service improving or getting worse	
Improving	25.1%
Staying the same – already good	58.3%
Staying the same – needs to improve	10.0%
Getting worse	1.3%
Not answered	5.2%
Number:	6446

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 across all specialisms in the following areas:

Specialised multidisciplinary working

It is suggested that service provision moves away from non-specialised or 'doctor only' clinics to an integrated multidisciplinary clinic or joint/parallel doctor and nurse specialist clinics. It is also recommended that earlier referral to physiotherapy, occupational therapy and speech and language therapy is considered as recommended by the NICE guideline.

Standardised practices

In clinics, recording of non-motor symptoms continues to be poor. This could be improved through use of, for example, the non-motor symptoms questionnaire. Bone health assessment could be rapidly assessed using a bone health app available on clinic desktops. Drivers should be identified at every review, and they should reaffirm that they are aware of their legal responsibility to notify the DVLA and their insurance company. They should also assess their ongoing driving ability. Many clinics have, as standardised practice, a clinic nurse who checks weight and an erect and supine blood pressure. This means they are assessing for malnutrition as well as orthostatic hypotension.

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 and Parkinson's* and the *European physiotherapy guideline for Parkinson's*. There should be clear evidence of goal setting as a result of the assessments and full documentation of test results.

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

Specialist induction programmes and ongoing support should be available for new therapists. Online learning and training modules could be considered.

Attendance at specialist meetings about Parkinson's and movement disorders is desirable as part of the portfolio of CPD for movement disorder specialists, occupational therapists, physiotherapists and speech and language therapists.

Communication and information sharing

Information regarding diagnosis and new medication should be available at all clinics. Information regarding Parkinson's local advisers should also be readily available.

Medicines management

Inpatient medicines management is poorly done according to the PREM results, with only two out of five patients consistently getting their medication on time. It is suggested that services may wish to audit their own practice and initiate quality improvement projects if shortcomings are highlighted. At outpatient clinics, patients should be asked about the development of any side effects pertaining to their medication including impulse control disorders and day time somnolence associated with driving. These things should also be documented.

Anticipatory care planning

The audit illustrates that medical staff are poorly documenting end-of-life care issues for those in the palliative phases. It is however, very encouraging that the speech and language therapy audit finds that those patients are consistently given information and support with anticipatory care planning. This supports specialised multidisciplinary working, communication and information sharing.

Conclusion

The results of the 2017 audit demonstrate real progress in improving the overall quality of Parkinson's services since 2015 and are a tribute to the hard work and dedication of the professionals involved. The developments in practice and services achieved through their improvement plans offer learning and inspiration for others taking their next step in the improvement cycle.

It's crucial we continue to work to close the gaps in services identified as priorities in the 2015 audit. In many cases simple adjustments will enable more standardised, evidence based care that can improve life for people affected by the condition. And a whole range of support, tools, data and training are available through the UK Parkinson's Excellence Network to help professionals deliver the change that's needed.

Together we can continue to drive up standards of care and make sure that everyone affected by Parkinson's can get the consistent high quality services they deserve.

Appendix A: UK Parkinson's Audit – Definition of phases of Parkinson's

Diagnosis

- From first recognition of symptoms/sign/problem
- Diagnosis not established or accepted.

Maintenance

- Established diagnosis of Parkinson's
- Reconciled to diagnosis
- No drugs or medication 4 or less doses/day
- Stable medication for >3/12
- Absence of postural instability.

Complex

- Drugs – 5 or more doses/day
- Any infusion therapy (apomorphine or duodopa)
- Dyskinesia
- Neuro-surgery considered / DBS in situ
- Psychiatric manifestations >mild symptoms of depression/anxiety/hallucinations/psychosis
- Autonomic problems – hypotension either drug or non-drug induced
- Unstable co-morbidities
- Frequent changes to medication (<3/12)
- Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues).

Palliative

- Inability to tolerate adequate dopaminergic therapy
- Unsuitable for surgery
- Advanced co-morbidity (life threatening or disabling).

Appendix B: Participating services

England

Elderly Care		
1	Portsmouth Hospitals NHS Trust	Oak Park Community Clinic
2	Berkshire Healthcare Foundation Trust	West Berkshire Community Hospital
3	Oxford University Hospitals NHS Foundation Trust	John Radcliffe Hospital
4	Royal Berkshire NHS Foundation Trust	Royal Berkshire Hospital
5	Taunton and Somerset Foundation Trust	Musgrove Park Hospital
6	Sheffield Teaching Hospitals NHS Foundation Trust	Northern General Hospital
7	Dorset Healthcare University NHS Foundation Trust	Parkinson's nurse specialist service
8	Brighton and Sussex University Hospitals NHS Trust	Princess Royal Hospital
9	Frimley Health Foundation Trust	Frimley Park Hospital
10	St Helens and Knowsley Teaching Hospitals NHS Trust	St Helens Hospital
11	Yeovil District Hospital NHS Foundation Trust	Yeovil District Hospital
12	West Hertfordshire NHS Trust	Watford General Hospital
13	Royal Liverpool and Broadgreen University Hospitals NHS Trust	Broadgreen Hospital
14	Airedale NHS Foundation Trust	Airedale Hospital
15	Northumbria Healthcare NHS Foundation Trust	North Tyneside District Hospital
16	Royal Devon and Exeter NHS Foundation Trust	Royal Devon and Exeter Hospital
17	Royal Devon and Exeter NHS Foundation Trust	Okehampton Community Hospital
18	Torbay and southern Devon NHS Foundation Trust	Torbay Hospital
19	Barnsley Hospital NHS Foundation Trust	Barnsley Hospital
20	Aintree University Hospital NHS Foundation Trust	Aintree University Hospital
21	Dartford and Gravesham NHS Trust	Darent Valley Hospital
22	Royal Free London NHS Foundation Trust	The Royal Free Hospital
23	Dorset Healthcare University Foundation Trust	Blandford Community Hospital
24	Central London Community Health Care NHS Trust	Edgware Community Hospital
25	Luton and Dunstable University Hospital Trust	Luton and Dunstable Hospital
26	Dudley Group of Hospitals Foundation Trust	Russells Hall Hospital
27	Newcastle Upon Tyne Hospitals Trust	Belsay Unit, Campus for Ageing and Vitality
28	Cornwall Partnership Foundation Trust	Royal Cornwall Hospital
29	Salford Royal NHS Foundation Trust	Salford Royal Hospital
30	Wye Valley NHS Trust	Hereford Hospital
31	The Mid Yorkshire Hospitals NHS Trust	Pinderfields Hospital
32	George Eliot Hospital NHS Trust	George Eliot Hospital
33	Poole Hospital NHS Foundation Trust	Poole Hospital
34	York Hospitals NHS Foundation Trust	Scarborough Hospital
35	Northampton General Hospital NHS Trust	Northampton General Hospital
36	North Cumbria University Hospitals NHS Trust	Cumberland Infirmary

37	United Lincolnshire Hospitals NHS Trust	Pilgrim Hospital
38	Southport and Ormskirk Hospitals NHS Trust	Southport and Formby District General Hospital
39	Southern Health NHS Foundation Trust	Gosport War Memorial Hospital
40	Norfolk and Norwich University Hospital	Norfolk and Norwich University Hospital
41	Northern Lincolnshire and Goole NHS Foundation Trust	Diana, Princess of Wales Hospital
42	North Tees and Hartlepool NHS FT	North Tees University Hospital
43	Portsmouth Hospitals NHS Trust	Laurel Assessment Unit, Petersfield Hospital
44	Portsmouth Hospitals NHS Trust	Amulree Assessment and Treatment Centre, St Marys Healthcare Campus
45	Hampshire Hospital Foundation Trust	Basingstoke and North Hampshire Hospital
46	Royal United Hospitals Bath NHS Foundation Trust	Chippenham Community Hospital
47	Royal United Hospitals Bath NHS Foundation Trust	St Martin's Hospital
48	Maidstone and Tunbridge Wells NHS Trust	Maidstone Hospital
49	Maidstone and Tunbridge Wells NHS Trust	Tunbridge Wells Hospital
50	Wirral University Teaching Hospital NHS Foundation Trust	Wirral University Teaching Hospital
51	Derby Teaching Hospitals NHS Foundation Trust	London Road Community Hospital
52	Nottingham University Hospitals NHS Trust	Queen's Medical Centre
53	Stockport NHS Foundation Trust	Stepping Hill Hospital
54	Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire Royal Hospital
55	Great Western Hospitals NHS Foundation Trust	Great Western Hospital
56	Sherwood Forest Hospitals NHS Foundation Trust	Mansfield Community Hospital
57	County Durham and Darlington Foundation Trust	Darlington Memorial Hospital
58	Royal Shrewsbury and Telford Hospital NHS Trust	Royal Shrewsbury Hospital
59	Newcastle upon Tyne NHS Foundation Trust	Melville Day Unit, Freeman Hospital
60	Cambridge University Hospitals Foundation Trust	Addenbrooke's and Brookfields Hospitals
61	Birmingham Community Health Care NHS Foundation Trust	Moseley Hall Hospital
62	Worcestershire Health and Care NHS Trust	Princess of Wales Community Hospital
63	The Rotherham NHS Foundation Trust	Rotherham Hospital
64	Salisbury NHS Foundation Trust	Salisbury District Hospital
65	Chesterfield Royal Hospital NHS Foundation Trust	Chesterfield Royal Hospital
66	United Lincolnshire Hospitals NHS Trust	Lincoln County Hospital
67	Ipswich Hospital NHS Trust	Ipswich Hospital
68	Surrey and Sussex Healthcare NHS Trust	East Surrey Hospital
69	Gateshead Health NHS Foundation Trust	Queen Elizabeth Hospital Gateshead
70	Northamptonshire Healthcare NHS Foundation Trust	Isebrook Hospital, Wellingborough
71	Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Christchurch Day Hospital
72	University Hospital of South Manchester NHS Foundation Trust	Wythenshawe Hospital, Buccleuch Lodge Day Hospital and community service
73	University Hospitals of Leicester NHS Trust	Leicester General Hospital
74	South Warwickshire NHS Foundation Trust	Warwick Hospital

75	Sandwell and West Birmingham Hospitals NHS Trust	City Hospital, Birmingham
76	Derbyshire Community Health Services	Ilkeston Community Hospital
77	Pennine Acute Hospitals NHS Trust	Fairfield General Hospital
78	Dorset County Hospital NHS Trust	Dorset County Hospital
79	Guy's and St Thomas' NHS Foundation Trust	Guy's and St Thomas' Hospitals
80	Sandwell and West Birmingham Hospitals NHS Trust	Sandwell Hospital
81	Buckinghamshire Healthcare NHS Trust	Stoke Mandeville Hospital
82	Croydon Health Services NHS Trust	Croydon University Hospital
83	North West Anglia Foundation Trust	Peterborough City Hospital
84	University Hospitals of Morecambe Bay NHS Trust	Royal Lancaster Infirmary and Westmorland General Hospital
85	Central Manchester University Hospitals NHS Foundation Trust	Trafford General Hospital
86	East and North Herts NHS Trust	Lister Hospital
87	King's College Hospital NHS Foundation Trust	King's College Hospital
88	Kettering General Hospital NHS Foundation Trust	Isebrook Hospital
89	Whittington Health (Whittington Hospital NHS Trust)	Whittington Hospital
90	Royal Surrey County Hospital NHS Foundation Trust	Royal Surrey County Hospital
91	Walsall Healthcare NHS Trust	Short Heath Clinic
92	East Kent Hospitals University NHS Foundation Trust	William Harvey Hospital
93	Hampshire Hospitals NHS Foundation Trust	Royal Hampshire County Hospital
94	Pennine Acute Hospitals NHS Trust	Rochdale Infirmary
95	North Bristol NHS Trust	Cossham Memorial Hospital
96	First Community Health and Care	Community service East Surrey
97	Southern Health NHS Foundation Trust	Romsey Community Hospital
98	Livewell Southwest	Mount Gould Hospital
99	South West Yorkshire Partnership NHS Foundation Trust	Barnsley General Hospital
100	Rotherham, Doncaster and South Humber NHS Foundation Trust	Tickhill Road Hospital
101	Weston Area Health Trust	Weston General Hospital
102	Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)	Peterborough City Care Centre
Neurology		
1	Frimley Health NHS Foundation Trust	Wexham Park Hospital
2	Airedale NHS Foundation Trust	Airedale General Hospital
3	King's College Hospital NHS Foundation Trust	King's College Hospital
4	Western Sussex Hospitals NHS Foundation Trust	St Richard’s Hospital
5	Central and Northwest London NHS Trust	Mount Vernon Hospital
6	Nottingham University NHS Trust	Queen’s Medical Centre
7	North West Anglia Foundation Trust	Hinchingbrooke Hospital
8	Royal United Hospitals Bath NHS Foundation Trust	Royal United Hospital

9	Taunton and Somerset NHS Foundation Trust	Musgrove Park Hospital
10	Royal Free London Foundation Trust	Royal Free Hospital
11	UHB Queen Elizabeth NHS Foundation Trust	Queen Elizabeth Hospital
12	London North West Hospitals Trust	Central Middlesex Hospital
13	Bradford Hospitals NHS Foundation Trust	St Luke's Hospital
14	East Sussex Healthcare NHS Trust	Conquest Hospital
15	James Paget University Hospitals NHS Foundation Trust	James Paget University Hospital
16	East Sussex Healthcare NHS Trust	Eastbourne Hospital
17	Dorset County Hospital NHS Foundation Trust	Dorset County Hospital
18	Poole Hospital NHS Foundation Trust	Poole Hospital
19	Essex Partnership University NHS Foundation Trust	Bedford Hospital
20	Dartford and Gravesham NHS Trust	Darent Valley Hospital
21	The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	Queen Elizabeth Hospital
22	Calderdale and Huddersfield NHS Trust	Calderdale Royal Hospital
23	Calderdale and Huddersfield NHS Trust	Huddersfield Royal Infirmary
24	Imperial College Health Care NHS Trust	Charing Cross Hospital
25	University Hospitals of Morecambe Bay NHS Foundation Trust	Furness General Hospital
26	Oxford University Hospitals NHS Foundation Trust	John Radcliffe Hospital
27	Dudley Group NHS Foundation Trust	Russells Hall Hospital
28	University College London Hospitals NHS Trust	National Hospital for Neurology and Neurosurgery
29	Norfolk and Norwich University Hospital NHS Foundation Trust	Norfolk and Norwich University Hospital
30	London North West Healthcare NHS Trust	Northwick Park Hospital
31	Cornwall Partnership Foundation Trust	Cornwall community hospitals
32	Northampton General Hospital NHS Trust	Northampton General Hospital
33	York Teaching Hospital NHS Foundation Trust	York Hospital
34	Stepping Hill Hospital NHS Foundation Trust	Stepping Hill Hospital
35	Royal Berkshire NHS Foundation Trust	Royal Berkshire Hospital
36	North East London NHS Foundation Trust (NELFT)	Long Term Conditions Centre
37	Southend University Hospital NHS Foundation Trust	Southend Hospital
38	United Lincolnshire Hospitals	Grantham and District Hospital
39	Lewisham and Greenwich NHS Trust	University Hospital Lewisham
40	Chelsea and Westminster NHS Trust	Chelsea and Westminster Hospital
41	Ipswich Hospital NHS Trust	Ipswich Hospital
42	Plymouth Hospitals NHS Trust	Derriford Hospital
43	Northern Lincolnshire and Goole NHS Foundation Trust	Diana, Princess of Wales Hospital
44	East and North Herts NHS Trust	Lister Hospital
45	Maidstone and Tunbridge Wells NHS Trust	Maidstone Hospital
46	Maidstone and Tunbridge Wells NHS Trust	Tunbridge Wells Hospital

47	Derby Teaching Hospitals NHS Foundation Trust	Royal Derby Hospital
48	Frimley Health NHS Foundation Trust	Frimley Park Hospital
49	Northamptonshire Healthcare Foundation trust	Favell house, Northampton
50	Ashford and St Peter's Hospitals NHS Foundation Trust	St Peter's Hospital
51	Colchester Hospital University NHS Foundation Trust	Colchester General Hospital
52	Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire Royal Hospital
53	University Hospital Southampton at Salisbury District Hospital	Salisbury District Hospital
54	London North West Healthcare NHS Trust	Ealing Hospital
55	Barts Health NHS Trust	The Royal London Hospital
56	Shrewsbury and Telford Hospitals NHS Trust	Royal Shrewsbury Hospital
57	University Hospitals Coventry and Warwickshire NHS Trust	University Hospitals Coventry and Warwickshire
58	South Tees Hospitals NHS Foundation Trust	The James Cook University Hospital
59	Norfolk Community Health and Care Trust	Dereham Hospital
60	Lancashire Teaching Hospitals NHS Trust	Royal Preston Hospital
61	University Hospitals Coventry and Warwickshire NHS Trust	University Hospital Coventry
62	Newcastle upon Tyne Hospitals NHS Foundation Trust	Centre for Aging and Vitality, Newcastle University
63	Hampshire Hospitals NHS Foundation Trust	Basingstoke and North Hampshire Hospital
64	Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital
65	University Hospitals Coventry and Warwickshire NHS Trust	University Hospital Coventry
66	Tameside and Glossop Integrated Care NHS Foundation Trust	Community Neuro rehab team
67	Luton and Dunstable University Hospital NHS Foundation Trust	Luton and Dunstable University Hospital
68	University Hospitals Coventry and Warwickshire NHS Trust	University Hospital Coventry
69	Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary
70	West Suffolk Hospital NHS Foundation Trust	West Suffolk Hospital
71	City Hospitals Sunderland Foundation Trust	Sunderland Royal Hospital
72	West Middlesex University Hospital NHS Trust	West Middlesex University Hospital
73	University Hospitals of North Midlands NHS Trust	Leighton Hospital Crewe, community of South Cheshire and Vale Royal
74	Luton and Dunstable University Hospital NHS Foundation Trust	Neuro Bedfordshire service
75	Lewisham and Greenwich NHS Trust	Queen Elizabeth Hospital
76	Homerton University Hospital NHS Foundation Trust	Homerton University Hospital
77	Salford Royal NHS Foundation Trust	Salford Royal Hospital
78	University Hospitals Coventry and Warwickshire NHS Trust	Nurse specialist-led service

79	Harrogate and District NHS Foundation Trust	Harrogate Hospital
80	Wrightington, Wigan and Leigh NHS Foundation Trust	Royal Albert Edward Infirmary
81	Milton Keynes University Hospital NHS Foundation Trust	Milton Keynes University Hospital
82	North West Anglia NHS Foundation Trust	Peterborough City Hospital
83	Hounslow and Richmond Community Health Care	Community Neuro rehab team
84	Guys and St Thomas' NHS Foundation Trust	Guys and St Thomas' Hospital
85	Isle of Wight NHS Trust	Laidlaw, St Mary's Hospital
86	Medway NHS Foundation Trust	Medway Maritime Hospital
87	St George's University NHS Foundation Trust	St George's Hospital
88	East Cheshire NHS Trust	Macclesfield District General Hospital
89	Barking Havering and Redbridge University Trust	Queen's Hospital
90	Norfolk Community Health and Care NHS Trust	Community Neurology team, St James'
91	Epsom and St Helier University Hospitals NHS Trust	Epsom Hospital
92	Epsom and St Helier University Hospitals NHS Trust	St Helier Hospital
93	Bridgewater Community Healthcare NHS Foundation Trust	Orford Jubilee Park Health Centre
94	Royal Free London Foundation Trust	Chase Farm Hospital
95	Royal Surrey County Hospital NHS Foundation Trust	Royal Surrey County Hospital
96	Cambridgeshire and Peterborough NHS Foundation Trust	Parkinson's Specialist nurse service
97	Nottingham CityCare	Community Neurology team
98	Coventry and Warwickshire Partnership Trust	City of Coventry Health Centre
99	Hampshire Hospitals NHS Foundation Trust	Royal Hampshire County Hospital
100	Walsall Healthcare NHS Trust	Short Heath Clinic
101	Barts Health NHS Trust	Whipps Cross University Hospital
102	East Kent Hospitals University NHS Foundation Trust	William Harvey Hospital, Canterbury Hospital and Queen Elisabeth the Queen Mother Hospital
103	Northern Devon Healthcare NHS Trust	North Devon District Hospital
104	Kingston Hospital NHS Foundation Trust	Kingston Hospital
105	Royal Free London Foundation Trust	Barnet Hospital
106	Brighton and Sussex University Hospitals NHS Trust	Royal Sussex County Hospital
107	Cheshire and Wirral Partnership NHS Foundation Trust	CWP West Physical Health - Specialist Nurse service
108	Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)	Brookfields Hospital
109	South West Yorkshire Partnership NHS Foundation Trust	Barnsley General Hospital
Occupational therapy		
1	University Hospitals of Leicester	Leicester General Hospital

