UK PARKINSON'S
Excellence
Network

2015 UK Parkinson's Audit
Reference Report

Contents

Foreword

The 2015 Parkinson's Audit provides the largest dataset yet obtained about the quality of care provided to people with Parkinson's across the UK. The unprecedented level of participation in the 2015 audit demonstrates the dedication and commitment of UK doctors, nurses, occupational therapists, physiotherapists and speech and language therapists to improving services for people with Parkinson's.

As in 2012, this summary report highlights that healthcare professionals are working to evidence-based standards and it confirms many areas of good practice.

For the first time the views of people with Parkinson's have been gathered as part of the audit process and their responses back up evidence of good practice. For example, 73% of respondents felt that the number of times that they were reviewed by their Consultant met their needs. Furthermore, an overwhelming number of comments made about the quality of service received were positive.

But this report shows that there are still important areas for improvement. For example, only 50% of patients reported getting their medication consistently on time whilst in hospital.

Access to a full multidisciplinary team of professionals is limited, with only 13% of services able to offer a fully integrated clinic model. Only 50% of patients are referred to a physiotherapist within two years of diagnosis, whilst only 13% of Speech and Language therapy services offered regular 6-12 month reviews. Occupational therapy services need to adopt standardised assessments more widely in order to achieve clear outcome measures for people with Parkinson's.

Assessment of several non-motor areas could still be improved, particularly in the documentation of potential side effects relating to dopamine agonists and enquiries about pain. Given how frequent falls are in people with Parkinson's, lack of attention to bone health also emerges as an area of concern.

It's vital that the audit findings are now used to drive improvements in services.

The results of the 2015 audit will provide a road map for the UK Parkinson's Excellence Network, which brings together the enthusiasm and knowledge of healthcare professionals, the resources and expertise of Parkinson's UK, and the voice of people with Parkinson's to bring about the change that's needed. This audit has played a central role in identifying key challenges and inequalities in Parkinson's services. Now we need to align our efforts, tackling these challenges together through the Excellence Network. Only then will we make progress on the scale needed to achieve quality services for everyone across the UK living with this hugely complex condition.

Introduction

This report outlines the findings of the 2015 UK Parkinson's Audit. A briefer Summary Report of the key audit results is also available.

The 2015 audit (the fifth to be completed) represents the largest audit of Parkinson's to date, with a 63% increase in the number of services taking part. It is also the first to include a Patient Reported Experience Measure (PREM), obtained by directly surveying clinic patients. In this report we present the complete PREM results.

Background

The UK-wide clinical audit was originally developed to address the concerns of professionals, patients and their representatives about the quality of care provided to people with Parkinson's. The audit uses evidence-based clinical guidelines as the basis for measuring the quality of care (we provide a list of the guidelines in this report).

The design of the audit has been changed from year-to-year, reflecting 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. This report therefore draws on separate service audits and care available to people with Parkinson's from doctors, Parkinson's nurses, occupational therapists, physiotherapists, and speech and language therapists. Where relevant, the results are compared with those from the 2012 audit.

This audit report is particularly timely, since the audit's launch was close to the launch of the UK Parkinson's Excellence Network in February 2015. The audit will serve two main roles within the Excellence Network. First, it will provide an important baseline against which progress can be measured. Second (and related) it will guide the formulation of both UK-wide and regional service improvement plans, in collaboration with colleagues involved in the Network.

Executive Summary

This executive summary summarises the key findings of the 2015 UK Parkinson's Audit. The audit is intended to measure the quality of care provided to people living with Parkinson's in comparison with a range of evidence-based guidance relating to the care of people with the condition.

This UK audit takes a multi-professional approach, involving Elderly Care[1] and Neurology consultants who care for people with movement disorders, Parkinson's nurses, and occupational therapists, physiotherapists and speech and language therapists who also care for people with Parkinson's. The audit engages services within these professions to measure the quality of their practice, within their model of care provision.

This audit reports on the care provided to 8,846 people with Parkinson's during the five month data collection period. This is more than double the number of patients in the 2012 audit.

In addition, 5,834 people with Parkinson's and their carers contributed to the PREM questionnaire, giving them an opportunity to provide their views of the service they attend.

Key messages:

The audit identified several areas of good practice and shortcomings in the services audited. Across all service areas, it identified a need for improvements in the following:

- Integrated services.
- Standardised practices.
- Communication and information sharing.
- Inpatient management.
- Anticipatory care planning.

Elderly Care and Neurology

Evidence of good practice

- Timely specialist review.
- Clear documentation of current Parkinson's medications.
- Documentation of advice given regarding potential adverse effects of new medication.

Shortcomings

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

- Lack of integrated clinics.
- Lack of documentation of discussions of excessive daytime sleepiness, and its relevance to driving.
- Poor documentation of the potential of impulse control disorders in those taking a dopamine agonist.
- Blood pressure poorly recorded in Neurology clinics. Pain and saliva poorly recorded generally.
- Lack of advance care planning.
- Poor management of bone health in both Elderly Care and Neurology.
- Underuse of Parkinson's local advisers (previously called Information and Support Workers).

Occupational therapy

Evidence of good practice

- Appropriate timing of referral to Occupational therapy in the majority of people referred.
- Availability of information essential for Occupational therapy assessment and intervention.
- Uptake of Parkinson's-related Continuing Professional Development (CPD).
- Use of evidence to inform clinical practice.

Shortcomings

- Inconsistent use of appropriate standardised assessments for people with Parkinson's based on best practice.
- Lack of an integrated model of service delivery.

Physiotherapy

Evidence of good practice

- Increased number of physiotherapists undertaking Parkinson's-related CPD.
- Use of good quality resources to guide clinical practice.
- Reduced waiting time between diagnosis and initial Physiotherapy referral.

Shortcomings

- Inconsistent use of appropriate standardised assessments for people with Parkinson's based on best practice.

- Low number of people with Parkinson's referred to Physiotherapy within a year of diagnosis.
- Significant number of physiotherapists not using outcome measures.

Speech and Language therapy

Evidence of good practice

- Availability of services for both communication and swallowing changes.
- Time taken from referral to receiving an appointment.
- Completeness of assessment on first referral.

Shortcomings

- Inconsistent use of appropriate standardised assessments for people with Parkinson's based on best practice.
- Failure to fully document test results on which management plans/reports are based.
- Proportion of people referred who have progressed beyond the initial stages of their Parkinson's.
- Variability in review policies.

Patient Reported Experience Measure (PREM)

Areas of satisfaction

- Most people with Parkinson's or carers were satisfied with the frequency of review by medical staff and their Parkinson's nurse.
- Over three-quarters rated the service received from medical staff and their Parkinson's nurse as excellent or good.
- Most people with Parkinson's felt listened to always or most of the time.