2	Derbyshire Community Health Services	Ripley Hospital
3	York Teaching Hospital NHS Foundation Trust	York Hospital
4	Royal Liverpool and Broadgreen University Hospitals NHS Trust	Broadgreen Hospital
5	Kings College Hospital London	King's College Hospital
6	Locala Community Partnership	Jubilee Rehabilitation Unit
7	Northern Lincolnshire and Goole NHS Foundation Trust	Diana, Princess of Wales Hospital
8	Queensway Treatment and Rehabilitation Unit	Yeovil District Hospital
9	Norfolk and Norwich University Hospital Trust	Norfolk and Norwich University Hospital
10	Buckinghamshire Healthcare Trust	Drake Day Unit, Wycombe Hospital
11	Wye Valley NHS Trust	Leominster Community Hospital
12	Derby Teaching Hospitals NHS Foundation Trust	London Road Community Hospital
13	Great Western Hospitals NHS Foundation Trust	Swindon adult community services
14	South Tees Foundation Trust	James Cook University Hospital
15	Virgin Care	St Martins Hospital, Clara Cross Centre
16	Central London Community Healthcare NHS Trust	Edgware Parkinson's Unit , Edgware Community Hospital
17	Northumbria Healthcare NHS Foundation Trust	North Tyneside General Hospital
18	Birmingham Community Health Care NHS Foundation Trust	Moseley Hall Hospital
19	Luton and Dunstable NHS Trust	Luton and Dunstable University Hospital
20	Somerset Partnership NHS Trust	Independent rehabilitation teams
21	South Essex Partnership Trust (SEPT)	Community team
22	Tameside and Glossop Integrated community care service	Community Neurological rehabilitation team
23	Homerton University Hospital	Adult Community rehabilitation team
24	The Rotherham NHS Foundation Trust	Rotherham Hospital
25	Leicestershire Partnership NHS Trust	Braunstone Health and Social Care Centre
26	Hertfordshire Community NHS Trust	Hertfordshire Neurological service
27	Royal Berkshire NHS Foundation Trust	Royal Berkshire Hospital
28	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Christchurch Day Hospital
29	St Helens and Knowsley Hospitals NHS Trust	Allen Day Unit, St Helen's Hospital
30	Nottinghamshire Local Partnerships	Retford Primary Care Centre
31	Harrogate and District NHS Foundation Trust	Harrogate Hospital
32	Sandwell and West Birmingham Hospitals NHS Trust	Community services
33	Gloucestershire Care Services NHS Trust	Quayside House
34	Derbyshire Community Health Services NHS Trust	Clay Cross Community Hospital
35	Walsall Healthcare NHS Trust	Short Heath Clinic
36	Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary
37	East Kent Hospitals University NHS Foundation Trust	Day hospital service
38	Derbyshire Community Health Service	Bolsover Hospital
39	Central London Community Healthcare NHS Trust	Community Neuro rehab team

40	County Durham and Darlington NHS Foundation Trust	Community Neuro rehab team, Chester-le-Street Community Hospital
41	Bolton NHS Foundation Trust	Breightmet Health Centre
42	London North West Healthcare NHS Trust	Enable team community services
43	Oxleas NHS Foundation Trust	Queen Mary's Hospital
Physiotherapy		
1	Derbyshire Community Health Services	Ripley Community Hospital
2	Worcester Acute Hospitals Trust	Acute outpatient rehab service
3	York Hospitals NHS Foundation trust	Neuro outpatients clinic
4	East Sussex Healthcare NHS Trust	Eastbourne District General Hospital
5	Central North West London NHS Foundation Trust	Community service
6	Royal Free London NHS Foundation Trust	Royal Free Hospital
7	Royal Liverpool and Broadgreen University Hospitals NHS Trust	Broadgreen Hospital
8	Central London Community Healthcare Trust	Parkinson's Unit, Edgware Day Hospital
9	East Sussex Healthcare NHS Trust	Conquest Hospital outpatient service
10	Derby Teaching Hospitals NHS Foundation Trust	Specialist Assessment and Rehabilitation Centre (SpARC), London Road Community Hospital
11	Cornwall Partnership NHS Foundation Trust	Camborne and Redruth Community Hospital
12	London North West Healthcare	Northwick Park Hospital
13	Southern Health NHS trust	Petersfield Hospital
14	Lancashire Care Foundation Trust	Community rehab service
15	Northern Lincolnshire and Goole NHS Foundation Trust	Diana, Princess of Wales Hospital
16	Luton and Dunstable University Hospital NHS Foundation Trust	Luton and Dunstable Hospital
17	East Cheshire NHS Trust	Macclesfield District General Hospital
18	Oxford University Hospitals NHS Foundation Trust	Horton Hospital
19	Yeovil District Hospital NHS Foundation Trust	Yeovil District Hospital, Queensway Treatment and Rehabilitation Unit
20	Norfolk and Norwich University Hospital Trust	Norfolk and Norwich University Hospital
21	Portsmouth Hospitals NHS Trust	St Mary's Community Health Campus
22	Royal Free London NHS Foundation Trust	Barnet and Chase Farm Hospitals
23	Oxford University Hospitals NHS Foundation Trust	Brackley Community Hospital
24	Locala Community Partnerships	Jubilee Rehabilitation Unit
25	Great Western Hospitals NHS Foundation Trust	Swindon Adult community services
26	Airedale NHS Foundation Trust	Airedale General Hospital
27	Birmingham Community Health Care NHS Foundation Trust	Moseley Hall Hospital
28	South Warwickshire NHS Foundation Trust	Royal Leamington Spa Rehabilitation Hospital
29	Sheffield Teaching Hospitals NHS Foundation Trust	Royal Hallamshire Hospital
30	East Coast Community Healthcare	Beccles Hospital, Shrublands Health Centre, Kirkley Mill Health Centre and Northgate Hospital

31	Oxford Health NHS Foundation Trust	Physical disability physiotherapy service
32	Gloucester Care Services NHS Trust	Redwood house, Stroud
33	Central Cheshire Integrated Care Partnership/Mid Cheshire Foundation Trust	Victoria Infirmary, Northwich and Leighton Hospital
34	Locala Community Partnerships	Mill Hill Health Centre
35	Homerton University Hospital NHS Foundation Trust	Adult Community rehabilitation
36	The Rotherham NHS Foundation Trust	Rotherham Hospital
37	Somerset Partnership NHS Trust	Independent rehabilitation teams
38	Leicestershire Partnership NHS Trust	Braunstone Health and Social Care Centre
39	St George's NHS Foundation Trust	St George's Hospital
40	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Christchurch Day Hospital
41	Leeds Teaching Hospitals NHS Trust	Chapel Allerton Hospital
42	King's College Hospital NHS Foundation Trust	King's College Hospital
43	Tameside and Glossop Integrated Care NHS Foundation Trust	Community Neuro rehabilitation team
44	Hertfordshire Community NHS Trust	Hertfordshire Neurological service
45	Royal Berkshire NHS Foundation Trust	Royal Berkshire Hospital
46	Norfolk Community Health and Care NHS Trust	South Norfolk community service
47	Hounslow and Richmond Community Healthcare Trust	Richmond Rehabilitation Unit
48	Nottinghamshire Local Partnerships	Retford Primary Care Centre
49	Norfolk Community Health and Care NHS Trust	Rebecca House, North Walsham Hospital
50	Lewisham and Greenwich NHS Trust	University Hospital Lewisham
51	Guys and St Thomas' NHS Foundation Trust	St Thomas' Hospital
52	Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire Royal Hospital
53	George Eliot Hospital NHS Trust	George Eliot Hospital
54	Cumbria Partnership Foundation Trust	Community bases across Cumbria
55	Brighton and Sussex University Hospitals NHS Trust	Princess Royal Hospital
56	Norfolk and Norwich University Hospitals NHS Foundation Trust	Norfolk and Norwich University Hospital
57	First Community Health and Care	Oxted Therapies Unit
58	Sandwell and West Birmingham Hospitals NHS Trust	Community team
59	Islington Community Rehabilitation -Whittington	Islington Outlook Centre
60	Royal Bolton NHS Foundation Trust	Breightmet Health Centre
61	Derbyshire Community Health Services NHS Trust	Clay Cross Community Hospital
62	Derbyshire Community Health Services NHS Foundation Trust	Bolsover Hospital
63	Hull and East Yorkshire Hospitals NHS Trust	Hull Royal Infirmary
64	Sirona Care and Health (Virgin Care)	St Martin's Hospital
65	Harrogate and District NHS Foundation Trust	Harrogate Hospital
66	Walsall Healthcare NHS Trust	Short Heath Clinic
67	North Tees and Hartlepool NHS Foundation Trust	Billingham Health Centre
68	Calderdale and Huddersfield NHS Trust	Support and Independence Team
69	University Hospital of South Manchester NHS Foundation Trust	Bucchleuch Lodge Day Hospital

70	Pennine Care NHS Foundation Trust	Oldham community provider services
71	Central London Community Healthcare NHS Trust	Community Neuro rehab team
72	County Durham and Darlington NHS Foundation Trust	Darlington RIACT Physiotherapy
73	County Durham and Darlington NHS Foundation Trust	Community Neuro rehab team, Chester-le-Street Community Hospital
74	City Hospitals Sunderland NHS Foundation Trust	Sunderland Royal Hospital
75	Derbyshire Community Health Services NHS Trust	Derbyshire Dales service
76	London North West Healthcare NHS Trust	Enable team (community services)
77	Oxleas NHS Foundation Trust	Queen Mary's Hospital Sidcup
Speech and language therapy		
1	Leeds Teaching Hospitals Trust	Chapel Allerton Hospital
2	Central London Community Healthcare NHS Trust	Edgware Community Hospital
3	Kings College Hospital NHS Foundation Trust	King's College Hospital
4	Royal Berkshire NHS Foundation Trust	Royal Berkshire Hospital
5	Anglian Community Enterprise	North East Essex community service
6	Wye Valley NHS Trust	Hereford County Hospital
7	East Lancashire Hospitals NHS Trust	Royal Blackburn Hospital
8	London North West Healthcare NHS Trust	Northwick Park and Willesden Centre for Health and Care
9	Homerton University Hospital NHS Foundation Trust	Homerton Hospital
10	Oxford University Hospitals NHS Foundation Trust	John Radcliffe Hospital
11	Hampshire Hospitals NHS Trust	Basingstoke and North Hampshire Hospital
12	East Sussex Healthcare NHS Trust	Irvine Unit, Bexhill Hospital
13	Airedale NHS Foundation Trust	Airedale General Hospital
14	Great Western Hospital NHS Foundation Trust	Great Western Hospital
15	Central and North West London NHS Foundation Trust	Mount Vernon Hospital
16	Lewisham and Greenwich NHS Trust	University Hospital Lewisham
17	North Tees and Hartlepool NHS Foundation Trust	University Hospital of North Tees
18	Kent Community Health NHS Foundation Trust	County-wide community service
19	Gloucestershire Care Services NHS Trust	Gloucestershire Royal Hospital
20	The Rotherham NHS Foundation Trust	Rotherham Hospital
21	Bradford District Care NHS Foundation Trust	Adult Community service
22	Leicestershire Partnership NHS Trust	Braunstone Health and Social Care Centre
23	Tameside and Glossop Integrated Care NHS Foundation Trust	Selbourne House
24	Harrogate and District NHS Foundation Trust	Harrogate Hospital
25	Nottinghamshire Healthcare Trust	Retford Primary Care Centre
26	Basildon and Thurrock University Hospitals NHS Foundation Trust	Basildon Hospital
27	Leeds Community Healthcare	St Mary's Hospital
28	County Durham and Darlington NHS Foundation	University Hospital North Durham

	Trust	
29	North Bristol NHS Trust	Southmead Hospital
30	Gateshead Health NHS Foundation Trust	Queen Elizabeth Hospital
31	Sandwell & West Birmingham Hospitals NHS Trust	Community services
32	First Community Health & Care	East Surrey Community
33	Cambridgeshire and Peterborough Foundation Trust	Chesterton Medical Centre
34	Walsall Healthcare NHS Trust	Short Heath Clinic
35	Hampshire Hospitals NHS Foundation Trust	Royal Hampshire County Hospital
36	Hertfordshire Community NHS Trust	County-wide sites, Hertfordshire
37	Sussex Community NHS Foundation Trust	Hove Polyclinic
38	Barts Health NHS Trust	Mile End Hospital
39	Warrington and Halton Hospitals NHS Foundation Trust	Warrington Hospital
40	Derby Hospitals NHS Foundation Trust	London Road Community Hospital
41	Central London Community Healthcare NHS Trust	Community Neuro rehab team
42	Norfolk Community Health and Care NHS Trust	Adult Community service
43	London North West Healthcare NHS Trust	Enable team (community services)
44	Oxleas NHS Foundation Trust	Queen Mary's Hospital, Sidcup
45	South Warwickshire NHS Foundation Trust	Community service

Scotland

Elderly Care		
1	NHS Tayside	Perth Royal Infirmary
2	NHS Lanarkshire	Hairmyres Hospital
3	NHS Lanarkshire	Monklands Hospital
4	NHS Greater Glasgow and Clyde	Glasgow Royal Infirmary and Lightburn Hospital
5	NHS Fife	Victoria Hospital
6	NHS Greater Glasgow and Clyde	Day Hospital Queen Elizabeth University Hospital
7	NHS Lanarkshire	Wishaw General Hospital
8	NHS Grampian	Aberdeen Royal Infirmary
9	NHS Forth Valley	Fourth Valley Royal Hospital, Stirling Community Hospital, Clackmannan Community Hospital
10	NHS Tayside	Royal Victoria Hospital
11	NHS Dumfries and Galloway	Dumfries and Galloway Royal Infirmary
12	NHS Ayrshire and Arran	Biggart Hospital
13	NHS Greater Glasgow and Clyde	Gartnavel General Hospital
14	NHS Borders	Borders General Hospital
15	NHS Lothian	Western General Hospital /Edinburgh Royal Infirmary
16	NHS Lanarkshire	Wishaw General Hospital
17	NHS Highland	Lorn and Islands Hospital
18	NHS Greater Glasgow and Clyde	Royal Alexandra Hospital
Neurology		

1	NHS Greater Glasgow and Clyde	Queen Elizabeth University Hospital
2	NHS Borders	Borders General Hospital
3	NHS Grampian	Aberdeen Royal Infirmary
4	NHS Lothian	Western General Hospital / Royal Infirmary of Edinburgh
5	NHS Tayside	Ninewells Hospital
6	NHS Greater Glasgow and Clyde	Queen Elizabeth University Hospital
Occupational Therapy		
1	NHS Fife	Whitefield Day Hospital, Queen Margaret Hospital
2	NHS Lanarkshire	Glenaffric Day Hospital and Coathill Hospital
3	NHS Greater Glasgow and Clyde	Stobhill Day Hospital
4	NHS Greater Glasgow and Clyde	New Victoria Hospital
5	NHS Grampian	Parkinson's Clinic, Kincardine Community Hospital
6	NHS Greater Glasgow and Clyde	Queen Elizabeth University Hospital
7	NHS Greater Glasgow and Clyde	Gartnavel General Hospital
8	NHS Greater Glasgow and Clyde	Lightburn Day Hospital
Physiotherapy		
1	Fife Health and Social Care Partnership	Whitefield Day Hospital and Queen Margaret Hospital
2	NHS Greater Glasgow and Clyde	Gartnavel General Hospital
3	NHS Tayside	Perth Royal Infirmary
4	NHS Greater Glasgow and Clyde	New Victoria Hospital
5	NHS Greater Glasgow and Clyde	Stobhill Hospital
Speech and Language Therapy		
1	NHS Greater Glasgow and Clyde	Queen Elizabeth University Hospital
2	NHS Greater Glasgow and Clyde	Gartnavel General Hospital
3	NHS Grampian	Inverurie Hospital
4	NHS Grampian	Aberdeen City Community service, The Health Village
5	NHS Greater Glasgow and Clyde	Stobhill Hospital
6	NHS Grampian	Moray Health and Social Care Partnership, The Glassgreen Centre
7	NHS Tayside	Royal Victoria Hospital
8	NHS Greater Glasgow and Clyde	Royal Alexandra Hospital
9	NHS Ayrshire and Arran	Various sites including Ayrshire Central Hospital, Irvine
10	NHS Lothian	Adult Community service

Wales

Elderly Care		
1	Betsi Cadwaladr University Health Board	Wrexham Maelor Hospital
2	Aneurin Bevan University Health Board	Princess of Wales Hospital
3	Hywel Dda University Health Board	Glangwili General Hospital
4	Betsi Cadwaladr University Health Board	Llandudno Hospital and Eryri Hospital

5	Aneurin Bevan University Health Board	St Woolos Hospital
6	Cwm Taf University Health Board	Dewi Sant Health Park
7	Powys Teaching Health Board	Bronllys Hospital
8	Aneurin Bevan University Health Board	Nevill Hall Hospital, Abergavenny
9	Aneurin Bevan University Health Board	Ysbyty Aneurin Bevan
11	Powys Teaching Health Board	Montgomery County Infirmary
Neurology		
1	Aneurin Bevan University Health Board	Royal Gwent Hospital
2	Abertawe Bro Morganwg University Health Board	Parkinsons Unit Gorseinon Hospital
Occupational Therapy		
1	Aneurin Bevan University Health Board	Nevill Hall Hospital
2	Powys Teaching Health Board	Community Neuro Service
3	Betsi Cadwaladr University Health Board	Chirk Community Hospital
4	Abertawe Bro Morganwg University	Parkinson's Unit, Gorseinon Hospital
Physiotherapy		
1	Powys Teaching Heath Board	Powys Community Neuro Service
2	Abertawe Bro Morganwg University Health Board	Princess of Wales Hospital
3	Abertawe Bro Morganwg University Health Board	Neath Port Talbot Hospital
4	Abertawe Bro Morganwg University Health Board	Parkinson's Unit, Gorseinon Hospital
5	Aneurin Bevan Health Board	Ystrad Mynach Hospital
Speech and Language Therapy		
1	Powys Teaching Health Board	Brecon War Memorial Hospital
2	Betsi Cadwaladr University Health Board (East)	Wrexham Maelor Hospital
3	Cardiff and Vale University Health Board	University Hospital Llandough and Rookwood Hospital
4	ABUHB	St Cadoc's Hospital
5	Hywel Dda University Health Board	Speech and Language Therapy
6	Abertawe Bro Morganwg University	Parkinson's Treatment Centre, Gorseinon Hospital
7	Betsi Cadwaladr University Health Board	Eryri Hospital

Northern Ireland

Elderly Care		
1	Northern Health and Social Care Trust	Antrim Area Hospital
2	Western Health and Social Care trust	Altnagelvin Hospital
3	Southern Health and Social Care Trust	Lurgan Hospital
4	South Eastern Health and Social Care Trust	Ulster Hospital
5	Southern Health and Social Care Trust	South Tyrone Hospital
6	Belfast Health and Social Care Trust	Musgrave Park Hospital
Neurology		
1	Western Trust (Southern Sector)	Western Trust (Southern Sector)

2	Belfast Health and Social Care Trust	Belfast City Hospital
3	Northern Health and Social Care Trust	Antrim Hospital
Occupational Therapy		
1	Belfast Health and Social Care Trust	Musgrave Park Hospital
2	Southern Health and Social Care Trust	Integrated Care Team for Older People
Physiotherapy		
1	Belfast Health and Social Care Trust	Royal Victoria Hospital
2	Belfast Health and Social Care Trust	Royal Group of Hospitals
3	Belfast Health and Social Care Trust	Musgrave Park Hospital
5	South Eastern Health and Social Care Trust	Ardarragh Resource centre
5	Northern Health and Social Care Trust	Ballymena Health and Care Centre
6	Southern Health and Social Care Trust	Kilkeel Primary Care Centre

Channel Islands and Isle of Man

Elderly Care		
1	Guernsey Health and Social Care	Princess Elizabeth Hospital
2	Isle of Man Department of Health and Social Care	Central Community Health Centre
Neurology		
1	Health and Social Services, States of Jersey	Jersey General Hospital
Occupational Therapy		
1	Health and Social Services, States of Jersey	Westmount Rehabilitation Centre
2	Isle of Man Department of Health and Social Care	Ramsey District Cottage Hospital
Physiotherapy		
1	Isle of Man Department of Health and Social Care	Nobles Hospital
Speech and Language Therapy		
1	Health and Social Services, States of Jersey	Eva Wilson Centre, Overdale Hospital
2	Isle of Man Department of Health and Social Care	Nobles Hospital

UK PARKINSON'S
Excellence
Network

2017 UK Parkinson's Audit Patient management: Elderly Care & Neurology

Standards and guidance

2017 UK Parkinson's Audit
Patient management:
Elderly Care and Neurology

Audit of national standards relating to Parkinson's care, incorporating the Parkinson's NICE guideline[1] and the National Service Framework for Long Term Neurological Conditions[2] quality standards.

Aim

The objective of the Parkinson's patient management audit is to ascertain if the assessment and management of patients with an established diagnosis of Parkinson's complies with national guidelines including the Parkinson's NICE guideline and the National Service Framework for Long Term Neurological Conditions (NSF LTNC).

Objectives

1. To encourage clinicians to audit compliance of their local Parkinson's service against Parkinson's guidelines, by providing a simple peer reviewed audit tool with the facility for central data analysis to allow benchmarking with other services.
2. To identify areas of good practice and areas for improvement to inform local, regional and UK-wide discussions leading to action plans to improve quality of care.
3. To establish baseline audit data to allow:
   - UK-wide mapping of variations in quality of care
   - local and UK-wide mapping of progress in service provision and patient care through participation in future audit cycles

The audit focuses on care provided by consultants who specialise in movement disorders in neurology and in elderly care, and Parkinson's nurse specialists. It includes patients at all phases of Parkinson's: early treatment, maintenance, complex care and palliative care.

It incorporates monitoring the physical status and current needs for support and, as appropriate, making referrals and providing treatment, education and support, and co-ordination of services among care providers and the patient and carer. The audit excludes people newly referred to the service for purposes of diagnosis.

[1] National Institute of Health and Clinical Excellence. *Parkinson's Disease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35.* (2006) Available at https://www.nice.org.uk/guidance/CG35

[2] Department of Health. *National Service Framework for Long Term Neurological Conditions*. (2005) Available at www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

Background

A multi-professional steering group[3] was established in 2007 under the chairmanship of Steve Ford, Chief Executive of Parkinson's UK, to develop national Parkinson's audit tools with the facility for central benchmarking. Standards are derived from the NICE guideline but incorporate other national guidance relevant to Parkinson's care, in particular the National Service Framework for Long Term Neurological Conditions (NSF LTNC) and the SIGN guidelines[4].

The audit is led by a steering group of professionals. This is the sixth round of the audit and includes parallel audits of the services provided to people with Parkinson's by occupational therapists, physiotherapists and speech and language therapists. The audit questions for this round have been refined to reflect feedback from the 2015 audit.

Methodology

The patient management audit is designed to examine how a patient has been managed and assessed over the previous year, rather than on a single visit, as this is more representative of actual patient care. For most patients, this will capture two to three assessments over a year if the service complies with the NICE guideline requirement for at least six to 12 monthly review.

A process flow chart (*How do I take part?*) can be found on page X of this document. Please note the importance of logging your participation in this national clinical audit with your Audit Department.

Definition of a service
There is considerable variation in how Parkinson's services are organised and delivered throughout the UK. There is, in addition, an ongoing reconfiguration of services and how they are commissioned.

A service is roughly defined as that provided by consultants with (or without) a Parkinson's nurse to a geographical area, regardless of who commissions the constituent parts. Clinicians are best placed to decide what constitutes a discrete service. To facilitate benchmarking, each patient management submission includes a brief service audit to clarify:

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[3] College of Occupational Therapists Specialist Section for Neurological Practice, Royal College of Speech and Language Therapists, Chartered Society of Physiotherapy, Parkinson's Disease Nurse Specialist Association, British Geriatric Society Movement Disorder Section, The British and Irish Neurologists Movement Disorder Section.
[4] Scottish Intercollegiate Guidelines Network. *Diagnosis and Pharmacological Management of Parkinson's Disease: A National Clinical Guideline 113* (2010) Available at www.sign.ac.uk/guidelines/fulltext/113/index.html

- how their service is delivered (purely medical or medical together with Parkinson's nurse)
- the geographical/commissioning areas covered
- the specialty – ie neurology or elderly care

The service as described is allocated an audit service number. If the consultant and Parkinson's nurse input into the service is provided from different organisations they will both be linked to that service number and appear in the report as a joint audit service.

The following will allow meaningful benchmarking:

1. Neurology and elderly care will be analysed as separate services. They should conduct separate audits and submit data on separate spreadsheets, even if patients share the same Parkinson's nurse input and cover the same geographical area.
2. Discrete services should be logged as separate audit sites and separate data submitted.
3. Parkinson's nurses should conduct the audit in collaboration with their patients' consultant service(s) – and vice versa.
4. The audit can be completed purely from the medical input received only in services without Parkinson's nurse cover.
5. Clinicians working across more than one discrete service - eg a consultant working with different Parkinson's nurses in different commissioning/geographical areas - should return separate audits for each service.

Patient sample

The minimum audit sample size is 20 consecutive people with idiopathic Parkinson's seen during the audit data collection period, which runs from 1 May 2017 to 30 September 2017.

Take account of the need to capture this minimum sample when deciding locally on your start date for collecting a consecutive patient sample. The data collection tool will have the capacity to capture as many consecutive patients as clinicians wish to audit.

A sample of 20 patients per audit has been chosen to minimise work for clinicians providing input into more than one discrete service eg a Parkinson's nurse auditing both neurology and elderly care patients, or a consultant who may work with different nurses in different commissioning areas.

Patients should only be included if the service is responsible for the person's ongoing management - ie not if seen as tertiary referral for advice.

Data collection and entry

The audit tool contains three sections:

- A **service audit** section, which consists of some general questions about your service (which needs to be completed only once).
- A **patient audit** section, which allows you to enter data on individual patients.
- An **instant reporting** section, which will build automatically as you enter your data, and produces pie charts for selected questions.

Patient data can be entered on the data collection tool which you have downloaded and saved locally and added to at your convenience. Complete a separate entry for each patient with Parkinson's. Remember to save the data each time you add new information.

Appendix A of this document is a version of the patient questions that you can print and use to record data in your clinics, if this would be useful.

A user guide for the data collection tool will be available, providing full instructions and information.

All data must be submitted by 30 October 2017. No submissions will be accepted after that date.

'No, but…' answers
This concept has been "borrowed" from the National Stroke Audit. A 'No, but…' answer implies there is a pre-determined accepted reason for non-compliance with the standard. The denominator for compliance can then be determined only for those patients where the standard was relevant - ie 'No, but…' answers can be removed from calculations of compliance.

Confidentiality

Patients
Please ensure that any information submitted does not include any personally identifiable information about your patients. Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it.[5]

When you complete the patient section of the audit, you will see that there is space for a patient identifier. It is suggested that you use code letters or a number here to help you keep track (for example the patient's initials or hospital number). **This data will not be**

included in the data you submit to Parkinson's UK – the data entry tool will prevent this. It will help if you keep a list of the code words or numbers securely yourself, so that if there is any query about the information you have submitted, you can track back to the original patient.

Employers
The Healthcare Quality Improvement Partnership (HQIP) recommends that services participating in a national clinical audit should be named in the audit reports. The audit reference report will list all participating organisations. It is therefore vital that you inform your clinical audit department about your participation in the audit.

Participants
Individual health professionals who participate and submit data will not be named in the audit report.

Data security

The data collection tool, which will be available for download from the audit webpage, will be password protected, allowing no one but eligible participants to enter and make changes to the data. The password will be emailed to the named lead for each service. Please make sure that the password is well protected and can't be accessed by other people. To ensure the security of your dataset, we also advise you to save and use your version of the tool on a secure computer at work and not on your personal computer at home. We ask you to comply with your organisation's Data Protection guidelines at all times.

After the data has been sent to Parkinson's UK it will be stored in password-protected files at Parkinson's UK in accordance with NHS requirements. Within Parkinson's UK, access to the raw data set is restricted to Kim Davis, Clinical Audit Manager, members of the Clinical Steering Group and Alison Smith, the Data and Analytics Adviser.

Raw data will not be accessible in the public domain. Services will be asked to report any discrepancies in the data received by the audit team in a summary sheet before data analysis begins.

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[5] Health Professionals Council. *Confidentiality – guidance for registrants*. (2012) Available at http://www.hpc-uk.org/assets/documents/100023F1Guidanceonconfidentiality FINAL.pdf [accessed 6 January 2017]

Patient Reported Experience Measure

All services participating in the audit are encouraged to participate in the Patient Reported Experience Measure (PREM). The PREM takes the form of a short paper questionnaire to be distributed to up to 50 consecutive patients between 1 May and 30 September 2017. These patients do not necessarily have to be those included in the main clinical audit.

The questionnaire asks 11 questions about patients' views of their Parkinson's service, and should take only five to 10 minutes to complete. If a carer has accompanied the patient on their clinic visit, they may assist the patient in completion of the form. Patients should feel comfortable and not overlooked while completing their questionnaire.

No identifiable information is collected, and the patient will seal their completed questionnaire in the envelope provided. These envelopes will then need to be collected before the patient leaves the clinic, and all the envelopes will then be returned to the audit team at Parkinson's UK in the large postage-paid envelope provided.

Each service will be provided with the following resources:

- 50 x copies of a paper questionnaire.
- 50 x sealable envelopes.
- 50 x patient information leaflets.
- An A3 laminated poster.
- A large postage-paid envelope for return of sealed envelopes to the audit team.

A minimum of 10 questionnaires will need to be returned for a service's PREM data to be included in the data analysis.

How the audit results will be communicated

The findings of both the clinical audit and the PREM will be presented in the form of a UK-wide summary report and an individual report for each service, benchmarking the results of individual services against the national average for each audit question in their specialty.

The summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. A bespoke patient and carer version of the summary report will also be produced, along with a reference report which will include all of the results, and a list of all participating services.

A link to the reports will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The reports will also be in the public domain via the Parkinson's UK website.

Data collected during the audit will be used to generate a national picture of service delivery and to compare this with the expectations detailed in national guidance. This data will provide valuable information about priority areas within the existing healthcare provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's.

The UK Parkinson's Excellence Network brings together health and social care professionals to transform the care that people with Parkinson's receive across the UK. The Network is there to ensure:

- that everyone affected by Parkinson's has access to high quality Parkinson's services that meet their needs. Their care should be delivered by an expert, integrated, multi-disciplinary team including a consultant, specialist nurse and range of therapists, whose involvement is key to maximising function and maintaining independence
- there are clear pathways to timely, appropriate information, treatments and services from the point of diagnosis, including access to specialist mental health services and the full range of information and support to take control of the condition offered by Parkinson's UK
- services will be involved in continuous quality improvement through audit and engagement of service users in improvement plans

Participating in the PREM will give individual elderly care and neurology services direct feedback from their service users about the quality of care, accessibility and general satisfaction.

Thank you for your participation in the 2017 National Parkinson's Audit

Parkinson's UK 215 Vauxhall Bridge Road, London SW1V 1EJ
T 020 7931 8080 **F** 020 7233 9908 **E** enquiries@parkinsons.org.uk **W** parkinsons.org.uk

How do I take part

Am I eligible to take part?

Any healthcare professionals who work regularly with people with Parkinson's can take part. This includes speech and language therapists, physiotherapists, occupational therapists, Parkinson's nurses, neurologists and geriatricians. You need to submit data on a minimum of 20 (patient management) or 10 (therapies) patients seen during the audit period (1 May to 30 September 2017) for your data to be included in the audit.

How do I take part if I am eligible?

Register your service

Complete and submit a registration form at **parkinsons.org.uk/audit** by 31 March 2017 for each service you wish to audit. You will then be emailed a service number and a password for the data collection tool – you will need these to enter your audit data. In mid-April you will be sent an Audit Pack containing Patient and Carer Information Leaflets and the materials required for the Patient Reported Experience Measure (PREM).

Inform your audit department

Please log your participation in this clinical audit with your audit department and discuss with Information Governance to determine if Caldicott approval is required.

Establish a local audit project group

Include key professional and medical staff collecting data – discuss the logistics for running the audit, and plan for disseminating the results and action planning. Agree a start date for acquiring patient sample. Agree a target sample size.

Data collection

You will be able to download a copy of the data collection tool from parkinsons.org.uk/audit from mid-April 2017, along with a data collection tool. Data entry begins on 1 May 2017.

1. Enter brief details about your service (the Service Audit).
2. Enter details of consecutive patients seen during the audit period 1 May 2017 to 30 September 2017 (the Patient Audit).
3. During this period, hand out Patient Reported Experience Measure questionnaires to up to 50 consecutive patients – these do not need to be the same patients you include in the main audit.

More information

If you have any queries, or for more information, please contact Kim Davis, Clinical Audit Manager, on 020 7963 3916 or email **audit@parkinsons.org.uk**

Table 1: Service Audit – Questions, data items/answer options and help notes

No.	Question	Data items/ Answer options	Help notes
1. General information			
1.1	Did this service take part in the Parkinson's audit 2015?	• Yes • No	
1.2	Who commissions this service?	• Free text	Please provide the name of the commissioning board/Local Health Board in Wales
1.3	Geographical area covered by this Parkinson's service	• Free text	Main towns covered
1.4	What is the most common model of service provision for the medical input to this service?	• Doctor alone • Joint/parallel doctor and nurse specialists clinics • Integrated clinics (doctor/nurse specialist/therapy in same venue)	• Joint/parallel - we are asking if the PDNS works in clinics with the Consultant (but AHPs located elsewhere) • Integrated clinics – multidisciplinary team working: neurologist or care of the elderly specialist, Parkinson's nurse and therapist, for example, occupational therapist and/or physiotherapist and/or speech and language therapist, seeing patients within the same clinic venue
1.5	Are clinic patients seen within specific Parkinson's/ Movement Disorder clinics?	• All patients • Most patients (>75%) • Some patients (25-74%) • Few patients (<25%) • None	A specialist service would be expected to have a) an identified lead clinician for training, service development and specialist opinion. **AND** b) The provision of specific Parkinson's/Movement Disorder

			clinics.
1.6	Is written information regarding Parkinson's routinely available when patients attend clinic venues?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	Routinely available means accessible to patients such as on tables or in racks and/or accessible to staff to distribute to patients.
2. Assessments			
2.1	Is a formal Activities of Daily Living assessment tool or check list **used** when Parkinson's patients are reviewed in this service?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	The use of a formal Activities of Daily Living (ADL) assessment tool is helpful in identifying practical difficulties in daily life and prompting referral for therapy input.
2.2	Is the Parkinson's non-motor symptoms questionnaire or other form of checklist **used** to screen for non-motor symptoms when Parkinson's patients are assessed?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	
2.3	Is a standardised assessment tool routinely **available** in clinic venues to assess and monitor cognitive function?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	The 10 point Abbreviated Mental Test Score is not sufficient to meet this standard.
2.4	Is a standardised assessment tool routinely **available** in clinic venues to assess mood?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	

Consultants and Parkinson's nurse specialists			
3.	**Consultants**		
3.1	Lead consultant name		
3.2	Specialty	• Geriatrician • Geriatrician with special interest in Parkinson's • Neurologist • Neurologist with special interest in Parkinson's	Tick one
3.3	Employing Trust/Board/Local Health Board		
3.4	Contact telephone number		
3.5	Contact email		
3.6	How many consultants routinely provide medical input for this service?	• The number of consultants • Names of the other consultants	Routinely means a regular clinic commitment. **Include:** Any consultant who sees Parkinson's patients for diagnosis and ongoing management. Non specialist consultants should be included if they keep Parkinson's patients under their care.
3.7	Have all consultants providing medical input to this service attended Movement Disorder specific external CME in the last 12 months?	• Yes • No	The question refers to **external** CME i.e. regional, national or international education updates relevant to Parkinson's.

3.7a	If no, please enter X out of X consultants have attended	Free text	
4.	**Parkinson's Nurse Specialists**		
4.1	Can patients in this service access a Parkinson's Nurse Specialist?	• Yes • No	
4.2	Parkinson's Nurse Specialist details	• Name • Employing Trust/Board/Local Health Board • Contact telephone number and email	
4.3	Have all Parkinson's Nurse Specialists associated with this service attended Parkinson specific external CME in the last 12 months?	• Yes • No • No Parkinson's Nurse Specialist	The question refers to **external** CME i.e. regional, national or international education updates relevant to Parkinson's.
4.3a	If no, please enter X out of X Parkinson's Nurse Specialists have attended	Free text	
4.4	What is the main arrangement for contact between Consultants and Parkinson's Nurse Specialists?	• Regular contact in Multidisciplinary meeting, joint or parallel clinic • Regular face to face contact outside clinic • Regular telephone/email contact with occasional face to face contact • Telephone/email contact only • No or rare contact • No Parkinson's Nurse Specialist	Regular is defined as at least twice a month

Table 2: Patient Audit - Questions, data items/answer options and help notes

No.	Question	Data items/Answer options	Help notes
1. Descriptive data			
1.1	Patient identifier	This can be used to identify audited patients	
1.2	Gender	• Male • Female	

1.3	Ethnicity	• White
		  o British,
		  o Irish
		  o Traveller
		  o Any other White background)
		• Asian/Asian British
		  o Bangladeshi
		  o Chinese
		  o Indian
		  o Pakistani
		  o Any other Asian background
		• Black/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic backgrounds
		  o mixed - White and Black
		  o mixed White and Asian
		  o mixed any other background)
		• Other
		  o Arab
		  o Other	

		• prefer not to say	
1.4	Year of birth		
1.5	Year of Parkinson's diagnosis		
1.6	Parkinson's Phase	• Diagnosis • Maintenance • Complex • Palliative	**Definitions of phases** **Diagnosis** • From first recognition of symptoms/sign/problem • Diagnosis not established or accepted. **Maintenance** • Established diagnosis of Parkinson's • Reconciled to diagnosis • No drugs or medication 4 or less doses/day • Stable medication for >3/12 • Absence of postural instability. **Complex** • Drugs – 5 or more doses/day • Any infusion therapy (apomorphine or duodopa) • Dyskinesia • Neuro-surgery considered / DBS in situ • Psychiatric manifestations >mild symptoms of depression/anxiety/hallucinations/psychosis • Autonomic problems – hypotension either drug or non-drug induced • Unstable co-morbidities • Frequent changes to medication (<3/12) • Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues). **Palliative**

			• Inability to tolerate adequate dopaminergic therapy • Unsuitable for surgery • Advanced co-morbidity (life threatening or disabling).
1.7	Living Alone	• Yes • No, • No, at residential home • No, at nursing home	
1.8	Is there evidence of a documented Parkinson's and related medication reconciliation at each patient visit?	• Yes • No • Patient on no medication	Resources: • Medicine reconciliation standards: o http://www.rpharms.com/current-campaigns-pdfs/1303---rps---transfer-of-care-10pp-professional-guidance---final-final.pdf o Scotland: Criteria 19.2: " Reconciliation of the Parkinson's medicine and dosages is undertaken at each patient visit to ensure that the patient, GP, consultant, pharmacist and Parkinson's disease nurse specialist and determine accurately the anti-Parkinson's disease drugs the patient is taking." o Scotland: Scottish Government guidance on medicines reconciliation – http://www.sehd.scot.nhs.uk/cmo/CMO(2013)18.pdf
2. Specialist Review			
Standard A: 100% of people with Parkinson's must be reviewed at 6-12 monthly intervals. (Parkinson's NICE:R12, R77; NSF LTC:QR2; Scotland: Clinical Standard 19.3).			

2.1	Has the patient been reviewed by a specialist within the last year? (can be doctor or nurse specialist)	• Yes • No	
2.2	Time since most recent medical review (by doctor or nurse specialist)	• Less than 6 months • 6-12 months • More than 1 year • More than 2 years • Never	
3. New / Recent Parkinson's medication			
Standard B: 100% of people with Parkinson's should be provided with both oral and written communication throughout the course of the disease, which should be individually tailored and reinforced as necessary.(Parkinson's NICE R3; Scotland - Clinical Standards 1.3 & 1.4)			
3.1	Is there documented evidence of a conversation with the patient/carer and/or provision of written information regarding potential adverse effects for any new medications?	• Yes • No • Not applicable – patient not started on Parkinson's medication for the first time during the previous year	The written information can include a copy of clinic letter if adverse effects are listed, or the Parkinson's UK medication leaflet. The manufacturer's package insert does not meet this standard. Resources: Parkinson's UK medication leaflets https://www.parkinsons.org.uk/content/drug-treatments-parkinsons
4. Specific adverse effect monitoring			
Standard C: 100% of people with Parkinson's who have sudden onset of sleep should be advised not to drive and to consider any occupational hazards (Parkinson's NICE R72) **Standard D: 100% of patients on dopaminagic therapies are monitored for impulse control behaviours including dopamine dysregulation syndrome** (Parkinson's NICE R54, SIGN 5.1.1) **Standard E: If an ergot-derived dopamine agonist is used, 100% of patients should have a minimum of renal function tests, erythrocyte sedimentation rate (ESR)and chest radiograph (CXR) performed before starting treatment, and annually thereafter** (Parkinson's NICE R30 and 40, SIGN 5.1.2)			

4.1	Is this patient on Parkinson's medication?	• Yes • No	[if no, Q4.4 to Q4.6 will be greyed out]
4.2	Evidence of enquiry re excessive daytime sleepiness	• Yes • No	
4.3	If excessive daytime sleepiness is documented as present and the patient is a driver, was the impact on driving discussed and advice given?	• Yes • No • Not applicable – no excessive daytime sleepiness and/or not a driver	
4.4	Evidence patients taking dopaminergic drugs are monitored re: compulsive behaviour	• Yes • No • Not applicable - not on dopaminergic drugs	Evidence means documentation that the patient was specifically asked about the presence of compulsive behaviour symptoms during the previous year if on any dopaminergic medication e.g. MAOI, Levodopa, dopamine agonist Resources: • Impulse Control Disorders in Parkinson Disease (Weintraub) https://www.ncbi.nlm.nih.gov/pubmed/20457959
4.5	Evidence patients taking dopamine agonists are monitored re: compulsive behaviour	• Yes • No • Not applicable - not on a dopamine agonist	Evidence means documentation that the patient was specifically asked about the presence of compulsive behaviour symptoms during the previous year
4.6	Evidence of patients taking ergot dopamine agonists having an echocardiogram carried out for fibrosis related adverse effects	• Yes • No • Not applicable - not on ergot dopamine agonists	Evidence means documentation that this test has been arranged by the PD Service directly or letter sent asking GP to arrange during the previous year
5. Advance Care Planning			

Standard F: For 100% of people with Parkinson's end of life care requirements should be considered throughout all phases of the disease. (Parkinson's NICE R82) **Standard G: 100% of people with Parkinson's and their carers should be given the opportunity to discuss end-of-life issues with appropriate healthcare professionals.** (Parkinson's NICE R 83)			
5.1	Is there evidence the patient/carer has been offered information about, or has set up a Lasting Power of Attorney?	• Yes • No	Resources: • https://www.gov.uk/power-of-attorney/make-lasting-power • Scotland: http://www.publicguardian-scotland.gov.uk/power-of-attorney
5.2	Are there markers of advanced disease e.g. dementia, increasing frailty, impaired swallowing, nursing home level of care required?	• Yes • No - skip to Section 6	
5.3	Are there any documented discussions regarding end of life care issues/care plans?	• Yes • No	Resources: • NHS End of Life Care Programme Guide: Capacity, Care Planning and Advance Care Planning in life limiting illness http://www.ncpc.org.uk/sites/default/files/ACP_Booklet_June_2011.pdf • http://www.parkinsons.org.uk/content/preparing-end-life-booklet • Scottish Palliative Care Guidelines, including care planning and guidance on capacity:

			• http://www.palliativecareguidelines.scot.nhs.uk • Wales: http://gov.wales/topics/health/nhswales/plans/end-of-life-care/?lang=en

6. Parkinson's assessment and care planning process scores (complete from medical and Parkinson's nurse notes)

Domain 1: Non-motor assessment during the previous year (12)

Domain 2: Motor and ADL assessment during the previous year (12)

Domain 3: Education and multi-disciplinary involvement during the previous year (10)

Total process score: 34
These assessments underpin achieving compliance with Parkinson's NICE standards contained in
Section 4: Communication with people with Parkinson's and their carers
Section 9: Non-motor features of Parkinson's
Section 10: Other key interventions - Parkinson's nursing, physiotherapy, occupational therapy

It is recognized that there may not be time – or a need to cover every aspect at every visit.
Base domain answers on whether the problem/issue has been addressed at least once over the previous year (including current visit).