Areas of concern

- Only two-thirds felt they received enough information about Parkinson's at diagnosis.
- Of those who responded, a quarter had either not been given information regarding contacting their driving licence authority or their insurance company, or they were unsure whether they had.

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 2015 to 30 September 2015. 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 2015. These patients did not necessarily have to be those included in the main clinical audit.

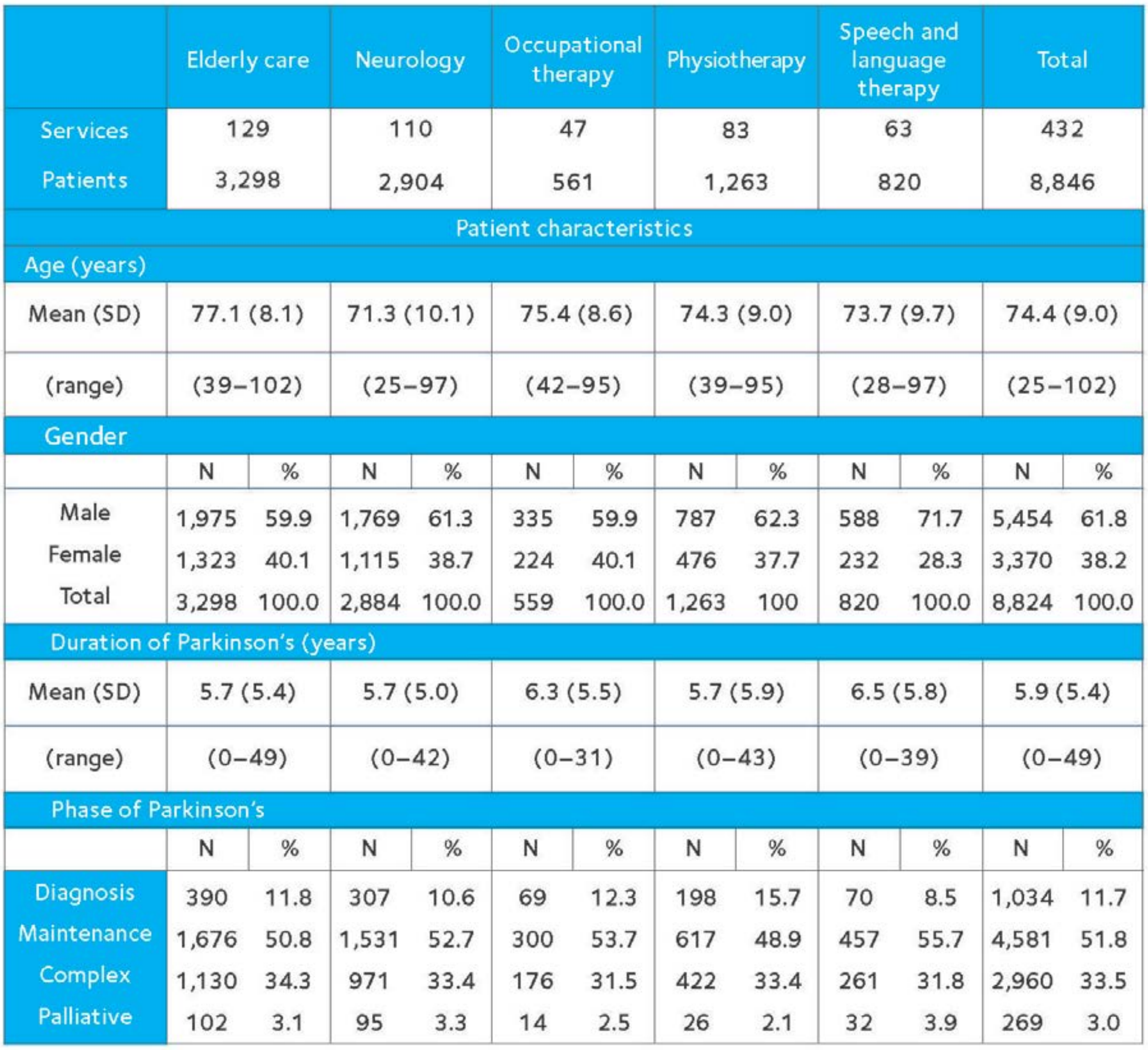
The questionnaire asked 11 questions about patients’ views of their Parkinson’s service. If a carer accompanied the patient on their clinic visit, they could assist the patient in completion of the form.