- **"Yes"** and **"No but"** answers will score 1
- **"No"** answers will score 0

Domain 1: Non-motor assessments during the previous year (Maximum score = 12)			
6.1.1	Blood pressure documented lying (or sitting) and standing	• Yes • No • No but, doesn't stand	
6.1.2	Evidence of	• Yes	

	enquiry/assessment re cognitive status	• No	
6.1.3	Evidence of enquiry re hallucinations/psychosis	• Yes • No	
6.1.4	Evidence of enquiry re: mood - this should include depression	• Yes • No	
6.1.5	Evidence of enquiry re communication difficulties	• Yes • No	
6.1.6	Evidence of enquiry re problems with swallowing function	• Yes • No	
6.1.7	Evidence of screening for malnutrition (weight checked at least yearly)	• Yes • No	
6.1.8	Evidence of enquiry re problems with saliva	• Yes • No	
6.1.9	Evidence of enquiry re bowel function	• Yes • No	
6.1.10	Evidence of enquiry re bladder function	• Yes • No	
6.1.11	Evidence of enquiry re pain	• Yes • No	
6.1.12	Evidence of enquiry re sleep quality	• Yes • No	

Domain 2: Motor and ADL assessment during the previous year (12)			
6.2.1	Evidence of enquiry re “On/Off” fluctuations	• Yes • No • No, but not yet on treatment • No, but less than 3 years from starting medication	
6.2.2	Evidence of enquiry/assessment re problems with gait including freezing	• Yes • No • No, but doesn't walk	
6.2.3	Evidence of enquiry re falls and balance	• Yes • No • No, but assisted for transfers and doesn't walk	
6.2.4	Evidence fracture risk/osteoporosis considered	• Yes • No • No, but notes document not falling and no concern re balance	
6.2.5	Evidence of enquiry re problems with bed mobility (e.g. getting in/out of bed, moving/rolling from side to side once in bed)	• Yes • No	
6.2.6	Evidence of enquiry re problems with transfers (e.g. out of chair/off toilet/car)	• Yes • No • No, but early/mild disease, active lifestyle	
6.2.7	Evidence of enquiry/assessment of tremor	• Yes • No • No, but no tremor	

6.2.8	Evidence of enquiry re problems with dressing	• Yes • No • No, but in care home	
6.2.9	Evidence of enquiry re problems with hygiene (e.g. washing/bathing/hair/ nails)	• Yes • No • No, but in nursing home	
6.2.10	Evidence of enquiry re difficulty eating and drinking (i.e. cutlery/managing drinks etc. not swallowing)	• Yes • No • No, but PEG fed	
6.2.11	Evidence of enquiry re domestic activities (cooking/cleaning/shopping)	• Yes • No • No, but in care home	
6.2.12	Evidence of enquiry re problems with function at work	• Yes • No • No, but retired or doesn't work	
Domain 3: Education and multi-disciplinary involvement during the previous year (10)			
6.3.1	Evidence of referral/input from Parkinson's nurse	• Yes • No • No, but declined	
6.3.2	Evidence of physiotherapy referral/assessment/input	• Yes, for therapy/assessment • No • No, but declined • No, but clear documentation no therapy need • No, but no achievable physiotherapy goals	The option "No but clear documentation no therapy need" should only be used if there is clear documentation of relevant enquiries/assessments re physiotherapy related problems (gait / balance/ posture/transfers) Use **"No but no achievable physiotherapy goals"** option only if no change and extensive prior physiotherapy input
6.3.3	Evidence of	• Yes, for therapy/assessment	The option "No but clear documentation no therapy need" can

	occupational therapy referral/assessment/input	• No • No, but, declined • No, but clear documentation no therapy need • No, but no achievable occupational therapy goals	only be used if there is clear documentation of assessment/enquiry re problems with activities of daily living and/or difficulties at work if working Use **"No but, no achievable occupational therapy goals"** option only if no change and extensive prior occupational therapy input
6.3.4	Evidence of speech and language therapy referral/input **for communication**	• Yes, for therapy/assessment • No • No, but declined • No, but clear documentation no therapy need • No, but no achievable SLT goals	The option "No but clear documentation no therapy need" can only be used if there is clear documentation of assessment/enquiry re communication Use **"No but, no achievable SLT goals"** option only if no change, extensive prior SLT input and alternative communication means already explored
6.3.5	Evidence of speech and language therapy referral/input **for swallowing**	• Yes • No • No, but declined • No, but swallow documented normal • No, but PEG fed or adequate care plan in place	
6.3.6	Evidence of social work referral/input	• Yes • No • No, but declined • No, but documented as self funding and referred to other sources of support and information re care • No, but social work input not required, as social care needs are being met.	Use **"No but social work input not required, as social care needs are being met"** option only if there is evidence that current care arrangements are working well or that the person is independent in mobility and personal care.
6.3.7	Evidence that patient's and carer's entitlement to financial benefits has been considered and advice given	• Yes • No • No, but independent in mobility and personal care • No, but previously addressed	Resources: http://www.parkinsons.org.uk/content/financial-help-and-support-carers http://www.parkinsons.org.uk/content/social-fund-and-local-welfare-provision-information-sheet

6.3.8	Evidence that patient and/or carer has been signposted to Parkinson's UK	• Yes • No • No, but previously signposted	
6.3.9	Evidence that patient and/or carer has been signposted to Information Support Worker	• Yes • No • No, but previously signposted	
6.3.10	Evidence of communication with carers about their entitlement to carer assessment and support services	• Yes • No • No, but in care home • No, but patient not in complex or palliative stage • No, but, no carer • No, but previously addressed, or no new issues	

Appendix A: Printable Patient Audit sheet

No.	Question	Data items/Answer options	
1. Descriptive data			
1.1	Patient identifier		
1.2	Gender	• Male • Female	

1.3	Ethnicity	• White
		  o British,
		  o Irish
		  o Traveller
		  o Any other White background)
		• Asian/Asian British
		  o Bangladeshi
		  o Chinese
		  o Indian
		  o Pakistani
		  o Any other Asian background
		• Black/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic backgrounds
		  o mixed - White and Black
		  o mixed White and Asian
		  o mixed any other background)
		• Other
		  o Arab
		  o Other
		  o prefer not to say	

1.4	Year of birth		
1.5	Year of Parkinson's diagnosis		
1.6	Parkinson’s Phase	• Diagnosis • Maintenance • Complex • Palliative	
1.7	Living Alone	• Yes • No, • No, at residential home • No, at nursing home	
1.8	Is there evidence of a documented Parkinson’s and related medication	• Yes • No	

	reconciliation at each patient visit?	Patient on no medication
2. Specialist Review		
2.1	Has the patient been reviewed by a specialist within the last year? (can be doctor or nurse specialist)	• Yes • No
2.2	Time since most recent medical review (by doctor or nurse specialist)	• Less than 6 months • 6-12 months • More than 1 year • More than 2 years • Never
3. New / Recent Parkinson's medication		
3.1	Is there documented evidence of a conversation with the patient/carer and/or provision of written information regarding potential adverse effects for any new medications?	• Yes • No • Not applicable – patient not started on Parkinson's medication for the first time during the previous year
4. Specific adverse effect monitoring		
4.1	Is this patient on Parkinson's medication?	• Yes • No
4.2	Evidence of enquiry re excessive daytime sleepiness	• Yes • No
4.3	If excessive daytime sleepiness is documented as present and the patient is a driver, was the impact on driving discussed and advice given?	• Yes • No • Not applicable – no excessive daytime sleepiness and/or not a driver
4.4	Evidence patients taking dopaminergic drugs are monitored re: compulsive behaviour	• Yes • No • Not applicable - not on dopaminergic drugs
4.5	Evidence patients taking dopamine agonists are monitored re: compulsive behaviour	• Yes • No • Not applicable - not on a dopamine agonist
4.6	Evidence of patients taking ergot dopamine agonists having an echocardiogram carried out for fibrosis related	• Yes • No • Not applicable - not on ergot dopamine agonists

	adverse effects	
5. Advanced Care Planning		
5.1	Is there evidence the patient/carer has been offered information about, or has set up a Lasting Power of Attorney?	• Yes • No
5.2	Are there markers of advanced disease e.g. dementia, increasing frailty, impaired swallowing, nursing home level of care required?	• Yes • No - skip to Section 6
5.3	Are there any documented discussions regarding end of life care issues/care plans?	• Yes • No
6. Parkinson's assessment and care planning process scores (complete from medical and Parkinson's nurse notes)		
Domain 1: Non-motor assessments during the previous year (Maximum score = 12)		
1	Blood pressure documented lying (or sitting) and standing	• Yes • No • No but, doesn't stand
2	Evidence of enquiry/assessment re cognitive status	• Yes • No
3	Evidence of enquiry re hallucinations/psychosis	• Yes • No
4	Evidence of enquiry re: mood - this should include depression	• Yes • No
5	Evidence of enquiry re communication difficulties	• Yes • No
6	Evidence of enquiry re problems with swallowing function	• Yes • No
7	Evidence of screening for malnutrition (weight checked at least yearly)	• Yes • No
8	Evidence of enquiry re problems with saliva	• Yes

		• No
9	Evidence of enquiry re bowel function	• Yes • No
10	Evidence of enquiry re bladder function	• Yes • No
11	Evidence of enquiry re pain	• Yes • No
12	Evidence of enquiry re sleep quality	• Yes • No
Domain 2: Motor and ADL assessment during the previous year (12)		
1	Evidence of enquiry re “On/Off” fluctuations	• Yes • No • No, but not yet on treatment • No, but less than 3 years from starting medication
2	Evidence of enquiry/assessment re problems with gait including freezing	• Yes • No • No, but doesn't walk
3	Evidence of enquiry re falls and balance	• Yes • No • No, but assisted for transfers and doesn't walk
4	Evidence fracture risk/osteoporosis considered	• Yes • No • No, but notes document not falling and no concern re balance
5	Evidence of enquiry re problems with bed mobility (e.g. getting in/out of bed, moving/rolling from side to side once in bed)	• Yes • No
6	Evidence of enquiry re problems with transfers (e.g. out of chair/off toilet/car)	• Yes • No • No, but early/mild disease, active lifestyle •
7	Evidence of	

	enquiry/assessment of tremor	• Yes • No • No, but no tremor
8	Evidence of enquiry re problems with dressing	• Yes • No • No, but in care home
9	Evidence of enquiry re problems with hygiene (e.g. washing/bathing/hair/nails)	• Yes • No • No, but in nursing home
10	Evidence of enquiry re difficulty eating and drinking (i.e. cutlery/managing drinks etc. not swallowing)	• Yes • No • No, but PEG fed
11	Evidence of enquiry re domestic activities (cooking/cleaning/shopping)	• Yes • No • No, but in care home
12	Evidence of enquiry re problems with function at work	• Yes • No • No, but retired or doesn't work
Domain 3: Education and multi-disciplinary involvement during the previous year (10)		
1	Evidence of referral/input from Parkinson's nurse	• Yes • No • No, but declined
2	Evidence of physiotherapy referral/assessment/input	• Yes, for therapy/assessment • No • No, but declined • No, but clear documentation no therapy need • No, but no achievable physiotherapy goals
3	Evidence of occupational therapy referral/assessment/input	• Yes, for therapy/assessment • No • No, but, declined • No, but clear documentation no therapy need • No, but no achievable occupational therapy goals
4	Evidence of speech and language therapy referral/input **for communication**	• Yes, for therapy/assessment • No • No, but declined

		• No, but clear documentation no therapy need • No, but no achievable SLT goals
5	Evidence of speech and language therapy referral/input **for swallowing**	• Yes • No • No, but declined • No, but swallow documented normal • No, but PEG fed or adequate care plan in place
6	Evidence of social work referral/input	• Yes • No • No, but declined • No, but documented as self funding and referred to other sources of support and information re care • No, but social work input not required, as social care needs are being met.
7	Evidence that patient's and carer's entitlement to financial benefits has been considered and advice given	• Yes • No • No, but independent in mobility and personal care • No, but previously addressed
8	Evidence that patient and/or carer has been signposted to Parkinson's UK	• Yes • No • No, but previously signposted
9	Evidence that patient and/or carer has been signposted to Information Support Worker	• Yes • No • No, but previously signposted
10	Evidence of communication with carers about their entitlement to carer assessment and support services	• Yes • No • No, but in care home • No, but patient not in complex or palliative stage • No, but, no carer • No, but previously addressed, or no new issues

UK PARKINSON'S
Excellence
Network

2017 UK Parkinson's Audit
Occupational therapy
Standards and guidance

2017 UK Parkinson's Audit
Occupational therapy

College of Occupational Therapists

Audit of national standards relating to Parkinson's care, incorporating the Parkinson's NICE guideline and the National Service Framework for Long Term Neurological Conditions quality standards.

Aim

The aim of the occupational therapy audit is to establish if occupational therapy services are providing quality services for people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

Objectives

1. To evaluate if occupational therapy services are currently providing assessment and interventions appropriate to the needs of people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

2. To identify areas of good practice and areas for improvement to inform local, regional and UK-wide discussions leading to action plans to improve quality of care.

3. To establish baseline audit data to allow:
    - UK-wide mapping of variations in quality of care
    - local and UK-wide mapping of progress in service provision and patient care through participation in future audit cycles

Background

The Parkinson's occupational therapy audit is part of the UK Parkinson's audit coordinated by Parkinson's UK and led by a steering group of professionals.

This is the fourth round in which occupational therapists will be able to take part, along with physiotherapists and speech and language therapists. Consultants in elderly care and neurology (and their Parkinson's nurses) can participate in the parallel patient management audit. The occupational therapy audit has received research governance approval by the College of Occupational Therapists. The audit questions for this round of the audit have been refined to reflect feedback from the 2015 audit.

Standards

The occupational therapy audit has been structured according to *Occupational therapy for people with Parkinson's: Best Practice Guidelines*[1] and the National Service Framework for Long Term Conditions[2]. It has also been structured according to principles of occupational therapy for Parkinson's, as outlined by the NICE guideline[3].

The principles of occupational therapy for Parkinson's include:

- early intervention to establish rapport, prevent activities and roles being restricted or lost and, where needed, to develop appropriate coping strategies
- patient centred assessment and intervention
- development of goals with the individual and carer
- employment of a wide range of interventions to address physical and psychosocial problems to enhance participation in everyday activities, such as self care, mobility, domestic and family roles, work and leisure (NICE 2006, quoted in *Occupational therapy for people with Parkinson's: Best Practice Guidelines* 2010 p16)

The NICE guideline (2006, p14) states that occupational therapy should be available for people with Parkinson's, and that particular consideration should be given to:

- maintenance of work and family roles, employment, home care and leisure activities
- improvement and maintenance of transfers and mobility
- improvement of personal self-care activities, such as eating, drinking, washing and dressing
- environmental issues to improve safety and motor function
- cognitive assessment and appropriate intervention

[1] Aragon A, Kings J (2010) *Occupational therapy for people with Parkinson's: Best Practice Guidelines* College of Occupational Therapists. In Partnership with Parkinson's UK and College of Occupational Therapists Specialist Section Neurological Practice. Available at http://www.parkinsons.org.uk/sites/default/files/publications/download/english/otparkinsons_guidelines.pdf

[2] Department of Health. *National Service Framework for Long Term Neurological Conditions*. (2005) Available at www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

[3] National Institute of Health and Clinical Excellence. *Parkinson's Disease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35.* (2006) Available at https://www.nice.org.uk/guidance/CG35

Methodology

This audit is open to all occupational therapy services and individual occupational therapists that work with people with Parkinson's in the UK, whether hospital or community based, clinic or domiciliary service (excluding acute hospital inpatients).

Standards agreed to be pertinent to occupational therapy have been transformed into a set of audit standards and statements reviewed by specialist occupational therapists. The full list of questions is given in Table 1 (Service audit) and Table 2 (Patient audit) at the end of this document.

A process flow chart (*How do I take part?*) can be found on page X of this document. Please note the importance of logging your participation in this national clinical audit with your Audit Department.

Patient sample

The minimum audit sample size is 10 consecutive people with idiopathic Parkinson's patients referred to an occupational therapy service and seen during the audit data collection period, which runs from 1 May 2017 to 30 September 2017.

Take account of the need to capture this minimum sample when deciding locally on your start date for collecting a consecutive patient sample. The data collection tool will have the capacity to capture as many consecutive patients as therapists wish to audit.

The inclusion criteria for audited patients are as follows:

a) Patients who are currently receiving active intervention (including education/counselling) at the start of the audit period.

b) Those who are seen on a review appointment (irrespective of whether they then go to start another episode of active treatment) during the audit period.

c) Patients newly referred to your service who undergo full assessment (again irrespective of whether they then proceed to immediate active intervention rather than being placed on review).

Data collection and entry

The audit tool contains three sections:

- A **service audit** section, which consists of some general questions about your service (which needs to be completed only once by a manager or senior colleague familiar with the service set-up and running).

- A **patient audit** section, which allows you to enter data on individual patients. These include both newly seen people with Parkinson's and follow ups, but each person should only be documented once, even if they attend more than once during this period.

- An **instant reporting** section, which will be built automatically as you enter your data, and produces pie charts for selected questions.

In some circumstances, people may have to audit notes from across a department, although we would prefer that, where possible, information is audited from one specific service in a particular type of setting.

Ideally the person entering data on the tool should not be the person who completed the notes but this may not always be possible. When reviewing someone else's notes, it may be necessary to speak with the clinician or therapist who wrote them.

It is good practice for the auditor to keep the occupational therapy notes separate from the medical notes. If possible, both sets of notes should be used to complete the audit.

Patient data can be entered on the data collection tool which you have downloaded and saved locally and added to at your convenience. Complete a separate entry for each patient with Parkinson's. Remember to save the data each time you add new information.

Appendix A of this document is a version of the patient questions that you can print and use to record data in your clinics, if this would be useful.

A user guide for the data collection tool will be available, providing full instructions and information.

All data must be submitted by 30 October 2017. No submissions will be accepted after that date.

'No, but…' answers

This concept has been borrowed from the National Stroke Audit. A 'No, but…' answer implies there is a pre-determined accepted reason for non- compliance with the standard. The denominator for compliance can then be determined only for those patients where the standard was relevant – ie 'No, but…' answers can be removed from calculations of compliance.

Confidentiality

Patients
Please ensure that any information you submit for the audit does not include any personally identifiable information about your patients. Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it[4].

When you complete the patient section of the audit, you will see that there is space for a patient identifier. It is suggested that you use code letters or a number here to help you keep track (for example the patient's initials or hospital number). **This data will not be included in the data you submit to Parkinson's UK – the data collection tool will prevent this.** It will help if you keep a list of the code letters or numbers securely yourself, so that if there is any query about the information you have submitted, you can track back to the original patient.

Employers
The Healthcare Quality Improvement Partnership (HQIP) recommends that services participating in a national clinical audit should be named in the audit reports. The audit reference report will list all participating organisations. It is therefore vital that you inform your clinical audit department about your participation in the audit.

Participants
Individual therapists who participate and submit data will not be named in the audit report.

Data security

The data collection tool which will be available for download from the audit webpage will be password protected, allowing no one but eligible participants to enter and make changes to the data. The password will be emailed to the named lead for each service. Please make sure that the password is protected and can't be accessed by other people.

[4] Health Professionals Council. *Confidentiality – guidance for registrants.* (2012) Available at http://www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf [accessed 6 January 2017]

To ensure the security of your data, we also advise you to save and use your version of the tool on a secure computer at work and not on your personal computer at home. We ask you to comply with your organisation's Data Protection guidelines at all times.

After the data has been sent to Parkinson's UK it will be stored in password-protected files at Parkinson's UK in accordance with NHS requirements. Within Parkinson's UK, access to the raw data set is restricted to Kim Davis, Clinical Audit Manager, members of the Clinical Steering Group and Alison Smith, the Data and Analytics Adviser.

Raw data will not be accessible in the public domain. Services will be asked to report any discrepancies in the data received by the audit team in a summary sheet before data analysis begins.

Patient Reported Experience Measure

All services participating in the audit are encouraged to participate in the Patient Reported Experience Measure (PREM). The PREM takes the form of a short paper questionnaire to be distributed to up to 50 consecutive patients between 1 May and 30 September 2017. These patients do not necessarily have to be those included in the main clinical audit.

The questionnaire asks 11 questions about patients' views of their Parkinson's service, and should take only five to 10 minutes to complete. If a carer has accompanied the patient on their clinic visit, they may assist the patient in completion of the form. Patients should feel comfortable and not overlooked while completing their questionnaire.

No identifiable information is collected, and the patient will seal their completed questionnaire in the envelope provided. These envelopes will then need to be collected before the patient leaves the clinic, and all the envelopes will then be returned to the audit team at Parkinson's UK in the large postage-paid envelope provided.

Each service will be provided with the following resources:

- 50 x copies of a paper questionnaire.
- 50 x sealable envelopes.
- 50 x patient information leaflets.
- An A3 laminated poster.
- A large postage-paid envelope for return of sealed envelopes to the audit team.

A minimum of 10 questionnaires will need to be returned for a service's data to be included in the data analysis.

How the audit results will be communicated

The findings of both the clinical audit and the PREM will be presented in the form of a UK-wide summary report and an individual report for each service, benchmarking the results of individual services against the national average for each audit question in their specialty.

The summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. A bespoke patient and carer version of the summary report will also be produced, along with a reference report which will include all of the results, and a list of all participating services.

A link to the reports will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The reports will also be in the public domain via the Parkinson's UK website.

Data collected during the audit will be used to generate a national picture of service delivery and to compare this with the expectations detailed in national guidance. This data will provide valuable information about priority areas within the existing healthcare provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson’s.

The UK Parkinson’s Excellence Network brings together health and social care professionals to transform the care that people with Parkinson’s receive across the UK. The Network is there to ensure:

- that everyone affected by Parkinson’s has access to high quality Parkinson’s services that meet their needs. Their care should be delivered by an expert, integrated, multi-disciplinary team including a consultant, specialist nurse and range of therapists, whose involvement is key to maximising function and maintaining independence
- there are clear pathways to timely, appropriate information, treatments and services from the point of diagnosis, including access to specialist mental health services and the full range of information and support to take control of the condition offered by Parkinson’s UK
- services will be involved in continuous quality improvement through audit and engagement of service users in improvement plans

Participating in the PREM will give individual occupational therapy services direct feedback from their service users about the quality of care, accessibility and general satisfaction.

How do I take part

Am I eligible to take part?

Any healthcare professionals who work regularly with people with Parkinson's can take part. This includes speech and language therapists, physiotherapists, occupational therapists, Parkinson's nurses, neurologists and geriatricians. You need to submit data on a minimum of 20 (patient management) or 10 (therapies) patients seen during the audit period (1 May to 30 September 2017) for your data to be included in the audit.

How do I take part if I am eligible?

Register your service

Complete and submit a registration form at **parkinsons.org.uk/audit** by 31 March 2017 for each service you wish to audit. You will then be emailed a service number and a password for the data collection tool – you will need these to enter your audit data. In mid-April you will be sent an Audit Pack containing Patient and Carer Information Leaflets and the materials required for the Patient Reported Experience Measure (PREM).

Inform your audit department

Please log your participation in this clinical audit with your audit department and discuss with Information Governance to determine if Caldicott approval is required.

Establish a local audit project group

Include key professional and medical staff collecting data – discuss the logistics for running the audit, and plan for disseminating the results and action planning. Agree a start date for acquiring patient sample. Agree a target sample size.

Data collection

You will be able to download a copy of the data collection tool from parkinsons.org.uk/audit from mid-April 2017, along with a data collection tool. Data entry begins on 1 May 2017.

1. Enter brief details about your service (the Service Audit).

2. Enter details of consecutive patients seen during the audit period 1 May 2017 to 30 September 2017 (the Patient Audit).

3. During this period, hand out Patient Reported Experience Measure questionnaires to up to 50 consecutive patients – these do not need to be the same patients you include in the main audit.

More information

If you have any queries, or for more information, please contact Kim Davis, Clinical Audit Manager, on 020 7963 3916 or email **audit@parkinsons.org.uk**

Table 1: Service Audit – questions, data items/answer options and help notes

	Question	Data items/answer options	Help notes
Your details			
1.1	Name of Lead Therapist completing the Service Audit	Free text	
1.2	Contact email of Lead Therapist	Free text	
Service Description			
2.1	Describe the setting in which you usually see individuals with Parkinson's	• Integrated medical and therapy Parkinson's clinic • In-patient acute service • In-patient rehabilitation service • Community rehabilitation service e.g. intermediate care • Social services including reablement • Outpatient/ day hospital • Other (please specify)	Choose one – the most common setting for the service
2.2	Does your service specialise in the treatment of individuals with neurological conditions?	• Yes • No	
2.3	Does your service specialise in the treatment of individuals with Parkinson's?	• Yes • No	
Individuals with Parkinson's			

3.1	Approximately how many referrals of individuals with Parkinson's are made to your service per year?	• Free text	New referrals, i.e. not those 'referred' for review who have previously been seen by this service. An approximate total is all that is required
3.2	Approximately what percentage of the individuals referred to your service annually have a diagnosis of Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-100%	
Occupational therapy Professionals			
4.1	Within your service, can you access Parkinson's related continuing professional development (at least yearly)?	• Yes • No	Training includes in-service within the Trust/similar body /Board/Local Health Board or external courses
4.2	Are there any documented induction and support strategies for new occupational therapists working with individuals with Parkinson's?	• Yes, specifically in relation to patients with Parkinson's • Yes, as part of more general competencies • No	
4.3	What support (e.g. education, advice) is available to individual therapists working in the service?	• They can consult any member of the Parkinson's specialist MDT as they are a member themselves • They can consult members of a general neurology/elderly care specialist service of which they are a member • They do not work directly in specialist Parkinson's clinics but can readily	Choose one

		access a Parkinson's specialist MDT/Parkinson's Nurse Specialist • They do not work directly in a specialist clinic but can readily access advice from a specialist neurology or elderly care MDT • They have no access to more specialised advice	
Clinical Practice			
5.1	How does your service approach assessment of an individual with Parkinson's?	• MDT assessment • Interview with patients and carer • Assessment during group work • Functional Assessment • Standardised assessment • Other (please specify)	Tick all that apply
5.2	How do you usually see your patients with Parkinson's?	• Individually • In a group setting • Both individually and in groups	
5.3	Please list the standardised assessments that you use:-	• Assessment of Motor and Process Skills • Canadian Occupational Performance Measure (Law et al 2005) • Functional assessment measure (FAM) • Functional Independence Measure(FIM) • Nottingham Extended Activities of Daily Living Assessment (NEADL) (Nouri and Lincoln 1987)	Tick all that apply

		• Fatigue Impact Scale (FIS) (Whitehead 2009) • PRPP Assessment (Perceive, Recall, Plan & Perform Assessment) • Parkinson's Disease Questionnaire (PDQ39 or PDQ 8) • Unified Parkinson's Disease Rating Scale (UPDRS) • Model of Human Occupation Screening Tool (MOHOST) • Non-motor Questionnaire • ACE-111(Addenbrookes Cognitive Examination 111) • MMSE-2 (Mini Mental State Examination - 2) • Mattis Dementia Rating Scale (MDRS) • Scales for Outcomes in Parkinson's Disease – Cognition (SCOPA-COG) • Rivermead Behavioural Memory Test (RBMT) • Behavioural Assessment of Dysexecutive Syndrome (BADS) • Other (please specify)	
5.4	What needs are addressed through your interventions?	• Work roles • Family roles • Domestic activities of daily living • Leisure activities • Transfers and mobility • Personal self care activities such as eating, drinking, washing and dressing • Environmental issues to improve safety	Tick all that apply

		and motor function • Mental wellbeing, including cognition, emotional and/or neuro-psychiatric problems • Management of fatigue • Education of condition and self-management • Social interaction/social support • Other (please specify)	
5.5	Where do you carry out the intervention?	• Individual's home • Community setting • Outpatient/day hospital/centre • Inpatient hospital	

Table 2: Patient audit: Audit standards, questions and supporting information

	Question	Data items/answer options	Help notes
1. Demographics			
1.1	Patient identifier	This can be used by you to identify audited patients	This data will be removed by the data entry tool when you submit your data
1.2	Gender	• Male • Female	

1.3	Ethnicity	• White
		  o British,
		  o Irish
		  o Traveller
		  o Any other White background)
		• Asian/Asian British
		  o Bangladeshi
		  o Chinese
		  o Indian
		  o Pakistani
		  o Any other Asian background
		• Black/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic backgrounds
		  o mixed - White and Black
		  o mixed White and Asian
		  o mixed any other background)	

		• Other o Arab o Other o prefer not to say	
1.4	Year of birth		
1.5	What setting does this Patient live in?	• Own home • Residential care home • Nursing home • Other (please specify)	
1.6	In what setting was the individual seen?	• NHS – inpatient • NHS – outpatient • NHS - Community • Private clinic • At home • Other	
1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative	**Definitions of phases** **Diagnosis** • From first recognition of symptoms/sign/problem • Diagnosis not established or accepted. **Maintenance** • Established diagnosis of Parkinson's • Reconciled to diagnosis • No drugs or medication 4 or less doses/day • Stable medication for >3/12 • Absence of postural instability. **Complex** • Drugs – 5 or more doses/day • Any infusion therapy (apomorphine or duodopa) • Dyskinesia • Neuro-surgery considered / DBS in situ

			• Psychiatric manifestations >mild symptoms of depression/anxiety/hallucinations/psychosis • Autonomic problems – hypotension either drug or non-drug induced • Unstable co-morbidities • Frequent changes to medication (<3/12) • Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues). **Palliative** • Inability to tolerate adequate dopaminergic therapy • Unsuitable for surgery • Advanced co-morbidity (life threatening or disabling).
2. Referral			
	Standard A: Occupational therapy should be available and considered at diagnosis and during each regular reviews for people with Parkinson's. (NICE: R12, R80) **Standard B: Occupational therapists reviewing people with Parkinson's should give particular consideration to (NICE R80):** • **maintenance of work and family roles, employment, home care and leisure activities** • **improvement and maintenance of transfers and mobility** • **improvement of personal self-care activities, such as eating, drinking, washing and dressing** • **environmental issues to improve safety and motor function** • **cognitive assessment and appropriate intervention**		

	Standard C: There is timely integrated assessment involving all relevant health agencies leading to individual care plans, which ensure that staffs have access to all relevant records and background information about the person's condition, test results and previous consultations. (NSF QR1)		
2.1	Who made the referral to OT?	• Neurologist • Geriatrician • Parkinson's nurse • Physiotherapist • GP • Dietician • Social care worker • Self-referral • Other • Unknown	
2.2	Year of Parkinson's diagnosis		
2.3	Date of referral letter for this episode	(dd/mm/yyyy)	Where the patient made the appointment themselves via a single point of access system, use the date contact was made.
2.4	Date of initial OT intervention for this episode	(dd/mm/yyyy)	
2.5	Has the person received previous OT for Parkinson's?	• Yes – please go to Q2.6 • No – please go to Q2.7 • Unknown – please go to Q2.7	Has the person has been seen by an occupational therapist working in any setting?
2.6	If yes, how many episodes of OT has s/he	(free text)	

	received for Parkinson's related problems, prior to this referral?		
2.7	Has this referral been triggered as a result of a medical review?	• Yes • No • Unknown	
2.8	What was the reason for referral to OT?	• Work roles • Family roles • Domestic activities of daily living • Leisure activities • Transfers and mobility • Personal self-care activities such as eating, drinking, washing and dressing • Environmental issues to improve safety and motor function • Mental wellbeing, including cognition, emotional and/or neuro-psychiatric problems • Management of fatigue • Other (please specify)	Tick all that apply
2.9	Was all the information essential for OT assessment and intervention on referral?	• Yes, most of it • Yes, some of it • No	<u>Resources</u>: • NSF QR1 - An integrated approach to assessment of care and support needs, and to the delivery of services is key to improving the quality of life for people with LTC. The most effective support is provide when local health and socials services team communicate ; have access to up to date case notes and patients held records and work together to provide a co-ordinated

			service
2.10	If 'no', what information was missing?		(Free text box)
2.11	As an occupational therapist, do you feel that the patient was referred at an appropriate time?	• Yes • No • Don't know	
2.12	Were reports made back to the referrer/other key people at the conclusion of the intervention period (or interim reports where treatment lasts a longer time)?	• Yes • No, but will be done at the end of this intervention • No	
3. Goals identified			
	Standard D: People with Parkinson's should have a comprehensive care plan agreed between the individual, their family and/or carers and specialist and secondary healthcare providers (NICE R5) **Occupational therapy process frameworks, principle 3: Development of goals in collaboration with the individual and carer with regular review (Occupational Therapy for People with Parkinson's: best practice guidelines, College of Occupational Therapists, 2010, p16).**		
3.1a	What occupational goals were identified?	• self-care • productivity • leisure	Tick all that apply 'The principles of occupational therapy for Parkinson's include development of goals in collaboration with the individual and carer, with regular review' (Occupational Therapy for people with Parkinson's: best practice guidelines 2010 p16). https://www.cot.co.uk/publication/cot-

			publications/occupational-therapy-people-parkinsons-disease 'Goal setting:- Goals identified by the Patient, in partnership with the therapist' (Figure 1, Jain et al 2005, reproduced Occupational Therapy for people with Parkinson's: best practice guidelines 2010 2010 p18) Resources: • 'Falls: assessment and prevention of falls in older people' NICE clinical guideline no. 21 (https://www.nice.org.uk/guidance/cg161) • 'Occupational therapy in the prevention and management of falls in adults' (2015) Practice guideline www.cot.co.uk/sites/default/files/general/public/Falls-guidelines.pdf • Scotland: Up and About – prevention and management of falls in Scotland http://www.healthcareimprovementscotland.org/default.aspx?page=13131
3.1b	Who identified goal(s)?	• Patient • Therapist • Family • Collaboration	Tick one
3.2	End of life care – who identified goals?	• Patient • Therapist • Family • Collaboration • Not appropriate at this stage	Tick one

4. Intervention strategies used			
4.1	Initiating and maintaining movement	• Promoting occupational performance abilities through trial of intrinsic cueing techniques • Promoting functional abilities through trial of extrinsic cueing techniques • Promoting functional ability throughout a typical day, taking account of medication • Promoting functional ability throughout a typical day, taking into account fatigue • None of the above treatment strategies applicable	Tick all that apply E.g. imagining action to be carried out in detail before starting movement E.g. stepping over line on the floor, use of metronome
4.1a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)	
4.2	Engagement, motivation, learning and carry-over	• Promoting mental wellbeing • Promoting new learning • None of the above strategies applicable	Tick all that apply E.g. intervention to address emotional, cognitive and/or neuropsychiatric impairment E.g. ensuring full conscious attention, demonstration of movement, ‘backward chaining’
4.2a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)	

4.3	Environmental adaptations/assistive technology – did intervention include assessment for:	• Small aids and adaptations • Wheelchair and seating • Major adaptations • Assistive technology • Other (please state) • None of the above treatment strategies applicable	Tick all that apply E.g. grab rails, perching stool, adaptive cutlery E.g. telecare, digital technologies
4.3a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)	
4.4	Ensuring community rehabilitation and social support – were referrals made to:	• Social services OT • Social worker/carers • Other allied health professions • Respite care • Voluntary services • Access to work • Other (please state) • None of the above treatment strategies applicable	Tick all that apply
4.4a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)	

4.5	Providing advice and guidance to support patient's self-management	• Work advice and resources • Specific ADL techniques • Cognitive strategies • Fatigue management • Relaxation/stress management • None of the above treatments strategies applicable	Tick all that apply
4.5a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)	
4.6	Providing information and support for family and carers	• Optimising function • Safe moving and handling • Support services • Managing changes in mood, cognition or behaviour • Other (please state) • None of the above treatment strategies applicable	Tick all that apply
4.6a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)	

4.7	Providing support to enable choice and control	• Positive attitude/emotional set • Developing self awareness/ adjustment to limitations • Increasing confidence • Explore new occupations • Other (please state) • None of the above treatment strategies applicable	Tick all that apply
4.7a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)	
5. About the Occupational Therapist			
5.1	What is the NHS banding/social service grade of the person who assessed this person?	• 4 • 5 • 6 • 7 • 8a • 8b • 8c • Social service grade – junior occupational therapist • Social service grade – senior occupational therapist • Private practitioner	

5.2	Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown	
6. Evidence base			
6.1	Which of the following sources of information inform your clinical practice around the management of Parkinson's?	• Clinical experience • Advice from colleague or supervisor • Recommendations given in OT Best Practice Guidelines? (Parkinson's UK & COT 2010) • Information from Parkinson's UK website • National Service Framework for Long term Conditions (2005) • NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017) • Published evidence in a peer reviewed journal • Training courses • Webinars, Social Media • None • Other (please specify)	Tick all that apply

Appendix A: Printable Patient Audit sheet

	Question	Data items/answer options
2. Demographics		
1.1	Patient identifier	
1.2	Gender	• Male • Female

1.3	Ethnicity	• White
		  o British,
		  o Irish
		  o Traveller
		  o Any other White background)
		• Asian/Asian British
		  o Bangladeshi
		  o Chinese
		  o Indian
		  o Pakistani
		  o Any other Asian background
		• Black/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic backgrounds
		  o mixed - White and Black
		  o mixed White and Asian
		  o mixed any other background)
		• Other
		  o Arab
		  o Other

		prefer not to say
1.4	Year of birth	
1.5	What setting does this Patient live in?	• Own home • Residential care home • Nursing home • Other (please specify)
1.6	In what setting was the individual seen?	• NHS – inpatient • NHS – outpatient • NHS - Community • Private clinic • At home • Other
1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative
2. Referral		
2.1	Who made the referral to OT?	• Neurologist • Geriatrician • Parkinson's nurse • Physiotherapist • GP • Dietician

		• Social care worker • Self-referral • Other • Unknown
2.2	Year of Parkinson's diagnosis	
2.3	Date of referral letter for this episode (Where the patient made the appointment themselves via a single point of access system, use the date contact was made.)	
2.4	Date of initial OT intervention for this episode	
2.5	Has the person received previous OT for Parkinson's?	• Yes – please go to Q2.6 • No – please go to Q2.7 • Unknown – please go to Q2.7
2.6	If yes, how many episodes of OT has s/he received for Parkinson's related problems, prior	

	to this referral?	
2.7	Has this referral been triggered as a result of a medical review?	• Yes • No • Unknown
2.8	What was the reason for referral to OT? Tick all that apply	• Work roles • Family roles • Domestic activities of daily living • Leisure activities • Transfers and mobility • Personal self-care activities such as eating, drinking, washing and dressing • Environmental issues to improve safety and motor function • Mental wellbeing, including cognition, emotional and/or neuro-psychiatric problems • Management of fatigue • Other (please specify)
2.9	Was all the information essential for OT assessment and intervention on referral?	• Yes, most of it • Yes, some of it • No
2.10	If 'no', what information was missing?	

2.11	As an occupational therapist, do you feel that the patient was referred at an appropriate time?	• Yes • No • Don't know
2.12	Were reports made back to the referrer/other key people at the conclusion of the intervention period (or interim reports where treatment lasts a longer time)?	• Yes • No, but will be done at the end of this intervention • No
3. Goals identified		
3.1a	What occupational goals were identified? Tick all that apply	• self-care • productivity • leisure
3.1b	Who identified goal(s)? Tick one	• Patient • Therapist • Family • Collaboration
3.2	End of life care – who identified goals? Tick one	• Patient • Therapist • Family • Collaboration • Not appropriate at this stage

4. Intervention strategies used		
4.1	Initiating and maintaining movement Tick all that apply	• Promoting occupational performance abilities through trial of intrinsic cueing techniques • Promoting functional abilities through trial of extrinsic cueing techniques • Promoting functional ability throughout a typical day, taking account of medication • Promoting functional ability throughout a typical day, taking into account fatigue • None of the above treatment strategies applicable
4.1a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)
4.2	Engagement, motivation, learning and carry-over Tick all that apply	• Promoting mental wellbeing • Promoting new learning • None of the above strategies applicable
4.2a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)

4.3	Environmental adaptations/assistive technology – did intervention include assessment for: Tick all that apply	• Small aids and adaptations • Wheelchair and seating • Major adaptations • Assistive technology • Other (please state) • None of the above treatment strategies applicable
4.3a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)
4.4	Ensuring community rehabilitation and social support – were referrals made to: Tick all that apply	• Social services OT • Social worker/carers • Other allied health professions • Respite care • Voluntary services • Access to work • Other (please state) • None of the above treatment strategies applicable
4.4a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)

4.5	Providing advice and guidance to support patient's self-management Tick all that apply	• Work advice and resources • Specific ADL techniques • Cognitive strategies • Fatigue management • Relaxation/stress management • None of the above treatments strategies applicable
4.5a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)
4.6	Providing information and support for family and carers Tick all that apply	• Optimising function • Safe moving and handling • Support services • Managing changes in mood, cognition or behaviour • Other (please state) • None of the above treatment strategies applicable
4.6a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)

4.7	Providing support to enable choice and control Tick all that apply	• Positive attitude/emotional set • Developing self awareness/ adjustment to limitations • Increasing confidence • Explore new occupations • Other (please state) • None of the above treatment strategies applicable
4.7a	If any specific treatment strategies above were applicable but not used, what was the reason for this?	• Lack of training in the technique • Lack of experience in the technique • Lack of time/not a priority • Lack of resources • Other (please state)
5. About the Occupational Therapist		
5.1	What is the NHS banding/social service grade of the person who assessed this person?	• 4 • 5 • 6 • 7 • 8a • 8b • 8c • Social service grade – junior occupational therapist • Social service grade – senior occupational therapist • Private practitioner
5.2	Approximately what percentage of people seen by the audited	• 0-19% • 20-39%

	therapist in a year have Parkinson's?	• 40-59% • 60-79% • 80-99% • 100% • Unknown
6. Evidence base		
6.1	Which of the following sources of information inform your clinical practice around the management of Parkinson's? Tick all that apply	• Clinical experience • Advice from colleague or supervisor • Recommendations given in OT Best Practice Guidelines? (Parkinson's UK & COT 2010) • Information from Parkinson's UK website • National Service Framework for Long term Conditions (2005) • NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017) • Published evidence in a peer reviewed journal • Training courses • Webinars, Social Media • None • Other (please specify)

UK PARKINSON'S
Excellence
Network

2017 UK Parkinson's Audit Physiotherapy

Standards and guidance

2017 UK Parkinson's Audit
Physiotherapy

Audit of national standards relating to Parkinson's care incorporating the Parkinson's NICE guideline and the National Service Framework for Long Term Neurological Conditions quality standards.

Aim

The aim of the physiotherapy audit is to establish if physiotherapy services are providing quality services for people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

Objectives

1. To evaluate if physiotherapy services are currently providing assessment and interventions appropriate to the needs of people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

2. To identify areas of good practice and areas for improvement to inform local, regional and UK-wide discussions leading to action plans to improve quality of care.