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

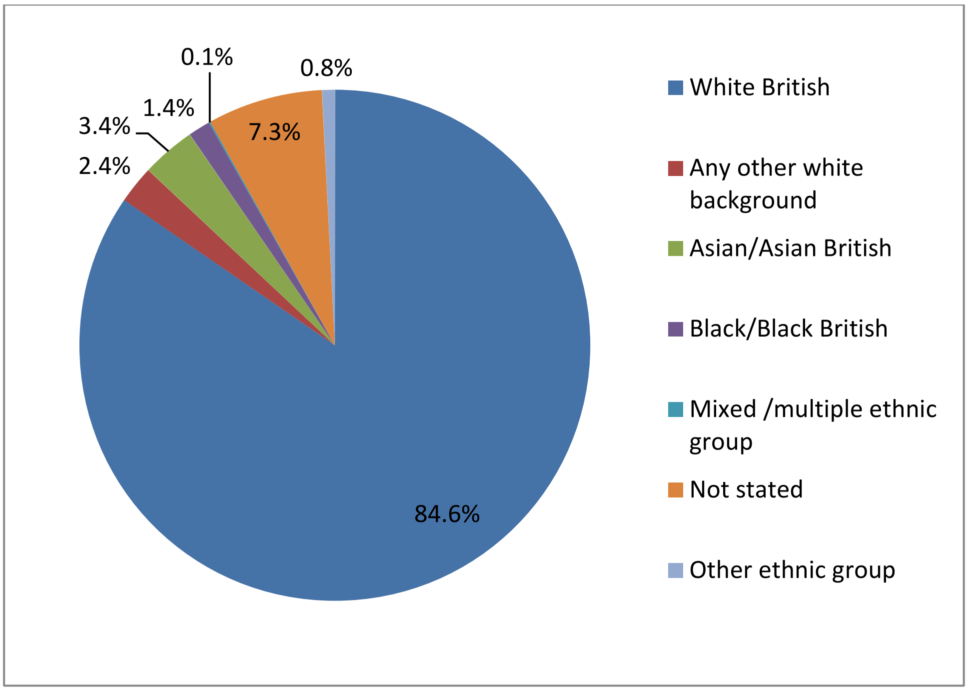


	Elderly care		Neurology		Occupational therapy		Physiotherapy		Speech and language therapy		Total	
Services	129		110		47		83		63		432	
Patients	3,298		2,904		561		1,263		820		8,846	
Patient characteristics												
Age (years)												
Mean (SD)	77.1 (8.1)		71.3 (10.1)		75.4 (8.6)		74.3 (9.0)		73.7 (9.7)		74.4 (9.0)	
(range)	(39–102)		(25–97)		(42–95)		(39–95)		(28–97)		(25–102)	
Gender												
	N	%	N	%	N	%	N	%	N	%	N	%
Male	1,975	59.9	1,769	61.3	335	59.9	787	62.3	588	71.7	5,454	61.8
Female	1,323	40.1	1,115	38.7	224	40.1	476	37.7	232	28.3	3,370	38.2
Total	3,298	100.0	2,884	100.0	559	100.0	1,263	100	820	100.0	8,824	100.0
Duration of Parkinson's (years)												
Mean (SD)	5.7 (5.4)		5.7 (5.0)		6.3 (5.5)		5.7 (5.9)		6.5 (5.8)		5.9 (5.4)	
(range)	(0–49)		(0–42)		(0–31)		(0–43)		(0–39)		(0–49)	
Phase of Parkinson's												
	N	%	N	%	N	%	N	%	N	%	N	%
Diagnosis	390	11.8	307	10.6	69	12.3	198	15.7	70	8.5	1,034	11.7
Maintenance	1,676	50.8	1,531	52.7	300	53.7	617	48.9	457	55.7	4,581	51.8
Complex	1,130	34.3	971	33.4	176	31.5	422	33.4	261	31.8	2,960	33.5
Palliative	102	3.1	95	3.3	14	2.5	26	2.1	32	3.9	269	3.0

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

Definitions of the phases of Parkinson's can be found at Appendix A.

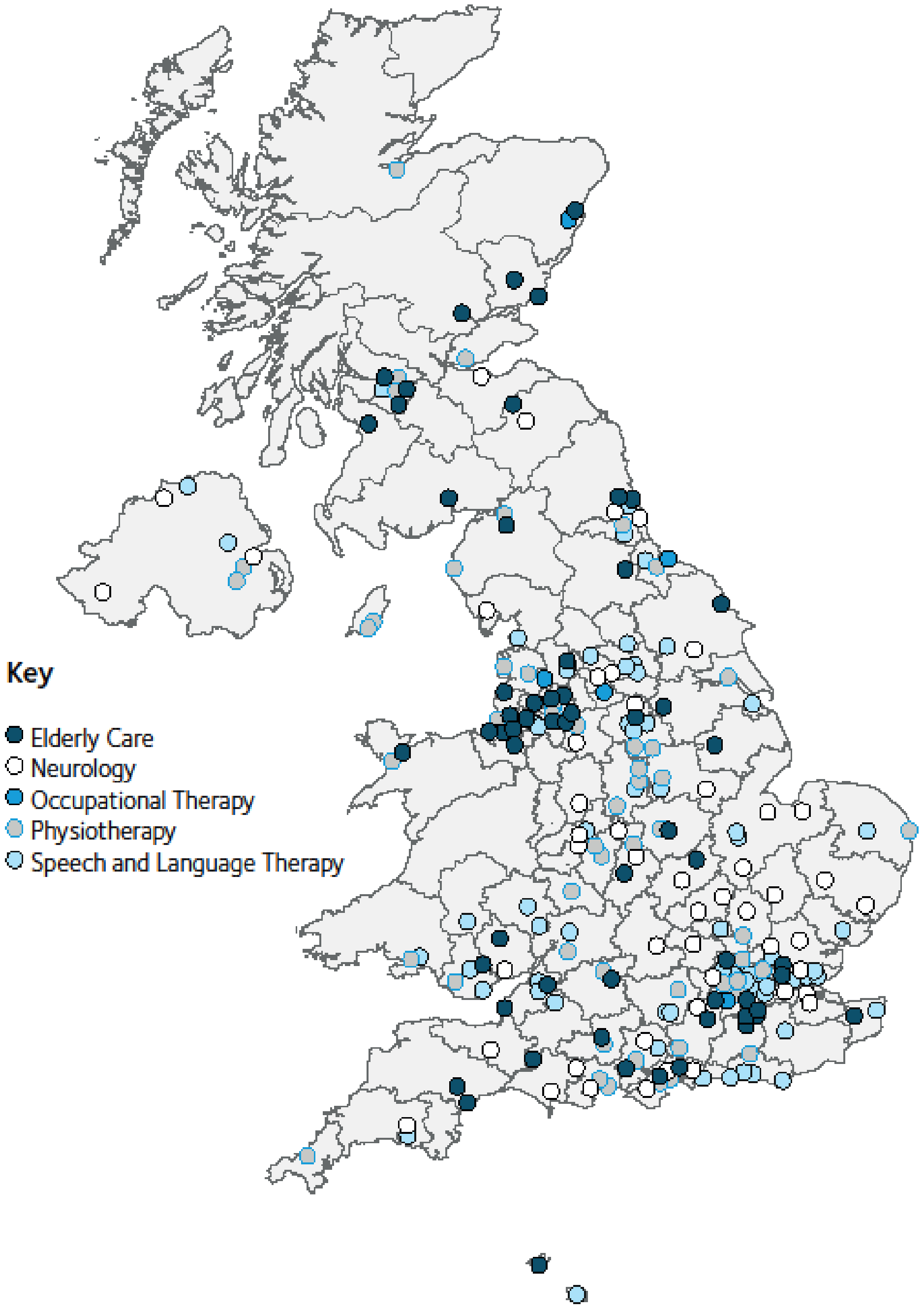
Figure 1: Ethnicity of people with Parkinson’s included in the audit



PREM

In addition to the audit data, 5,834 people with Parkinson’s and their carers attending 225 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.

Parkinson's Audit –
Participating services



Note: Some circles overlap so not all services are visible. A complete list of participating services is available at Appendix B.

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 and Neurology clinics, and also to describe the models of service delivery used. They allow benchmarking of services against good practice standards and guidance relating to the quality of care for people with Parkinson’s. The Standards and Guidance document for Elderly Care and Neurology can be found at Appendix C.

Demographics

Elderly Care and Neurology services saw 6,202 people with Parkinson’s who were included in the audit. These patients were aged between 39 and 102 years (mean: 74.4 years; standard deviation [SD] 9.6 years), and the majority were male (60.6%).