3. To establish baseline audit data to allow:
    - UK-wide mapping of variations in quality of care
    - local and UK-wide mapping of progress in service provision and patient care through participation in future audit cycles

Background

The Parkinson's physiotherapy audit is part of the UK Parkinson's Audit coordinated by Parkinson's UK and led by a steering group of professionals.

This is the fourth round in which physiotherapists will be able to take part, along with occupational therapists and speech and language therapists. Consultants in elderly care and neurology (and their Parkinson's nurses) can participate in the parallel patient management audit. The audit questions for this round of the audit have been refined to reflect feedback from the 2015 audit.

Standards

The Parkinson's NICE guideline[1] states that physiotherapy should be available for all people with Parkinson's, and that particular consideration should be given to:

- re-educating gait (improving balance and flexibility)
- enhancing aerobic capacity
- improving movement initiation
- improving functional independence (including mobility and activities of daily living)
- providing advice about safety at home

The National Service Framework for Long Term Neurological Conditions (NSF LTNC)[2] is a key tool for delivering the government's strategy to support people with long term conditions such as Parkinson's. In particular, aspects of the quality requirements 1, 4, 5 and 7 have been highlighted as important when considering the needs of people with long term conditions.

A group of key clinical, academic and research physiotherapists undertook work to adapt the Dutch guidelines for physical therapy in Parkinson's disease *Quick Reference Cards*[3], principally in relation to the use of outcome measures, for use by physiotherapists working with people with Parkinson's in the UK[4]. In addition, this group worked to provide standards for service delivery.

The *European Physiotherapy Guideline for Parkinson's Disease* [5] is an evidence-based guideline, which is an update of the Dutch guidelines, and was developed according to international standards, including practice recommendations for physiotherapists.

Methodology

This audit is open to all physiotherapy services and individual physiotherapists that work with people with Parkinson's in the UK, whether hospital or community based, clinic or domiciliary service (excluding acute hospital inpatients).

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[1] National Institute of Health and Clinical Excellence. *Parkinson's Disease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35.* (2006) Available at https://www.nice.org.uk/guidance/CG35

[2] Department of Health. *National Service Framework for Long Term Neurological Conditions*. (2005) Available at www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

[3] Keus S et al. 'Guidelines for physical therapy in patients with Parkinson's disease.' *Dutch Journal of Physiotherapy.* (2004) 114 (3): Supplement 1–94.

[4] Ramaswamy B et al. *Quick Reference Cards (UK) and guidance notes for physiotherapists working with people with Parkinson's disease.* (2009) Available at http://www.parkinsons.org.uk/content/quick-reference-cards-uk-physiotherapists

[5] Keus S et al. *European Physiotherapy Guideline for Parkinson's Disease.* (2014) KNGF/ ParkinsonNet, The Netherlands

Standards agreed to be pertinent to physiotherapy have been transformed into a set of audit standards and statements reviewed by specialist physiotherapists. The full list of questions is given in Table 1 (Service audit) and Table 2 (Patient audit) at the end of this document.

A process flow chart (*How do I take part?*) can be found on page X of this document. Please note the importance of logging your participation in this national clinical audit with your Audit Department.

Patient sample

The minimum audit sample size is 10 consecutive patients with idiopathic Parkinson's , referred to a physiotherapy service and seen during the audit data collection period, which runs from 1 May 2017 to 30 September 2017.

Take account of the need to capture this minimum sample when deciding locally on your start date for collecting a consecutive patient sample. The data collection tool will have the capacity to capture as many consecutive patients as therapists wish to audit.

The inclusion criteria for audited patients are as follows:

a) Patients who are currently receiving active intervention (including education/counselling) at the start of the audit period.

b) Those who are seen on review appointment (irrespective of whether they then go on to start another period of active treatment) during the audit period.

c) Patients newly referred to your service who undergo full assessment (again irrespective of whether they then proceed to immediate active intervention rather than being placed on review).

Data collection and entry

The audit tool contains three sections:

- A **service audit** section, which consists of some general questions about your service (which needs to be completed only once by a manager or senior colleague familiar with the service set-up and running).
- A **patient audit** section, which allows you to enter data on individual patients. These include both newly seen people with Parkinson's and follow ups, but each person should only be documented once, even if they attend more than once during this period.
- An **instant reporting** section, which will build automatically as you enter your data, and produces pie charts for selected questions.

In some circumstances, people may have to audit notes from across a department, although we would prefer that, where possible, information is audited from one specific service in a particular type of setting.

Ideally the person entering data on the tool should not be the person who completed the notes but this may not always be possible. When reviewing someone else's notes, it may be necessary to speak with the clinician or therapist who wrote them.

It is good practice for the auditor to keep the physiotherapy notes separate from the medical notes. If possible, both sets of notes should be used to complete the audit.

Patient data can be entered on the data collection tool which you have downloaded and saved locally and added to at your convenience. Complete a separate entry for each patient with Parkinson's. Remember to save the data each time you add new information.

Appendix A of this document is a version of the patient questions that you can print and use to record data in your clinics, if this would be useful.

A user guide for the data collection tool will be available, providing full instructions.

All data must be submitted by 30 October 2017. No submissions will be accepted after that date.

'No, but…' answers

This concept has been borrowed from the National Stroke Audit. A 'No, but…' answer implies there is a pre-determined accepted reason for non-compliance with the standard. The denominator for compliance can then be determined only for those patients where the standard was relevant – ie 'No, but…' answers can be removed from calculations of compliance.

Confidentiality

Patients

Please ensure that any information you submit for the audit does not include any personally identifiable information about your patients. Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it[6].

When you complete the patient section of the audit, you will see that there is space for a patient identifier. It is suggested that you use code letters or a number here to help you keep track (for example the patient's initials or hospital number). **This data will**

[6] Health Professionals Council. *Confidentiality – guidance for registrants*. (2012) Available at http://www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf [accessed 6 January 2017]

not be included in the data you submit to Parkinson's UK – the data collection tool will prevent this. It will help if you keep a list of the code letters or numbers securely yourself, so that if there is any query about the information you have submitted, you can track back to the original patient.

Employers
The Healthcare Quality Improvement Partnership (HQIP) recommends that services participating in a national clinical audit should be named in the audit reports. The audit reference report will list all participating organisations. It is therefore vital that you inform your clinical audit department about your participation in the audit.

Participants
Individual therapists who participate and submit data will not be named in the audit report.

Data Security

The data collection tool which will be available for download from the audit webpage will be password protected, allowing no one but eligible participants to enter and make changes to the data. The password will be emailed to the named lead for each service. Please make sure that the password is protected and can't be accessed by other people. To ensure the security of your data, we also advise you to save and use your version of the tool on a secure computer at work and not on your personal computer at home. We ask you to comply with your organisation's Data Protection guidelines at all times

After the data has been submitted to Parkinson's UK it will be stored in password-protected files at Parkinson's UK in accordance with NHS requirements. Within Parkinson's UK, access to the raw data set is restricted to Kim Davis, Clinical Audit Manager, members of the Clinical Steering Group and Alison Smith, the Data and Analytics Adviser.

Raw data will not be accessible in the public domain. Services will be asked to report any discrepancies in the data received by the audit team in a summary sheet before data analysis begins.

Patient Reported Experience Measure

All services participating in the audit are encouraged to participate in the Patient Reported Experience Measure (PREM). The PREM takes the form of a short paper questionnaire to be distributed to up to 50 consecutive patients between 1 May and 30 September 2017. These patients do not necessarily have to be those included in the main clinical audit.

The questionnaire asks 11 questions about patients' views of their Parkinson's service, and should take only five to 10 minutes to complete. If a carer has accompanied the patient on

their clinic visit, they may assist the patient in completion of the form. Patients should feel comfortable and not overlooked while completing their questionnaire.

No identifiable information is collected, and the patient will seal their completed questionnaire in the envelope provided. These envelopes will then need to be collected before the patient leaves the clinic, and all the envelopes will then be returned to the audit team at Parkinson's UK in the large postage-paid envelope provided.

Each service will be provided with the following resources:

- 50 x copies of a paper questionnaire.
- 50 x sealable envelopes.
- 50 x patient information leaflets.
- An A3 laminated poster.
- A large postage-paid envelope for return of sealed envelopes to the audit team.

A minimum of 10 questionnaires will need to be returned for a service's data to be included in the data analysis.

How the audit results will be communicated

The findings of both the clinical audit and the PREM will be presented in the form of a UK-wide summary report and an individual report for each service, benchmarking the results of individual services against the national average for each audit question in their specialty.

The summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. A bespoke patient and carer version of the summary report will also be produced, along with a reference report which will include all of the results, and a list of all participating services.

A link to the reports will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The reports will also be in the public domain via the Parkinson's UK website.

Data collected during the audit will be used to generate a national picture of service delivery and to compare this with the expectations detailed in national guidance. This data will provide valuable information about priority areas within the existing healthcare provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's.

The UK Parkinson's Excellence Network brings together health and social care professionals to transform the care that people with Parkinson's receive across the UK. The Network is there to ensure:

- that everyone affected by Parkinson's has access to high quality Parkinson's services that meet their needs. Their care should be delivered by an expert, integrated, multi-disciplinary team including a consultant, specialist nurse and

range of therapists, whose involvement is key to maximising function and maintaining independence
- there are clear pathways to timely, appropriate information, treatments and services from the point of diagnosis, including access to specialist mental health services and the full range of information and support to take control of the condition offered by Parkinson's UK
- services will be involved in continuous quality improvement through audit and engagement of service users in improvement plans

The data from the Physiotherapy audit will enable individual services to assess how well their service complies with guidance and whether physiotherapists working within that service are using appropriate outcome measures and treatment strategies. It will also give important information about access to training in Parkinson's related physiotherapy.

Participating in the PREM will give individual physiotherapy services direct feedback from their service users about the quality of care, accessibility and general satisfaction.

How do I take part

Am I eligible to take part?

Any healthcare professionals who work regularly with people with Parkinson's can take part. This includes speech and language therapists, physiotherapists, occupational therapists, Parkinson's nurses, neurologists and geriatricians. You need to submit data on a minimum of 20 (patient management) or 10 (therapies) patients seen during the audit period (1 May to 30 September 2017) for your data to be included in the audit.

How do I take part if I am eligible?

Register your service

Complete and submit a registration form at **parkinsons.org.uk/audit** by 31 March 2017 for each service you wish to audit. You will then be emailed a service number and a password for the data collection tool – you will need these to enter your audit data. In mid-April you will be sent an Audit Pack containing Patient and Carer Information Leaflets and the materials required for the Patient Reported Experience Measure (PREM).

Inform your audit department

Please log your participation in this clinical audit with your audit department and discuss with Information Governance to determine if Caldicott approval is required.

Establish a local audit project group

Include key professional and medical staff collecting data – discuss the logistics for running the audit, and plan for disseminating the results and action planning. Agree a start date for acquiring patient sample. Agree a target sample size.

Data collection

You will be able to download a copy of the data collection tool from parkinsons.org.uk/audit from mid-April 2017, along with a data collection tool. Data entry begins on 1 May 2017.

1. Enter brief details about your service (the Service Audit).
2. Enter details of consecutive patients seen during the audit period 1 May 2017 to 30 September 2017 (the Patient Audit).
3. During this period, hand out Patient Reported Experience Measure questionnaires to up to 50 consecutive patients – these do not need to be the same patients you include in the main audit.

More information

If you have any queries, or for more information, please contact Kim Davis, Clinical Audit Manager, on 020 7963 3916 or email **audit@parkinsons.org.uk**

Table 1: Physiotherapy Service Audit – questions, data items/answer options and help notes

No.	Question	Data items/ Answer options	Help notes
Your details			
1.1	Name of Lead Therapist completing the Service Audit	Free text	
1.2	Contact email of Lead Therapist	Free text	
Service Description			
2.1	Describe the setting in which you usually see individuals with Parkinson's	• Integrated medical and therapy Parkinson's clinic • In-patient acute service • In-patient rehabilitation service • Acute outpatient rehabilitation • Community rehabilitation service • Social services • Other (please specify)	Choose one – the most common setting for the service
2.2	Does your service specialise in the treatment of individuals with neurological conditions?	• Yes • No	
2.3	Does your service specialise in the treatment of individuals with Parkinson's?	• Yes • No	
Individuals with Parkinson's			
3.1	Approximately how many referrals of individuals with Parkinson's are	• Free text	New referrals, i.e. not those 'referred' for review who have previously been seen by

	made to your service per year?		this service.
3.2	Approximately what percentage of the individuals referred to your service annually have a diagnosis of Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-100%	
Physiotherapy professionals			
4.1	Within your service, can you access Parkinson's related continuing professional development (at least yearly)?	• Yes • No	Training includes in-service within the Trust/similar body/Board/Local Health Board or external courses
4.2	Are there any documented induction and support strategies for new physiotherapists working with individuals with Parkinson's?	• Yes • No	
4.3	What support (e.g. education, advice) is available to individual therapists working in the service?	• They can consult any member of the Parkinson's specialist MDT as they are a member themselves • They can consult members of a general neurology/elderly care specialist service of which they are a member • They do not work directly in specialist Parkinson's clinics but can readily access a Parkinson's specialist MDT/Parkinson's Nurse Specialist • They do not work directly in a specialist clinic but can readily access advice from a specialist neurology or elderly care MDT • They have no access to more specialised advice	Choose one

Clinical Practice			
5.1	How does your service offer assessment of a patient with Parkinson's?	• MDT assessment • Physiotherapy assessment • Other (please specify)	Tick all that apply
5.2	How do you usually see your clients with Parkinson's?	• Individually • In a group setting • Both individually and in groups	
5.3	If your intervention includes group work, what needs are addressed in these groups?	• Education • Exercise • No group work • Other (please specify)	

Table 2: Physiotherapy Patient Audit – questions, data items/answer options and help notes

No.	Question	Answer options	Help notes
1. Demographics			
1.1	Patient identifier	This can be used by you to identify audited patients	This data will be removed by the data entry tool when you submit your data
1.2	Gender	• Male • Female	

1.3	Ethnicity	• White
		  o British,
		  o Irish
		  o Traveller
		  o Any other White background)
		• Asian/Asian British
		  o Bangladeshi
		  o Chinese
		  o Indian
		  o Pakistani
		  o Any other Asian background
		• Black/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic backgrounds
		  o mixed - White and Black
		  o mixed White and Asian
		  o mixed any other background)
		• Other
		  o Arab
		  o Other	

		o prefer not to say)	
1.4	Year of birth		
1.5	What setting does this client live in?	• Own home • Residential care home • Nursing home • Other (please specify)	
1.6	In what health setting was the patient seen?	• NHS – inpatient • NHS – outpatient • NHS – Community • Private physiotherapy clinic • At home • Other (please state)	
1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative	**Definitions of phases** **Diagnosis** • From first recognition of symptoms/sign/problem • Diagnosis not established or accepted. **Maintenance** • Established diagnosis of Parkinson's • Reconciled to diagnosis • No drugs or medication 4 or less doses/day • Stable medication for >3/12 • Absence of postural instability. **Complex** • Drugs – 5 or more doses/day • Any infusion therapy (apomorphine or duodopa) • Dyskinesia • Neuro-surgery considered / DBS in situ • Psychiatric manifestations >mild symptoms of depression/anxiety/hallucinations/psychosis

			• Autonomic problems – hypotension either drug or non-drug induced • Unstable co-morbidities • Frequent changes to medication (<3/12) • Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues). **Palliative** • Inability to tolerate adequate dopaminergic therapy • Unsuitable for surgery • Advanced co-morbidity (life threatening or disabling).
2. Referral			
2.1	Year of Parkinson's diagnosis		
2.2	Has the person received previous physiotherapy specifically for Parkinson's?	• Yes, please go to Q 2.3 • No, please skip to Q 3 • Offered but declined • Unknown	This question asks whether the person with Parkinson's had physiotherapy specifically for Parkinson's before the current referral.
2.3	Date of the first referral letter	(dd/mm/yyyy)	We are trying to establish the length of time between diagnosis and first referral to physiotherapy. If the actual date is not known please give the estimated year of that initial referral in the following format - 01/07/2016 (for July 2016)
3. Time from referral to initial assessment			
3.1	Date of referral letter to this episode	(dd/mm/yyyy)	This is the date that the letter was written. If the actual date is not known please give the estimated month/year of that initial referral in the following format - 01/07/2016 (for July 2016). If your service runs a series of rolling appointments, rather than 'new' referrals, please use the date of the initial referral as long as this is within the last 18 months. If the patient initially was referred to your service more than 18 months ago, please exclude them from the audit.

3.2	Was the referral urgent or routine?	• Urgent • Routine • Unknown	Urgent or routine may be stated on referral letter or the physiotherapy department/ physiotherapist may have decided whether to treat as urgent of routine according to details in the letter
3.3	Date of initial physiotherapy assessment	(dd/mm/yyyy)	If the actual date is not known please give the estimated month/year of that initial referral in the following – 01/07/2016 (for July 2016).
3.4	Did it meet your local standard for time from referral to initial assessment for urgent or routine?	• Yes • No • No local standard	The department /physiotherapist may have a local standard of seeing people with Parkinson's within a certain time frame e.g. 4 weeks from receipt of referral
3.5	Were reports made back to the referrer/other key people at the conclusion of the intervention period (or in interim reports where treatment lasts a longer time)?	• Yes • No, but will be done at the end of this intervention • No	

The next set of questions captures implementation of national recommendations from NICE CG35, the NSF LTNC and the Quick Reference Cards (UK).

4. Implementation of national recommendations			
4.1	Do the physiotherapy notes include an action/goal plan?	• Yes • No	
4.2	Were outcome measures used in this case?	• Yes • No	
	If yes, please tick all that apply	• UPDRS • MDS – UPDRS	

		• Lindop Parkinson's Assessment (LPAS) • Berg • Six minute walk distance • 10 metre walk • Time Up and Go (TUG) • Modified Parkinson's Activity Scale (M-PAS) Gait • Modified Parkinson's Activity Scale (M-PAS) Chair • Modified Parkinson's Activity Scale (M-PAS) Bed • Activities Balance Confidence scale (ABC) • Retropulsion Test • Push & Release Test • Tragus to wall • Five times sit to stand test (FTSTS) • Dynamic Gait index • Functional Gait Assessment • New Freezing of Gait Questionnaire • Rapid turns test • History of Falls Questionnaire • 3-Step Falls Prediction model • Goal attainment scaling • The Falls Efficacy Scale - International (Short FES-I) • Mini BEST • EQ-5D tool • Patient Specific Index for Parkinson's Disease (PSI-PD) • Other (please list)	
5. About the physiotherapist			
5.1	What band (grade) is the physiotherapist who assessed this person?	• Band 4 • Band 5 • Band 6 • Band 7	

		• Band 8a • Band 8b • Band 8c • Other	
5.2	Approximately what percentage of people seen by the audited physiotherapist in a year have Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown	
6. Evidence base			
6.1	Which of the following did the physiotherapist use to inform clinical practice or guide intervention?	• Clinical experience • Advice from colleague or supervisor • European Physiotherapy Guideline for Parkinson's Disease (2013) • Quick Reference Cards (UK, 2009) • Information from Parkinson's UK website • NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017) • Published evidence in a peer reviewed journal (read within last 12 months) • Postgraduate training (e.g. attending courses/lectures specific to Parkinson's) within last 24 months • Other (please state) • None	Tick all that apply

Appendix A: Printable Patient Audit sheet

No.	Question	Answer options
1. Demographics		
1.1	Patient identifier	
1.2	Gender	• Male • Female
1.3	Ethnicity	• White o British, o Irish o Traveller o Any other White background) • Asian/Asian British o Bangladeshi o Chinese o Indian o Pakistani o Any other Asian background • Black/Black British o African o Caribbean o any other Black background • Mixed/multiple ethnic backgrounds o mixed - White and Black o mixed White and Asian o mixed any other background) • Other o Arab o Other prefer not to say)
1.4	Year of birth	
1.5	What setting does this client live in?	• Own home • Residential care home • Nursing home • Other (please specify)
1.6	In what health setting was the patient seen?	• NHS – inpatient • NHS – outpatient • NHS – Community • Private physiotherapy clinic • At home • Other (please state)
1.7	Parkinson's phase	

		• Diagnosis • Maintenance • Complex • Palliative
2. Referral		
2.1	Year of Parkinson's diagnosis	
2.2	Has the person received previous physiotherapy specifically for Parkinson's?	• Yes, please go to Q 2.3 • No, please skip to Q 3 • Offered but declined • Unknown
2.3	Date of the first referral letter	
3. Time from referral to initial assessment		
3.1	Date of referral letter to this episode If your service runs a series of rolling appointments, rather than 'new' referrals, please use the date of the initial referral as long as this is within the last 18 months. If the patient initially was referred to your service more than 18 months ago, please exclude them from the audit.	
3.2	Was the referral urgent or routine?	• Urgent • Routine • Unknown
3.3	Date of initial physiotherapy assessment	
3.4	Did it meet your local standard for time from referral to initial assessment for urgent or routine?	• Yes • No • No local standard
3.5	Were reports made back to the referrer/other key people at the conclusion of the intervention period (or in interim reports where treatment lasts a longer time)?	• Yes • No, but will be done at the end of this intervention • No

4. Implementation of national recommendations		
4.1	Do the physiotherapy notes include an action/goal plan?	• Yes • No
4.2	Were outcome measures used in this case?	• Yes • No
	If yes, please tick all that apply	• UPDRS • MDS – UPDRS • Lindop Parkinson's Assessment (LPAS) • Berg • Six minute walk distance • 10 metre walk • Time Up and Go (TUG) • Modified Parkinson's Activity Scale (M-PAS) Gait • Modified Parkinson's Activity Scale (M-PAS) Chair • Modified Parkinson's Activity Scale (M-PAS) Bed • Activities Balance Confidence scale (ABC) • Retropulsion Test • Push & Release Test • Tragus to wall • Five times sit to stand test (FTSTS) • Dynamic Gait index • Functional Gait Assessment • New Freezing of Gait Questionnaire • Rapid turns test • History of Falls Questionnaire • 3-Step Falls Prediction model • Goal attainment scaling • The Falls Efficacy Scale - International (Short FES-I) • Mini BEST • EQ-5D tool • Patient Specific Index for Parkinson's Disease (PSI-PD) • Other (please list)
5. About the physiotherapist		
5.1	What band (grade) is the physiotherapist who assessed this person?	• Band 4 • Band 5 • Band 6 • Band 7 • Band 8a • Band 8b • Band 8c • Other
5.2	Approximately what percentage of people	• 0-19%

	seen by the audited physiotherapist in a year have Parkinson's?	• 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown
6. Evidence base		
6.1	Which of the following did the physiotherapist use to inform clinical practice or guide intervention? Tick all that apply	• Clinical experience • Advice from colleague or supervisor • European Physiotherapy Guideline for Parkinson's Disease (2013) • Quick Reference Cards (UK, 2009) • Information from Parkinson's UK website • NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017) • Published evidence in a peer reviewed journal (read within last 12 months) • Postgraduate training (e.g. attending courses/lectures specific to Parkinson's) within last 24 months • Other (please state) • None

UK PARKINSON'S
Excellence
Network

2017 UK Parkinson's Audit
Speech and language therapy
Standards and guidance

2017 UK Parkinson's Audit
Speech and language therapy

Audit of national standards relating to Parkinson's care, incorporating the Parkinson's NICE guideline and the National Service Framework for Long Term Neurological Conditions quality standards

Aim

The aim of the speech and language therapy audit is to establish if speech and language therapy services are providing quality services for people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

Objectives

1. To evaluate if speech and language therapy services are currently providing assessment and interventions appropriate to the needs of people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

2. To identify areas of good practice and areas for improvement to inform local, regional and UK-wide discussions leading to action plans to improve quality of care.