Table 2: Gender of Elderly Care and Neurology patients

Gender	Elderly Care	Neurology	Elderly Care and Neurology
Male	59.9%	61.3%	60.6%
Female	40.1%	38.7%	39.4%
Number:	3298	2884	6182

Table 3: Ethnicity of Elderly Care and Neurology patients

Ethnicity	Elderly Care	Neurology	Elderly Care and Neurology
White British	85.8%	81.1%	83.6%
Any other White background	2.0%	3.3%	2.6%
Black/Black British	0.9%	1.9%	1.4%
Asian/Asian British	2.3%	5.0%	3.6%
Mixed/multiple ethnic group	0.1%	0.1%	0.1%
Not stated	8.1%	7.7%	7.9%
Other ethnic group	0.8%	0.9%	0.9%
Number:	3298	2904	6202

Patients seen at Neurology services (mean age: 71.3 years; SD 10.1 years) tended to be younger than in Elderly Care (mean age: 77.1 years; SD 8.1 years).

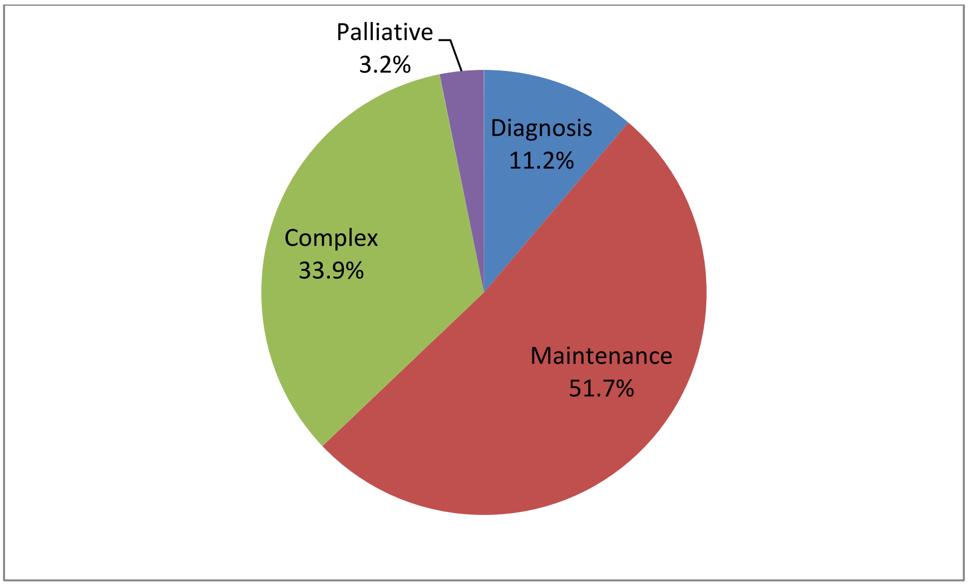
Mean age at diagnosis was 68.6 years (SD 10.9 years) (Elderly Care: 71.3 [SD 9.9]; Neurology: 65.5 [SD 11]), and patients audited had a mean disease duration of 5.7 years (SD 5.2; range 0–49 years). The distributions of phase of Parkinson's were very similar across Elderly Care and Neurology audits (see Figure 2).

The majority of patients included in this audit cycle were either in the maintenance or complex stage. Only 3.2% were in the palliative phase.[2]

Table 4: Parkinson's phase of Elderly Care and Neurology patients

Parkinson's phase	**Elderly Care**	**Neurology**	**Elderly Care and Neurology**
Diagnosis	11.8%	10.6%	11.2%
Maintenance	50.8%	52.7%	51.7%
Complex	34.3%	33.4%	33.9%
Palliative	3.1%	3.3%	3.2%
Number:	3298	2904	6202

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



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[2] Definitions of the Parkinson's phases can be found in Appendix A.

Table 5: Elderly Care and Neurology patients living alone

Patient lives alone	Elderly Care	Neurology	Elderly Care and Neurology
Yes	28.0%	22.1%	25.2%
No	63.2%	73.1%	67.8%
No, at residential home	3.7%	2.1%	3.0%
No, at nursing home	5.2%	2.7%	4.0%
Number:	3298	2904	6202

Service audit

Model of service provision

Parkinson’s is a complex and chronic condition, and it is accepted that people with Parkinson’s receive the best care within specialist Parkinson’s or movement disorder clinics. Within the specialist clinic setting, this is further supported by an integrated whole systems 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
Similar to findings in the 2012 audit, 87.6% of Elderly Care services see all or most (more than 75%) of their patients in such a setting. Neurology services have improved since 2012, with 62.8% of audited services now seeing all or most (more than 75%) of their patients in specific clinics (compared with 60% in 2012). Disappointingly, 11.7% of all services still see few (less than 25%) or none of their patients in dedicated clinics, although this figure is lower in Elderly Care (4.7%) than in Neurology (20.0%).

Table 6: Percentage of patients seen within specific Parkinson’s or movement disorder clinics

Patients seen in Parkinson’s or movement disorder clinic	Elderly Care	Neurology	Elderly Care and Neurology
All patients	57.4%	37.3%	48.1%
Most patients (>75%)	30.2%	25.5%	28.0%
Some patients (25–74%)	7.8%	17.3%	12.1%
Few patients (<25%)	0.8%	2.7%	1.7%
None	3.9%	17.3%	10.0%
Number:	129	110	239

b) Integrated clinics

The fully integrated clinic model is only available at 12.6% of all clinics, though this is more common for Elderly Care (18.6%) than Neurology (5.5%). The most common model of service provision is that of a joint or parallel doctor and nurse specialist clinic (59.0%). A significant proportion of clinics in both Elderly Care and Neurology remain staffed by a doctor alone (26.4% and 30.9%, respectively).

Table 7: Most common model of service provision for medical input in each service

Service provision model	**Elderly Care**	**Neurology**	**Elderly Care and Neurology**
Doctor alone	26.4%	30.9%	28.5%
Joint/parallel doctor and nurse specialist clinics	55.0%	63.6%	59.0%
Integrated clinics	18.6%	5.5%	12.6%
Number:	129	110	239

Access to Parkinson's nurse

Similar to previous audits, the majority of people with Parkinson's (94.1%) could access a Parkinson's nurse. Despite this, only 74.6% of people with Parkinson's who completed a PREM questionnaire reported that they could contact their Parkinson's nurse for advice between review appointments. As the patients included in the clinical audit were not necessarily the same as those who completed the PREM, this apparent disparity may reflect differences in the populations sampled.

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

Access to Parkinson's nurse	**Elderly Care**	**Neurology**	**Elderly Care and Neurology**
Yes	93.0%	95.5%	94.1%
No	7.0%	4.5%	5.9%
Number:	129	110	239

The PREM questionnaire asked whether people felt their needs were met by the number of review sessions with their Parkinson's nurse. While 17.4% did not respond, 81.8% of those who did respond answered positively.

The majority of participating Parkinson's nurses had undertaken Parkinson's-related continual medical education (CME) in the previous 12 months.