3. To establish baseline audit data to allow:
    - UK-wide mapping of variations in quality of care
    - local and UK-wide mapping of progress in service provision and patient care through participation in future audit cycles

Background

The Parkinson's speech and language therapy audit is part of the UK Parkinson's Audit coordinated by Parkinson's UK and led by a steering group of professionals.

This is the fourth round in which speech and language therapists will be able to take part, along with occupational therapists and physiotherapists. Consultants in elderly care and neurology (and their Parkinson's nurses) can participate in the parallel patient management audit. The audit questions for this round of the audit have been refined to reflect feedback from the 2015 audit.

Standards

Various guidelines published in recent years offer recommendations for speech language therapists in the management of people with Parkinson's. These include in particular the Parkinson's NICE guideline[1] and sections/quality requirements of the National Service Framework for Long Term Neurological Conditions (NSF LTNC)[2].

The Royal College of Speech and Language Therapists (RCSLT) has also published guidelines pertinent to Parkinson's in their Clinical Guidelines documents[3] and Communicating Quality (CQ) Live[4]. The Dutch Speech Language Therapy organisation, in conjunction with the wider Parkinson Net organisation, has also published detailed speech and language therapy (SLT) guidelines for Parkinson's[5].

Methodology

This audit is open to all speech and language therapy services and individual speech and language therapists that work with people with Parkinson's in the United Kingdom whether hospital or community based, clinic or domiciliary service (excluding acute hospital inpatients).

Standards agreed to be pertinent to speech and language therapy have been transformed into a set of audit standards and statements reviewed by specialist speech and language therapists. The full list of questions is given in Table 1 (Service audit) and Table 2 (Patient audit) at the end of this document.

A process flow chart (*How do I take part?*) can be found on page X of this document. Please note the importance of logging your participation in this national clinical audit with your Audit Department.

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[1] National Institute of Health and Clinical Excellence. *Parkinson's Disease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (2006) Available at http://www.nice.org.uk/guidance/CG35

[2] Department of Health. *National Service Framework for Long Term Neurological Conditions*. (2005) Available at www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

[3] Royal College of Speech and Language Therapists/Speechmark. *Royal College of Speech and Language Therapists Clinical Guidelines (Dysarthria)* (2012)

[4] Royal College of Speech and Language Therapists. *Communicating Quality (CQ) Live.* Available at https://www.rcslt.org/cq_live/introduction

[5] H Kalf et al. *Logopedie bij de ziekte van Parkinson (Speech therapy in Parkinson's)*. Lemma (2008)

Patient sample

The minimum audit sample size is 10 consecutive people with idiopathic Parkinson's referred to a speech and language therapy service and seen during the audit data collection period, which runs from 1 May 2017 to 30 September 2017.

Take account of the need to capture this minimum sample when deciding locally on your start date for collecting a consecutive patient sample. The data collection tool will have the capacity to capture as many consecutive patients as therapists wish to audit.

The inclusion criteria for audited patients are as follows:

a) Patients who are currently receiving active intervention (including education or counselling) at the start of the audit period.
b) Those who are seen on a review appointment (irrespective of whether they then go to start another episode of active treatment) during the audit period.
c) Patients newly referred to your service who undergo full assessment (again irrespective of whether they then proceed to immediate active intervention rather than being placed on review).

Data collection and entry

The audit tool contains three sections:

- A **service audit** section, which consists of some general questions about your service (which needs to be completed only once by a manager or senior colleague familiar with the service set-up and running).

- A **patient audit** section, which allows you to enter data on individual patients. These include both newly seen people with Parkinson's and follow ups, but each person should only be documented once, even if they attend more than once during this period.

- An **instant reporting** section, which will build automatically as you enter your data, and produces pie charts for selected questions.

In some circumstances, people may have to audit notes from across a department, although we would prefer that, where possible, information is audited from one specific service in a particular type of setting.

Ideally the person entering data on the tool should not be the person who completed the notes but this may not always be possible. When reviewing

someone else's notes, it may be necessary to speak with the clinician or therapist who wrote them.

Patient data can be entered on the data collection tool which you have downloaded and, saved locally and added to at your convenience. Complete a separate entry for each patient with Parkinson's. Remember to save the data each time you add new information.

Appendix A of this document is a version of the patient questions that you can print and use to record data in your clinics, if this would be useful.

A user guide for the data collection tool will be available, providing full instructions and information.

All data must be submitted by 30 October 2017. No submissions will be accepted after that date.

'No, but…' answers

This concept has been borrowed from the National Stroke Audit. A 'No, but…' answer implies there is a pre-determined accepted reason for non-compliance with the standard. The denominator for compliance can then be determined only for those patients where the standard was relevant – ie 'No, but…' answers can be removed from calculations of compliance.

Confidentiality

Patients

Please ensure that any information you submit for the audit does not include any personally identifiable information about your patients. Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it[6].

When you complete the patient section of the audit, you will see that there is space for a patient identifier. It is suggested that you use code letters or a number here to help you keep track (for example the patient's initials or hospital number). **This data will not be included in the data you submit to Parkinson's UK – the data collection tool will prevent this.** It will help if you keep a list of the code letters or

[6] Health Professionals Council. *Confidentiality – guidance for registrants*. (2012) Available at http://www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf [accessed 6 January 2017]

numbers securely yourself, so that if there is any query about the information you have submitted, you can track back to the original patient.

Employers
The Healthcare Quality Improvement Partnership (HQIP) recommends that services participating in a national clinical audit should be named in the audit reports. The audit reference report will list all participating organisations. It is therefore vital that you inform your clinical audit department about your participation in the audit.

Participants
Individual therapists who participate and submit data will not be named in the audit report.

Data security

The data collection tool which will be available for download from the audit webpage will be password protected, allowing no one but eligible participants to enter and make changes to the spreadsheet. The password will be emailed to the named lead for each service. Please make sure that the password is protected and can't be accessed by other people. To ensure the security of your data, we also advise you to save and use your version of the tool on a secure computer at work and not on your personal computer at home. We ask you to comply with your organisation's Data Protection guidelines at all times.

After the data has been sent to Parkinson's UK it will be stored in password-protected files at Parkinson's UK in accordance with NHS requirements. Within Parkinson's UK, access to the raw data set is restricted to Kim Davis, Clinical Audit Manager, members of the Clinical Steering Group and Alison Smith, the Data and Analytics Adviser.

Raw data will not be accessible in the public domain. Services will be asked to report any discrepancies in the data received by the audit team in a summary sheet before data analysis begins.

Patient Reported Experience Measure

All services participating in the audit are encouraged to participate in the Patient Reported Experience Measure (PREM). The PREM takes the form of a short paper questionnaire to be distributed to up to 50 consecutive patients between 1 May and 30 September 2017. These patients do not necessarily have to be those included in the therapy audit.

The questionnaire asks 11 questions about patients' views of their Parkinson's service, and should take only five to 10 minutes to complete. If a carer has accompanied the

patient on their clinic visit, they may assist the patient in completion of the form. Patients should feel comfortable and not overlooked while completing their questionnaire.

No identifiable information is collected, and the patient will seal their completed questionnaire in the envelope provided. These envelopes will then need to be collected before the patient leaves the clinic, and all the envelopes will then be returned to the audit team at Parkinson's UK in the large postage-paid envelope provided.

Each service will be provided with the following resources:

- 50 x copies of a paper questionnaire.
- 50 x sealable envelopes.
- 50 x patient information leaflets.
- An A3 laminated poster.
- A large postage-paid envelope for return of sealed envelopes to the audit team.

A minimum of 10 questionnaires will need to be returned for a service's data to be included in the data analysis.

How the audit results will be communicated

The findings of both the clinical audit and the PREM will be presented in the form of a UK-wide summary report and an individual report for each service, benchmarking the results of individual services against the national average for each audit question in their specialty.

The summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. A bespoke patient and carer version of the summary report will also be produced, along with a reference report which will include all of the results, and a list of all participating services.

A link to the reports will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The report will also be in the public domain via the Parkinson's UK website.

Data collected during the audit will be used to generate a national picture of service delivery and to compare this with the expectations detailed in national guidance. This data will provide valuable information about priority areas within the existing healthcare provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's.

The UK Parkinson's Excellence Network brings together health and social care professionals to transform the care that people with Parkinson's receive across the UK. The Network is there to ensure:

- that everyone affected by Parkinson's has access to high quality Parkinson's services that meet their needs. Their care should be delivered by an expert, integrated, multi-disciplinary team including a consultant, specialist nurse and range of therapists, whose involvement is key to maximising function and maintaining independence
- there are clear pathways to timely, appropriate information, treatments and services from the point of diagnosis, including access to specialist mental health services and the full range of information and support to take control of the condition offered by Parkinson's UK
- services will be involved in continuous quality improvement through audit and engagement of service users in improvement plans

National surveys[7, 8] indicate that SLT provision for people with Parkinson's is highly variable across the country, with potential for improvement in many areas. This audit will allow SLT services to be audited in relation to NICE, NSF LTNC and other key national and international guidelines and enable SLT managers to compare their service with the pattern nationally of all responding SLT services. It will permit colleagues to identify strengths and key areas for development in both overall service organisation (service audit) and in individual case management (patient audit). Repeating the audit in subsequent years will enable services to chart maintenance of strengths and progress in the implementation of action plans.

Participating in the PREM will give individual speech and language therapy services direct feedback from their service users about the quality of care, accessibility and general satisfaction.

[7] Miller N., Noble E., Jones D., Deane K., Gibb C. (2011) 'Survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: patients' and carers' perspectives.' *International Journal of Language and Communication Disorders.* 46 (2):179-188.

[8] Miller N., Deane K., Jones D., Noble E., Gibb C. (2011) 'National survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: therapists' practices.' *International Journal of Language and Communication Disorders.* 46 (2):189-201.

How do I take part

Am I eligible to take part?

Any healthcare professionals who work regularly with people with Parkinson's can take part. This includes speech and language therapists, physiotherapists, occupational therapists, Parkinson's nurses, neurologists and geriatricians. You need to submit data on a minimum of 20 (patient management) or 10 (therapies) patients seen during the audit period (1 May to 30 September 2017) for your data to be included in the audit.

How do I take part if I am eligible?

Register your service

Complete and submit a registration form at **parkinsons.org.uk/audit** by 31 March 2017 for each service you wish to audit. You will then be emailed a service number and a password for the data collection tool – you will need these to enter your audit data. In mid-April you will be sent an Audit Pack containing Patient and Carer Information Leaflets and the materials required for the Patient Reported Experience Measure (PREM).

Inform your audit department

Please log your participation in this clinical audit with your audit department and discuss with Information Governance to determine if Caldicott approval is required.

Establish a local audit project group

Include key professional and medical staff collecting data – discuss the logistics for running the audit, and plan for disseminating the results and action planning. Agree a start date for acquiring patient sample. Agree a target sample size.

Data collection

You will be able to download a copy of the data collection tool from parkinsons.org.uk/audit from mid-April 2017, along with a data collection tool. Data entry begins on 1 May 2017.

1. Enter brief details about your service (the Service Audit).
2. Enter details of consecutive patients seen during the audit period 1 May 2017 to 30 September 2017 (the Patient Audit).
3. During this period, hand out Patient Reported Experience Measure questionnaires to up to 50 consecutive patients – these do not need to be the same patients you include in the main audit.

More information

If you have any queries, or for more information, please contact Kim Davis, Clinical Audit Manager, on 020 7963 3916 or email **audit@parkinsons.org.uk**

Table 1: Speech & Language Therapy Service Audit – questions, data items/answer options and help notes

No.	Question	Data items/ Answer options	Help notes
Your details			
1.1	Name of Lead Therapist completing the Service Audit	Free text	
1.2	Contact email of Lead Therapist	Free text	
1.3	What is your job description?	• Overall SLT (speech-language therapy) service manager • Parkinson's specialist SLT • Specialist SLT who sees patients with Parkinson's • Generalist SLT who sees patients with Parkinson's	
Service Description			
2.1	Describe the setting in which you usually see individuals with Parkinson's	• In a specialist clinic for people with Parkinson's • In more general neurology clinic • In an elderly care/older person's clinic • In SLT adult/acquired disorders service mainly based in a hospital • In SLT adult/acquired disorders service mainly based in a community clinic • In SLT adult/acquired disorders service mainly domicilary based • In generalist SLT service mainly based in a hospital	Choose one – the most common setting for the service

		• In generalist SLT service mainly based in a community clinic • In generalist SLT service mainly domiciliary based	
2.2	Does your service specialise in the treatment of individuals with neurological conditions?	• Yes • No	
2.3	Does your service specialise in the treatment of individuals with Parkinson's?	• Yes • No	
2.4	Does your service offer the Lee Silverman Voice Treatment (LSVT) for individuals with Parkinson's who meet inclusion criteria (louder voice stimulable; motivated; physically able to cope with intensity)?	• LSVT global prescribed service offered as required • Not all eligible candidates able to receive full service • Variant(s) of LSVT offered • LSVT not offered because there's no LSVT trained SLT • LSVT not offered because there's no service delivery decision	
2.5	Is SLT available for all individuals with Parkinson's for issues with communication irrespective of when in the course of their Parkinson's the referral was made?	• Full service, all referrals seen • Not full service, some patients not seen depending on stage of their Parkinson's • Not full service, restricted by number of hours assigned (e.g. patients can receive only 10 hours before discharge/re-referral/placed on review) • Not full service, some patients not seen depending on postcode/area • Not full service, some patients not seen depending on service (e.g. neurology vs elderly care • Not full service, some patients not seen	Tick all that apply

		depending on issue (e.g. communication vs swallowing) • Not full service, some patients not seen depending on prioritization in SLT Parkinson's service • Not full service, some patients not seen depending on prioritization in overall SLT service • No service	
2.6	Is SLT available for all individuals with Parkinson's for issues with eating/swallowing irrespective of when in the course of their Parkinson's the (re)referral was made?	• Full service available, all referrals seen • Not full service, some patients not seen depending on the stage of their Parkinson's • Not full service, restricted by number of hours assigned (e.g. patients can receive only 10 hours before discharge/re-referral/placed on review) • Not full service, some patients not seen depending on postcode/area • Not full service, some patients not seen depending on service (e.g. neurology vs elderly care • Not full service, some patients not seen depending on issue (e.g. communication vs swallowing) • Not full service, some patients not seen depending on prioritization in SLT Parkinson's service • Not full service, some patients not seen depending on prioritization in overall SLT service • No service	Tick all that apply
2.7	Is SLT available for all individuals with Parkinson's for issues with drooling irrespective of when in the course of their Parkinson's the (re)referral was made?	• Full service available, all referrals seen • Not full service, some patients not seen depending on the stage of their Parkinson's • Not full service, restricted by number of hours assigned (e.g. patients can receive only 10 hours before discharge/re-referral/placed on review)	Tick all that apply

		• Not full service, some patients not seen depending on postcode/area • Not full service, some patients not seen depending on service (e.g. neurology vs elderly care • Not full service, some patients not seen depending on issue (e.g. communication vs swallowing) • Not full service, some patients not seen depending on prioritization in SLT Parkinson's service • Not full service, some patients not seen depending on prioritization in overall SLT service • No service	
2.8	Are individuals who require assistive technology (AAC) able to receive timely, appropriate equipment to support them to live independently?	• Yes, it is part of the service • Yes, full access via other AAC service • Restricted AAC service due to financial restrictions • Restricted AAC service due to equipment range • Only able to access AAC if patient meets the complex technology specialist referral criteria applicable within the relevant devolved government • No service	
Individuals with Parkinson's			
3.1	Approximately how many referrals of individuals with Parkinson's are made to your service per year?	• Free text	New referrals, i.e. not those 'referred' for review who have previously been seen by this service
3.2	Approximately what percentage of	• 0-19%	

	the individuals referred to your service annually have a diagnosis of Parkinson's?	• 20-39% • 40-59% • 60-79% • 80-100%	
Speech and Language therapy professionals			
4.1	Within your service, can you access Parkinson's related continuing professional development (at least yearly)?	• Yes • No	Training includes in-service within the Trust/similar body/Board/Local Health Board or external courses, RCSLT CENs
4.2	Are there documented induction and support strategies for new SLT therapists working with individuals with Parkinson's?	• Yes, specifically in relation to patients with Parkinson's • Yes, as part of more general competencies • No	
4.3	What support (e.g. education, advice) is available to individual therapists working in the service?	• They can consult any member of the Parkinson's specialist MDT as they are a member themselves • They can consult members of a general neurology/elderly care specialist service of which they are a member • They do not work directly in specialist Parkinson's clinics but can readily access a Parkinson's specialist MDT/Parkinson's Nurse Specialist • They do not work directly in a specialist clinic but can readily access advice from a specialist neurology or elderly care MDT • There is access to motor speech disorder specialist colleagues in the SLT team • They have no access to more specialised advice • Work alone	Choose one

4.4	Are SLT assistants involved in the delivery of care to individuals with Parkinson's?	• Always • Sometimes • Never	
Clinical Practice			
5.1	Are individuals with Parkinson's within the local SLT service reviewed at between 6-12 monthly intervals?	• All patients in SLT service routinely reviewed within 6-12 months • Some patients reviewed at request of wider MDT/Parkinson's nurse • Some patients reviewed according to local prioritization • Patients are not automatically reviewed • No fixed time set for review • Patients are discharged after a set number of treatment sessions/ episode of care	
5.2	Are there specifically stipulated measures that must be carried out at initial assessment and at each review point?		
5.2a	Communication	• Standardised assessments of all speech/voice and language variables • Selective range of speech-voice and/or language formal assessments • Disease specific informal assessment proforma used • No specific assessments stipulated	
5.2b	Swallowing	• Standardised assessments of swallowing	

		• Selective range of formal assessments • Disease specific informal assessment proforma used • No specific assessments stipulated	
5.2c	Is saliva management included in the SLT assessment and treatment plan if required?	• Yes • No	

Table 2: Speech & Language Therapy Patient Audit – questions, data items/answer options and help notes

No.	Question	Answer options	Help notes
1. Demographics			
1.1	Patient identifier	This can be used by you to identify audited patients	This data will be removed by the data entry tool when you submit your data
1.2	Gender	• Male • Female	

1.3	Ethnicity	• White
		  o British,
		  o Irish
		  o Traveller
		  o Any other White background)
		• Asian/Asian British
		  o Bangladeshi
		  o Chinese
		  o Indian
		  o Pakistani
		  o Any other Asian background
		• Black/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic backgrounds
		  o mixed - White and Black
		  o mixed White and Asian
		  o mixed any other background)
		• Other
		  o Arab	

		o Other • prefer not to say	
1.4	Year of birth		
1.5	What setting does this patient live in?	• Own home • Residential care home • Nursing home • Other (please specify)	
1.6	In what health setting was the patient seen?	• NHS – inpatient • NHS – outpatient • NHS – Community • Private clinic • At home • Other (please state)	
1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative	**Definitions of phases** **Diagnosis** • From first recognition of symptoms/sign/problem • Diagnosis not established or accepted. **Maintenance** • Established diagnosis of Parkinson's • Reconciled to diagnosis • No drugs or medication 4 or less doses/day • Stable medication for >3/12 • Absence of postural instability. **Complex** • Drugs – 5 or more doses/day • Any infusion therapy (apomorphine or duodopa) • Dyskinesia • Neuro-surgery considered / DBS in situ • Psychiatric manifestations >mild symptoms of

			depression/anxiety/hallucinations/psychosis • Autonomic problems – hypotension either drug or non-drug induced • Unstable co-morbidities • Frequent changes to medication (<3/12) • Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues). **Palliative** • Inability to tolerate adequate dopaminergic therapy • Unsuitable for surgery • Advanced co-morbidity (life threatening or disabling).
2. Referral			
Standard A: 100% of people with Parkinson's must be reviewed at 6-12 monthly intervals. (Parkinson's NICE:R12, R77; NSF LTC:QR2)			
2.1	Year of Parkinson's diagnosis		
2.2	Date of first referral to SLT service involved in the current audit	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of diagnosis in the following format - July 2016 will be 01/07/2016.
2.3	Referred by:	• Elderly care clinic • General neurology clinic • Parkinson's nurse specialist • General/non PDNS nurse • Allied health professions colleague (PT, OT) • SLT colleague • Self/relative • Other (please specify)	

2.4	Reason for referral to service involved in the current audit	• General assessment opinion • Specific assessment opinion: breathing; voice; speech; swallowing; drooling; other • Treatment • Unknown	
2.5	Is this the first episode of SLT care for this patient in any SLT service?	• Yes • No • Not known	
2.6	When the person was first referred to any SLT service, at what stage of their Parkinson's were they?	• Diagnosis • Maintenance • Complex • Palliative • Not known	
2.7	Describe current episode of care	• Initial assessments only • Review appointment only • Group treatment only • Individual treatment only • Group and individual treatment • Other: specify	
2.8	Was the target time from referral to first SLT appointment met?	• Yes • No, and no reason documented for why • No, but reason documented (e.g. clinician leave)	
2.9	Was SLT intention to treat decision to first appointment wait time	• Yes • No, there was no intention to treat	

	target met?	• No, and no reason documented for why • No, but reason documented (e.g. failed appointment) • Service does not have prescribed target time	

3. Assessments

Standard B: It is recommended to make audio or video recordings of spontaneous speech (Dutch Guidelines: R9a, RCSLT Guidelines)

Standard C: It is recommended that the speech and language therapist expressly takes note of the individual's "on/off" periods during treatment (Dutch Guidelines:R6, R19b)

Standard D: A full profile of each individual's communication skills should be carried out to include at a minimum:

- **Strengths and needs**
- **Usage in current and likely environments**
- **Partner's own skills and usage**
- **Impact of environment on communication**
- **Identification of helpful or disadvantageous factors in environment**

(RCSLT Guidelines)

Standard E: Particular consideration should be given to review and management to support the safety and efficiency of swallowing and to minimise the risk of aspiration:

- **There should be early referral to SLT for assessment, swallowing advice and where indicated further instrumental assessment**
- **Problems associated with eating and swallowing should be managed on a case by case basis**
- **Problems should be anticipated and supportive measures employed to prevent complications where possible**

(RCSLT Guidelines)

3.1	Full assessment carried out on a first referral for communication	• Yes • No reference to assessments documented • No, but reasons for not appropriate to	If seen for swallow only, go to Q3.16

		assess documented • No, referred for swallow assessment only	
3.2	Full assessment carried out on a first referral for swallowing	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented • No, referred for communication assessment only	Swallowing also covers drooling
3.3	Assessment carried out at each review for communication?	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented • Initial assessment only • No, referred for swallow assessment only	If seen for swallow only, go to Q3.16
3.4	Assessment carried out at each review for swallowing?	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented • Initial assessment only • No, referred for communication assessment only	
3.5	Was an audio or video recording made at initial assessment and follow-	• Yes and available • Yes but not available • No, Trust/Board governance rules do	

	up referrals to the service being audited and is this available?	not permit acquisition or storage of digital data • No, client did not consent • No	
3.6	Are strengths and needs for communication in current and likely environments documented?	• All test scores and interpretation/implications documented • Limited information documented • No information documented	
3.7	Is there a clear plan of management based on assessment outcomes?	• All plans detailed in notes • Some restricted plans documented • No plans documented	
	Assessment of speech subsystems **Standard F: A perceptual assessment should be made, including respiration, phonation, resonance, articulation, prosody and intelligibility, to acquire an accurate profile for analysis (RCSLT Clinical Guidelines).**		
3.8	Are assessment results available for all speech subsystems for the initial assessment and all review appointments?	• Yes, subsystems assessed in both stimulated and unstimulated conditions • Restricted range of subsystems and/or conditions assessed, justification documented • Restricted range of subsystems and/or conditions assessed, justification not documented • No assessments documented, but with justification documented • No assessments and with no justification documented	

3.9	What tasks/contexts does assessment cover? (Tick all that apply)	• Speaking • Reading • Writing • One to one context • Group context	
3.10	Which voice-respiration and prosody parameters were assessed? (Tick all that apply)	• Loudness/amplitude level and variation • Pitch, pitch range and variation • Voice quality • Speech/articulation rate	
3.11	Was intelligibility assessed?	• Standardised diagnostic intelligibility test completed and score given • Informal assessment, non-standardised tool/subsection of other test completed and score given • Informal assessment (e.g. rating scale) completed • No assessment/results documented but justification given • No assessment documented and no justification given	
	Communication **Standard G: People with Parkinson's should be asked explicitly about difficulties with word finding and conversations (Dutch Guidelines: R11).**		
3.12	Was AAC identified and need addressed?	• Yes, fully • Yes, partially, awaiting action from outside AAC service • Yes, partially, limited range of AAC devices available • Not addressed as not indicated	

		• Indicated but no action documented	
3.13	Does assessment cover:		
3.13a	communication participation?	• Yes • No	
3.13b	the impact of Parkinson's on communication?	• Yes • No	
3.13c	the impact of communication changes on partner/carer?	• Yes • No • No carer	
	Results of assessment		
3.14	Were results and rationale for resulting actions (e.g. review period; intervention plans) conveyed and explained to patient and carer?	• Explanation of causal/maintaining factors aimed to patient and carer documented • No explanation made/documented but justification documented • No explanation made/documented and no justification documented	
3.15	Was information about communication and/or swallowing supplied by the therapist to the client (and, if relevant, carers) to help make informed decisions about care and treatment?	• Intervention specifically includes education and advice on self management and is documented • No explanation made/documented but justification documented • No explanation made/documented and no justification documented	

3.16	Where notes recommend onward referrals (e.g. ENT, video fluoroscopy), have these been made?	• Yes • None and reasons documented • None and reasons not documented • No onward referrals recommended	
4. Interventions			
Standard H: Speech and language therapists should give particular attention to improvement of vocal loudness, pitch range and intelligibility (NICE: R81). **Standard I: Speech and language therapists should report back to the referrer at the conclusion of an intervention period. Reports should detail intervention, duration, frequency, effects and expected prognosis (Dutch Guidelines: R2b).**			
4.1	Is intervention prophylactic and anticipative and not just symptomatic?	• Yes, education/planning for upcoming issues included • No, no prophylactic component indicated	
4.2	If a patient is in later stages, is there indication that there was earlier preparation for the current phase?	• Yes • No • Not referred in early stages • Patient not in later stages	
4.3	Which of the following does intervention target: (tick all that apply)	• Pitch (range) • Prosody • Improvement of vocal loudness • Strategies to optimise intelligibility • Patient seen for swallowing only	

4.4	Does intervention target features outside of direct speech/voice work? (Tick all that apply) Please specify if Other	• Patient education/advice • Managing patient participation • Managing patient impact • Managing generalisation outside clinic • Carer education/advice • Managing career impact • Other	
4.5	Were reports made back to the referrer/other key people at the conclusion of an intervention period (or when treatment lasts a longer time there are interim reports)?	• Yes • No	
4.5a	Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?	• Yes • No	
4.6	Do referral letters to other agencies contain the following? (Tick all that apply)	• Relevant history • Question(s) that the referrer wishes to have answered • Type of referral requested (e.g. single consultation for advice/initiation of treatment) • No need for onward referral currently indicated	
5. About the Speech and Language Therapist			
5.1	What is your NHS	• 5	

	banding/social service grade?	• 6 • 7 • 8a • 8b • 8c	
5.2	Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown	
6. Evidence base			
6.1	Which of the following sources of information inform your clinical practice around the management of Parkinson's?	• Own clinical experience • Advice from colleagues • RCSLT Clinical Guidelines (CQ Live) • RCSLT Communicating Quality Live • 2017 NICE Guideline: Parkinson's disease: Diagnosis and management in primary and secondary care and other relevant NICE guidelines • National Service Framework for Long Term Neurological Conditions (NSF – LTNC) guidelines • Published evidence in a peer reviewed journal • None • Other (please specify)	Tick all that apply

Appendix A: Printable Patient Audit sheet

No.	Question	Answer options
1. Demographics		
1.1	Patient identifier	
1.2	Gender	• Male • Female

1.3	Ethnicity	• White
		  o British,
		  o Irish
		  o Traveller
		  o Any other White background)
		• Asian/Asian British
		  o Bangladeshi
		  o Chinese
		  o Indian
		  o Pakistani
		  o Any other Asian background
		• Black/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic backgrounds
		  o mixed - White and Black
		  o mixed White and Asian
		  o mixed any other background)
		• Other
		  o Arab
		  o Other
		  o prefer not to say

1.4	Year of birth	
1.5	What setting does this patient live in?	• Own home • Residential care home • Nursing home • Other (please specify)
1.6	In what health setting was the patient seen?	• NHS – inpatient • NHS – outpatient • NHS – Community • Private clinic • At home • Other (please state)

1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative
2. Referral		
2.1	Year of Parkinson's diagnosis	
2.2	Date of first referral to SLT service involved in the current audit	
2.3	Referred by:	• Elderly care clinic • General neurology clinic • Parkinson's nurse specialist • General/non PDNS nurse • Allied health professions colleague (PT, OT) • SLT colleague • Self/relative • Other (please specify)
2.4	Reason for referral to service involved in the current audit	• General assessment opinion • Specific assessment opinion: breathing; voice; speech; swallowing; drooling; other • Treatment • Unknown
2.5	Is this the first episode of SLT care for this patient in any SLT service?	• Yes • No • Not known
2.6	When the person was first referred to any SLT service, at what stage of their Parkinson's were they?	• Diagnosis • Maintenance • Complex • Palliative • Not known
2.7	Describe current episode of care	• Initial assessments only • Review appointment only • Group treatment only • Individual treatment only

		• Group and individual treatment • Other: please specify
2.8	Was the target time from referral to first SLT appointment met?	• Yes • No, and no reason documented for why • No, but reason documented (e.g. clinician leave)
2.9	Was SLT intention to treat decision to first appointment wait time target met?	• Yes • No, there was no intention to treat • No, and no reason documented for why • No, but reason documented (e.g. failed appointment) • Service does not have prescribed target time
3. Assessments		
3.1	Full assessment carried out on a first referral for communication	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented • No, referred for swallow assessment only **If patient seen for swallow assessment only, please go to Question 3.14**
3.2	Full assessment carried out on a first referral for swallowing	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented • No, referred for communication assessment only
3.3	Assessment carried out at each review for communication?	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented • Initial assessment only • No, referred for swallow assessment only
3.4	Assessment carried out at each review for swallowing?	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented • Initial assessment only • No, referred for communication assessment only

3.5	Was an audio or video recording made at initial assessment and follow-up referrals to the service being audited and is this available?	• Yes and available • Yes but not available • No, Trust/Board governance rules do not permit acquisition or storage of digital data • No, client did not consent • No
3.6	Are strengths and needs for communication in current and likely environments documented?	• All test scores and interpretation/implications documented • Limited information documented • No information documented
3.7	Is there a clear plan of management based on assessment outcomes?	• All plans detailed in notes • Some restricted plans documented • No plans documented
	Assessment of speech subsystems	
3.8	Are assessment results available for all speech subsystems for the initial assessment and all review appointments?	• Yes, subsystems assessed in both stimulated and unstimulated conditions • Restricted range of subsystems and/or conditions assessed, justification documented • Restricted range of subsystems and/or conditions assessed, justification not documented • No assessments documented, but with justification documented • No assessments and with no justification documented
3.9	What tasks/contexts does assessment cover? (Tick all that apply)	• Speaking • Reading • Writing • One to one context • Group context
3.10	Which voice-respiration and prosody parameters were assessed? (Tick all that apply)	• Loudness/amplitude level and variation • Pitch, pitch range and variation • Voice quality • Speech/articulation rate
3.11	Was intelligibility assessed?	• Standardised diagnostic intelligibility test completed and score given • Informal assessment, non-standardised

		tool/subsection of other test completed and score given • Informal assessment (e.g. rating scale) completed • No assessment/results documented but justification given • No assessment documented and no justification given
	Communication	
3.12	Was AAC identified and need addressed?	• Yes, fully • Yes, partially, awaiting action from outside AAC service • Yes, partially, limited range of AAC devices available • Not addressed as not indicated • Indicated but no action documented
3.13	Does assessment cover:	
3.13a	communication participation?	• Yes • No
3.13b	the impact of Parkinson's on communication?	• Yes • No
3.13c	the impact of communication changes on partner/carer?	• Yes • No • No carer
	Results of assessment	
3.14	Were results and rationale for resulting actions (e.g. review period; intervention plans) conveyed and explained to patient and carer?	• Explanation of causal/maintaining factors aimed to patient and carer documented • No explanation made/documented but justification documented • No explanation made/documented and no justification documented
3.15	Was information about communication and/or swallowing supplied by the therapist to the client (and, if relevant, carers) to help make informed decisions about care and treatment?	• Intervention specifically includes education and advice on self management and is documented • No explanation made/documented but justification documented • No explanation made/documented and no justification documented
3.16	Where notes recommend onward	• Yes

	referrals (e.g. ENT, video fluoroscopy), have these been made?	• None and reasons documented • None and reasons not documented • No onward referrals recommended
4. Interventions		
4.1	Is intervention prophylactic and anticipative and not just symptomatic?	• Yes, education/planning for upcoming issues included • No, no prophylactic component indicated
4.2	If a patient is in later stages, is there indication that there was earlier preparation for the current phase?	• Yes • No • Not referred in early stages • Patient not in later stages
4.3	Which of the following does intervention target: (tick all that apply)	• Pitch (range) • Prosody • Improvement of vocal loudness • Strategies to optimise intelligibility • Patient seen for swallowing only
4.4	Does intervention target features outside of direct speech/voice work? (Tick all that apply)	• Patient education/advice • Managing patient participation • Managing patient impact • Managing generalisation outside clinic • Carer education/advice • Managing career impact • Other (please specify)
4.5	Were reports made back to the referrer/other key people at the conclusion of an intervention period (or when treatment lasts a longer time there are interim reports)?	• Yes • No
4.5a	Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?	• Yes • No
4.6	Do referral letters to other agencies contain the following? (Tick all that apply)	• Relevant history • Question(s) that the referrer wishes to have answered

		• Type of referral requested (e.g. single consultation for advice/initiation of treatment) • No need for onward referral currently indicated
5. About the Speech and Language Therapist		
5.1	What is your NHS banding/social service grade?	• 5 • 6 • 7 • 8a • 8b • 8c
5.2	Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown
6. Evidence base		
6.1	Which of the following sources of information inform your clinical practice around the management of Parkinson's? Tick all that apply	• Own clinical experience • Advice from colleagues • RCSLT Clinical Guidelines (CQ Live) • RCSLT Communicating Quality Live • 2017 NICE Guideline: Parkinson's disease: Diagnosis and management in primary and secondary care and other relevant NICE guidelines • National Service Framework for Long Term Neurological Conditions (NSF – LTNC) guidelines • Published evidence in a peer reviewed journal • None • Other (please specify)

UK PARKINSON'S Excellence Network

2017 UK Parkinson's Audit – patient reported experience measure (PREM) questionnaire

The service code **must** be entered here by healthcare staff before handing to the patient or carer:

About the patient

I am the **patient** ☐

I am the **patient's carer** ☐ (If so, please complete on the patient's behalf)

1. Age

Under 20 ☐ 20 – 29 ☐ 30 – 39 ☐ 40 – 49 ☐

50 – 59 ☐ 60 – 69 ☐ 70 – 79 ☐ 80 – 89 ☐ Over 90 ☐

2. Gender

Male ☐ Female ☐

Other ☐ Prefer not to say ☐

3. Ethnicity

White (British, Irish, Traveller, any other White background ☐

Asian/Asian British/Bangladeshi/Chinese/Indian/Pakistani/any other Asian background ☐

Black/Black British (African/Caribbean/any other Black background ☐

Mixed/multiple ethnic backgrounds (mixed White and Black/mixed White and Asian/ mixed any other background) ☐

Other (Arab/other/prefer not to say) ☐

4. What are your living arrangments?

I live with my husband/wife/partner ☐

I live with other family/friends ☐

I live on my own ☐

I live in a care home ☐

Other (specify) .....

5. How long ago were you diagnosed?

Less than 2 years ☐

2-10 years ☐

11-20 years ☐

20 years and over ☐

6. Approximately how long have you been attending your current Parkinson's service?

Less than 1 year ☐ 1 – 2 years ☐ 3 – 5 years ☐ More than 5 years ☐

About your Parkinson's service

7. Do you feel the amount of times you see your consultant or Parkinson's nurse (if you have one) for a review at a face-to-face appointment or by telephone meets your needs?

	Yes	No – less than I need	No – more than I need	No access
Consultant				
Parkinson's nurse				

8a. Are you able to access the following services?

	Yes	No - but have tried	No – don't need it	Not sure
Parkinson's nurse				
Occupational therapist				
Physiotherapist				
Speech and language therapist				

8b. If using any of these services, are you able to contact them between scheduled reviews?

	Yes	No	I don't need it	Not sure
Parkinson's nurse				
Occupational therapist				
Physiotherapist				
Speech and language therapist				

9. How would you rank the quality of service provided by the various parts of your Parkinson's service?

	Excellent	Good	Fair	Poor	Very poor	I don't use this service	Not sure
Consultant							
Parkinson's nurse							
Occupational therapist							
Physiotherapist							
Speech and language therapist							

10. Thinking back to when you were diagnosed, do you think you were given enough information about Parkinson's?

Yes ☐ No ☐ Not sure ☐

When being prescribed new medication, do you feel you are given enough information, including potential side-effects?

Yes ☐ No ☐ Not sure ☐ I haven't started any medication ☐

11. Does your Parkinson's service give you information about:

	Yes	No	Not sure
How to access Parkinson's UK support services			
The role of social workers and other professionals who support people with Parkinson's			
Support for carers			
How to take part in clinical trials			

12. Have you raised concerns and/or been asked if you have any concerns regarding: (tick all that apply)

Balance and falls ☐
Mood and memory (e.g. anxiety, depression) ☐
Speech, swallowing or salivary (drooling) problems ☐
Bladder problems ☐
Your bowels (constipation) ☐
Sleep ☐
Uncontrollable movements (e.g. tremor, dyskinesia) ☐

13. If you are a driver, have you been given verbal and/or written advice by your Parkinson's service about contacting the DVLA and your car insurance company?

Yes ☐
No ☐
Not sure ☐
Not a driver ☐

14. Do you feel your Parkinson's service involves you in decisions about your care?

Always ☐
Mostly ☐
Sometimes ☐
Rarely ☐
Never ☐
Not sure ☐

Do you feel listened to?

Always ☐
Mostly ☐
Sometimes ☐
Rarely ☐
Never ☐
Not sure ☐

15. Have you been admitted to hospital in the last 12 months?

Yes ☐
No ☐

(If no, please go to Question 16)

If yes, how often did you receive your Parkinson's medication on time?

- Always ☐
- Mostly ☐
- Sometimes ☐
- Rarely ☐
- Never ☐
- Not sure ☐

If you didn't get your Parkinson's medication on time in hospital, to what extent did this affect your condition?

- It had a significant negative effect ☐
- It had a negative effect ☐
- It had no effect ☐
- It had a positive effect ☐
- Not sure ☐

While in hospital, did you want to manage and take your own Parkinson's medication which you brought from home?

Yes ☐ No ☐

Was it possible for you to manage and take your own Parkinson's medication in hospital?

Yes ☐ No ☐ Not sure ☐

16. Do you feel your Parkinson's service treats you as an individual, taking into account your own unique concerns and cultural needs (this may include other conditions you have, if relevant)?

- Always ☐
- Mostly ☐
- Sometimes ☐
- Rarely ☐
- Never ☐
- Can't say ☐

17. Do you feel that your Parkinson's service is:

- Improving ☐
- Staying the same – already good ☐
- Staying the same – needs to improve ☐
- Getting worse ☐

We would be pleased to hear any other views you may have about your Parkinson's service:

Please now put your questionnaire in the envelope provided, seal the envelope and return it to the person who gave it to you.
Many thanks for taking the time to complete this questionnaire.

Acknowledgements

The work of the following groups and individuals was central to the successful running of the 2017 UK Parkinson's Audit:

Governance Board:

Dr Anne-Louise Cunnington – Clinical Lead

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

Fiona Lindop – Clinical Steering Group representative

Lisa Brown – Parkinson's Nurse representative

Val Buxton – Director of Strategic Intelligence and Excellence, Parkinson's UK

Daiga Heisters – Head of UK Parkinson's Excellence Network, Parkinson's UK

Cathal Doyle – Head of Strategic Intelligence

Kim Davis – Clinical Audit Manager, Parkinson's UK

Elaine Evans – User representative

Clinical Steering Group:

Dr Anne-Louise Cunnington – Elderly Care

Dr Rob Skelly – Elderly care

Dr Sara Evans – Elderly care

Dr Veronica Lyell – Elderly care

Dr Donald Grosset - Neurology

Dr Nin Bajaj – Neurology

Dr Paul Worth - Neurology

Paul Cooper – Occupational therapy

Hannah Reynolds – Speech and language therapy

Dr Julia Johnson – Speech and language therapy

Fiona Lindop – Physiotherapy

Lisa Brown – Parkinson's Nurse

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Nick Wingrave

Data analysis:

Sigita Konstancija – Acting Data and Analytics Advisor, Parkinson's UK

Reporting Group:

Membership as per Clinical Steering Group, with the addition of:

Kate Hayward – Occupational therapy

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

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

UK PARKINSON'S
Excellence
Network