Table 9: Percentage of services in which all Parkinson's nurses had attended Parkinson's-specific external CME in the previous 12 months

Parkinson's-specific CME in previous 12 months	Elderly Care	Neurology	Elderly Care and Neurology
Yes	96.7%	95.2%	90.4%
No	3.3%	4.8%	3.3%
No access to Parkinson's nurse	0.0%	0.0%	6.3%
Number:	120	105	239

Table 10: Main arrangement for contact between consultants and Parkinson's nurses

Type of contact	Elderly Care	Neurology	Elderly Care and Neurology
Regular contact in multidisciplinary meeting, joint or parallel clinic	51.2%	33.6%	43.1%
Regular face-to-face contact outside clinic	14.0%	18.2%	15.9%
Regular telephone/email contact with occasional face-to-face contact	17.8%	34.5%	25.5%
Telephone/email contact only	10.1%	7.3%	8.8%
No or rare contact	0.8%	1.8%	1.3%
No access to Parkinson's nurse	6.2%	4.5%	5.4%
Number:	129	110	239

Availability of written information

Written information about Parkinson's and Parkinson's medication is routinely available all or most of the time at 82.4% of clinics. This is higher than was found in the 2012 audit, but written information about Parkinson's is still not routinely available in 5.9% of outpatient clinics.

Table 11: Availability of written information in Parkinson's clinic

Written information available	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	65.9%	50.9%	59.0%
Most clinics (>75%)	19.4%	28.2%	23.4%
Some clinics	8.5%	15.5%	11.7%
Not routinely available	6.2%	5.5%	5.9%
Number:	129	110	239

However, providing written information in the clinic may not be enough, as the PREM data suggests only 64.9% of patients feel they are given enough information at diagnosis.

Assessments

In the majority of clinics, formal Activities of Daily Living (ADL) tools or checklists are not being used. Services with low scores in this domain may wish to review their practice.

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

Assessment of ADL conducted	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	26.4%	16.4%	21.8%
Most clinics (>75%)	17.8%	19.1%	18.4%
Some clinics	25.6%	22.7%	24.3%
Not routinely available	30.2%	41.8%	35.6%
Number:	129	110	239

In just under a fifth of services, a Parkinson's non-motor symptom questionnaire is not routinely available, whereas it is always or mostly always used in over half of clinics. Services with low scores in this domain may wish to review their practice.

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	30.2%	20.9%	25.9%
Most clinics (>75%)	24.8%	29.1%	26.8%
Some clinics	27.1%	30.0%	28.5%
Not routinely available	17.8%	20.0%	18.8%
Number:	129	110	239

Standardised assessment tools to assess cognitive function are available in the majority of clinics.

Table 14: Availability of standardised assessment tools for cognitive function

Standardised assessment for cognition available	**Elderly Care**	**Neurology**	**Elderly Care and Neurology**
All clinics	63.6%	53.6%	59.0%
Most clinics (>75%)	21.7%	19.1%	20.5%
Some clinics	7.8%	14.5%	10.9%
Not routinely available	7.0%	12.7%	9.6%
Number:	129	110	239

In a third of clinics, standardised assessment tools to evaluate mood are not routinely available. However, it should be noted that many of these tools are readily accessible online if a clinic has internet access.

Table 15: Availability of standardised assessment tools to assess mood

Standardised assessment of mood available	**Elderly Care**	**Neurology**	**Elderly Care and Neurology**
All clinics	36.4%	20.0%	28.9%
Most clinics (>75%)	19.4%	19.1%	19.2%
Some clinics	20.2%	19.1%	19.7%
Not routinely available	24.0%	41.8%	32.2%
Number:	129	110	239

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, 98.6% of patients attending Elderly Care and Neurology services had received a specialist review in the preceding 12 months.

Table 16: Review by a specialist within the last year

Review in last year	Elderly Care	Neurology	Elderly Care and Neurology
Yes	98.9%	98.3%	98.6%
No	1.1%	1.7%	1.4%
Number:	3298	2904	6202

Table 17: Time since most recent medical review by a specialist

Time since medical review	Elderly Care	Neurology	Elderly Care and Neurology
Less than 6 months	81.4%	75.0%	78.3%
6–12 months	16.6%	20.0%	18.2%
More than 1 year	0.9%	2.1%	1.5%
More than 2 years	0.4%	1.9%	1.1%
Never, new patient	0.7%	1.0%	0.8%
Number:	3298	2904	6202

Medicines management

Over 90% of people with Parkinson’s in the audit had the checking and recording of their current prescription (medicines reconciliation) documented at a clinical review, in both Elderly Care (93.5%) and Neurology (91.6%).

Table 18: Evidence of medicines reconciliation

Medicines reconciliation documented	Elderly Care	Neurology	Elderly Care and Neurology
Yes	93.5%	91.6%	92.6%
No	6.5%	8.4%	7.4%
Number:	3298	2904	6202

There was evidence recorded for 83.3% of people with Parkinson's that they had been given information about potential side effects of new medication. Interestingly, the PREM data suggest that only 62.8% of patients feel they have enough information about new medication. Of the remaining patients, 17.9% were not sure or had not received new medication, 17.2% did not receive enough information, and 2.1% did not answer (see Table 157).

Table 19: Patients given information about potential adverse side effects of new medication

Information about side effects provided	Elderly Care	Neurology	Elderly Care and Neurology
Yes	82.1%	84.7%	83.3%
No	17.9%	15.3%	16.7%
Number:	2012	1929	3941

Since the previous audit, there has been an improvement in the number of Elderly Care and Neurology services recording enquiries about compulsive behaviours in patients taking dopamine agonists. However, 22.5% of patients still appear to have not received advice about potential compulsive behaviours related to their medication.

Table 20: Evidence recorded that people with Parkinson's taking dopamine agonists are monitored for compulsive behaviours (2012 and 2015 audits)

Compulsive behaviours monitored	Elderly Care		Neurology		Elderly Care and Neurology
	2012	2015	2012	2015	2015
Yes	59.6%	73.1%	76.4%	81.5%	77.5%
No	40.4%	26.9%	23.6%	18.5%	22.5%
Number:	–	1238	–	1317	2555

Table 21: Evidence that patients taking dopaminergic drugs are monitored for compulsive behaviours (only those on dopaminergic drugs included)

Compulsive behaviours monitored	Elderly Care	Neurology	Elderly Care and Neurology
Yes	61.0%	68.0%	64.2%
No	39.0%	32.0%	35.8%
Number:	2780	2353	5133

It is concerning that approximately three-quarters of patients prescribed an ergot dopamine agonist have not had an echocardiogram to monitor for development of fibrosis-related adverse effects.

Table 22: 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	24.8%	28.7%	26.8%
No	75.2%	71.3%	73.2%
Number:	121	136	257

Driving and excessive daytime sleepiness

Questioning about excessive daytime sleepiness was recorded in just under three-quarters of cases (71.0% in Elderly Care; 66.9% in Neurology). Where excessive daytime sleepiness was recorded, its impact on driving was documented in only about half of drivers.

Table 23: Evidence of enquiry about excessive daytime sleepiness

Enquiry about excessive daytime sleepiness	Elderly Care	Neurology	Elderly Care and Neurology
Yes	71.0%	33.1%	69.1%
No	29.0%	66.9%	30.9%
Number:	3298	2892	6190

Table 24: Documented discussions of the impact of known excessive daytime sleepiness in people with Parkinson’s who are drivers

Discussion of impact of daytime sleepiness on driving documented	Elderly Care	Neurology	Elderly Care and Neurology
Yes	60.6%	52.1%	56.5%
No	39.4%	47.9%	43.5%
Number	808	758	1566

Advance care planning

Of those people with Parkinson’s who had markers of advanced disease (23.5%), discussions about end of life care issues and advice about lasting power of attorney were recorded in only 25.6% and 25.5 % respectively for Elderly Care and 31.2% and 27.4% for Neurology. Overall, this reflects discussions with just 7% of people with Parkinson’s. This raises the question of whether advanced disease is sufficiently well recognised, whether appropriate conversations about end of life care are started early enough, and whether health care professionals feel empowered and able to initiate such conversations.

Table 25: 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	25.8%	20.9%	23.5%
No	74.2%	79.1%	76.5%
Number:	3298	2904	6202

Table 26: 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	25.6%	31.2%	28.0%
No	74.4%	68.8%	72.0%
Number:	944	702	1646

Table 27: Evidence the patient or carer has been offered information about, or has set up, a lasting power of attorney or power of attorney in Scotland (where there are markers of advanced disease)

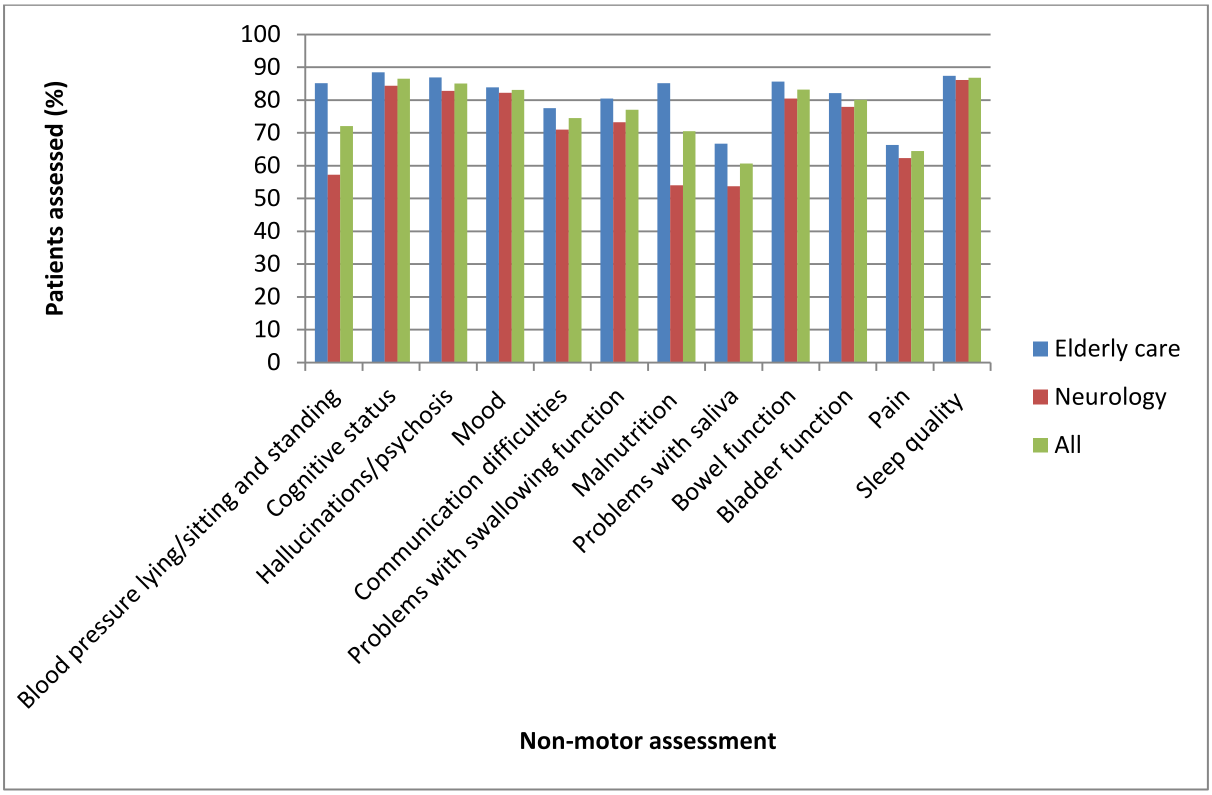
Lasting power of attorney considered or set up	Elderly Care	Neurology	Elderly Care and Neurology
Yes	25.5%	27.4%	26.3%
No	74.5%	72.6%	73.7%
Number:	978	709	1687

Domain scores

The audit recorded whether services completed assessments in three domains: (i) non-motor symptoms; (ii) motor symptoms and activities of daily living (ADL); and (iii) education and multidisciplinary involvement.

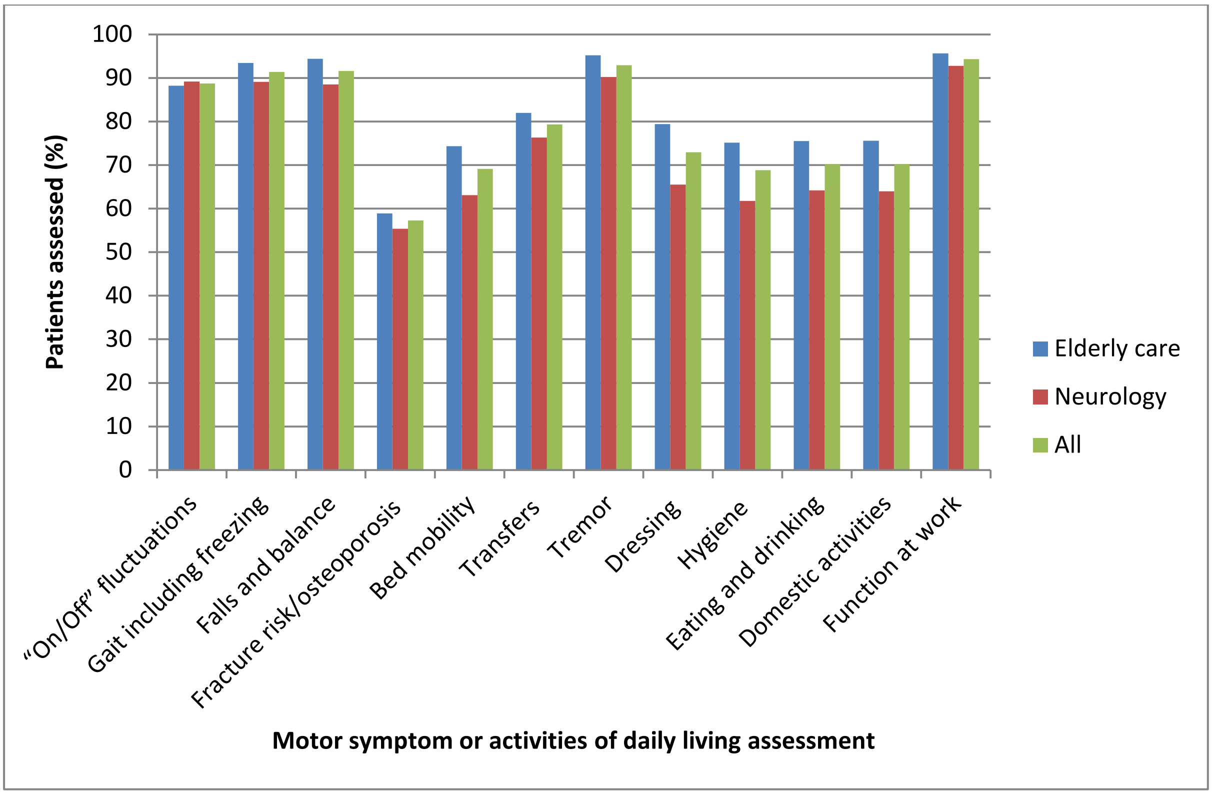
For each element within a domain, total scores were calculated by summing passes (scoring 1) and fails (scoring 0) for each patient. A pass was achieved if the assessment was done. However, a pass was also achieved if an assessment was not done but was considered and not felt to be indicated or appropriate. A fail indicates when an assessment was neither done nor considered. Total domain scores were then calculated for each domain.

Figure 3: Domain 1 – Assessment of non-motor symptoms during the previous year



Neurology clinics scored poorly compared with Elderly Care clinics in documenting blood pressure (54.6% and 81.5%, respectively) and screening for malnutrition (54.0% and 85.1%, respectively). However, assessments of pain and saliva problems were poorly documented across both services.

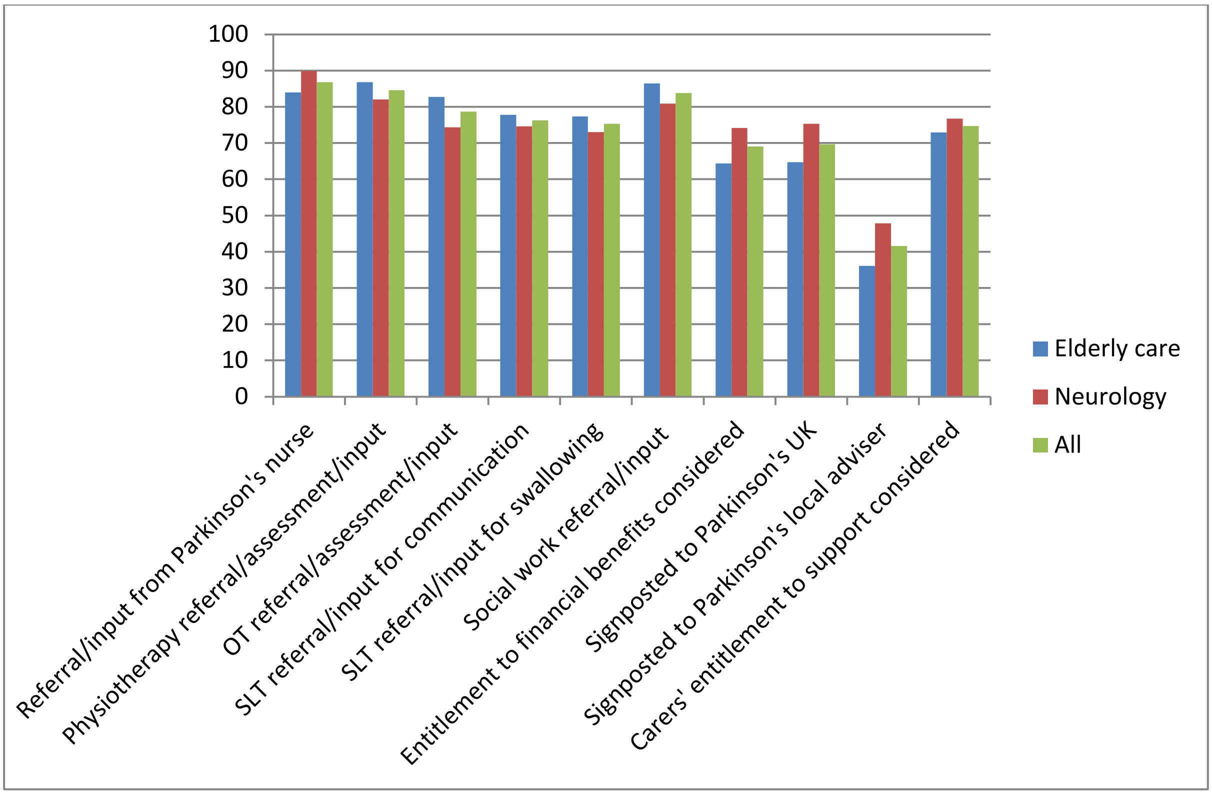
Figure 4: Domain 2 – Assessment of motor symptoms and ADL during the previous year



Where there were concerns about falls and/or balance, fracture risk or osteoporosis was considered in only 36.4% of people with Parkinson's (40.6% in Elderly Care; 31.4% in Neurology).

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

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



The results show that signposting to a Parkinson's local adviser is poor for people with Parkinson's and/or their carers. This is only considered in 36.1% of Elderly Care and 47.8% of Neurology patients.

Occupational therapy

Aims

The Occupational therapy (OT) audit measures the referral, assessment and management of people with Parkinson's in OT services. It also aimed to describe the models of service delivery used. It identifies the measures used in assessment and outcome, the guidance and education available to occupational therapists, and adherence to national guidance. The Standards and Guidance document for OT can be found in Appendix D.

Demographics

OT services saw 561 people with Parkinson's who were included in the audit. The majority were over 70 years of age (mean age: 75.4 years; SD 8.6 years), male (59.9%) and white British (87.5%). The mean length of time between diagnosis and referral for OT was 6.1 years (SD 5.5 years). Typically, people seen by OT services live in their own homes (90.3%), and are referred during the maintenance or complex phase of Parkinson's.

Table 28: Gender of OT patients

Gender	Patients
Male	59.9%
Female	40.1%
Number:	559

Table 29: Ethnicity of OT patients

Ethnicity	Patients
White British	87.5%
Any other White background	2.0%
Black/Black British	1.1%
Asian/Asian British	2.7%
Mixed/multiple ethnic group	0.4%
Not stated	5.0%
Other ethnic group	1.4%
Number:	559

Table 30: Settings in which OT patients live

Home setting	Patients
Own home	90.3%
Residential care home	3.2%
Nursing home	2.3%
Other	4.1%
Number:	559

Table 31: Health settings in which OT patients are seen

Health setting	Patients
NHS – inpatient	8.6%
NHS – outpatient	25.8%
NHS – community	24.5%
At home	38.1%
Other	3.0%
Number:	559

Table 32: Parkinson's phase of OT patients

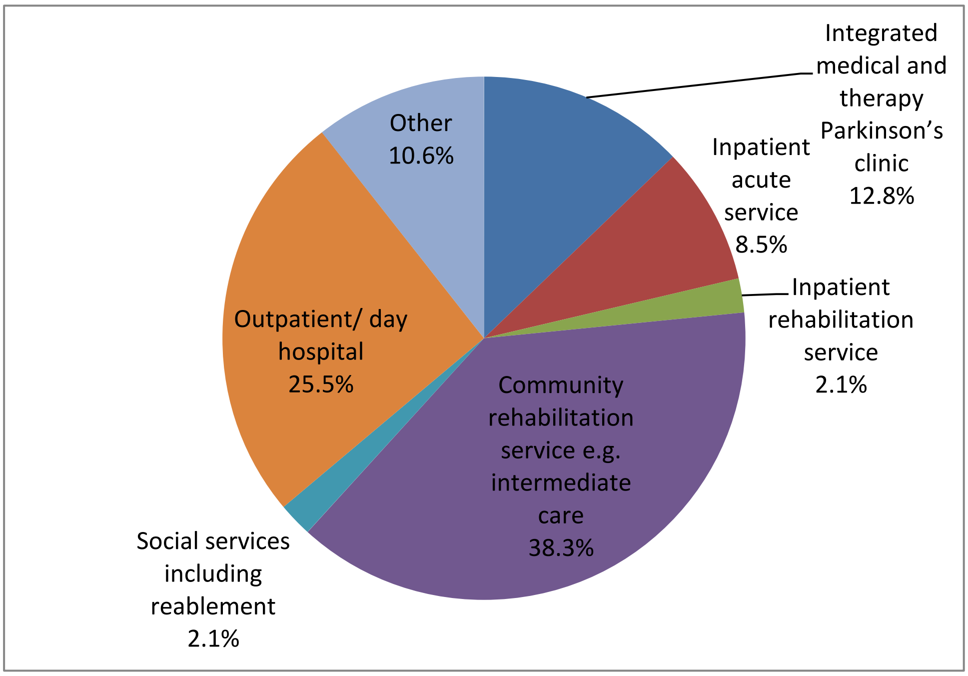
Phase	Patients
Diagnosis	12.3%
Maintenance	53.7%
Complex	31.5%
Palliative	2.5%
Number:	559

Service audit

Models of service provision

The 47 OT services that supplied data for the service audit provide services for people with Parkinson's in a variety of care settings.

Figure 6: Usual setting in which people with Parkinson's receive OT services



Fewer than 13% of OT services reported working in an integrated clinic when occupational therapists see people with Parkinson's. The majority of OT services (65.9%) were based in the community, within rehabilitation, reablement or day hospital teams.

Only 44.7% of OT services reported being members of a Parkinson's specialist multidisciplinary team, while another 14.9% reported being members of a general Neurology or Elderly Care service.

Thirty of the OT services audited specialise in neurological conditions, with 29 specialising in the treatment of Parkinson's.

Table 33: Services specialising in treatment of people with neurological conditions

Service specialises in neurological conditions	Services
Yes	63.8%
No	36.2%
Number:	47

Table 34: Services specialising in treatment of people with Parkinson’s

Service specialises in Parkinson’s treatment	Services
Yes	61.7%
No	38.3%
Number:	47

The majority of services (55.3%) employed one or two full-time equivalent occupational therapists.

OT services received an average of between 100 and 200 referrals of people with Parkinson’s each year. In 20 OT services, up to 19% of their referrals were patients with a Parkinson‘s diagnosis.

Table 35: Percentage of people referred to the service annually with a diagnosis of Parkinson’s

Referred	Services
0–19%	42.6%
20–39%	19.1%
40–59%	10.6%
60–79%	10.6%
80–100%	17.0%
Number:	47

Accessing Parkinson’s-related CPD

Of the occupational therapists audited, 91.5% reported having opportunities to undertake Parkinson’s-related CPD.

Table 36: Access to Parkinson’s-related CPD at least yearly

Access to yearly CPD	Services
Yes	91.5%
No	8.5%
Number:	47

Support was accessed through their specialist multidisciplinary team by 37 occupational therapists (78.7%). The remaining 10 (21.3%) accessed advice through their specialist Elderly Care or Neurology team.

Specific induction and support strategies for working with people with Parkinson’s was given to new staff in only 11 OT services (23.4%), and 17 (36.2%) included Parkinson’s within their general competencies.

Table 37: 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	23.4%
Yes, as part of more general competencies	36.2%
No	40.4%
Number:	47

Table 38: 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	44.7%
Consult members of a general Neurology/Elderly Care specialist service of which they are a member	14.9%
Doesn't work directly in specialist Parkinson’s clinics, but has access to Parkinson’s specialist MDT/Parkinson’s nurse	34.0%
Doesn't work directly in a specialist clinic, but has access to advice from a specialist Neurology or Elderly Care MDT	6.4%
No access to more specialist advice	0.0%
Number:	47

Use of standardised assessment and outcome measures

Table 39: Approaches of services to assessment of people with Parkinson’s

Assessment	Services
MDT assessment	80.9%
Interview with clients and carer	87.2%
Assessment during group work	14.9%
Functional assessment	89.4%
Standardised assessment	55.3%
Other	8.5%
Number:	47

Table 40: How patients with Parkinson’s are usually seen

How patients seen	Services
Individually	74.5%
In a group setting	0.0%
Both individually and in groups	25.5%
Number:	47

Just over half (55.3%) of OT services in the audit use standardised assessments with people with Parkinson’s. This has increased since the 2012 audit. However, services are still using a wide range of standardised tools and it is unclear whether assessments are repeated to measure outcomes.

Figure 7: Standardised assessments used by OT services

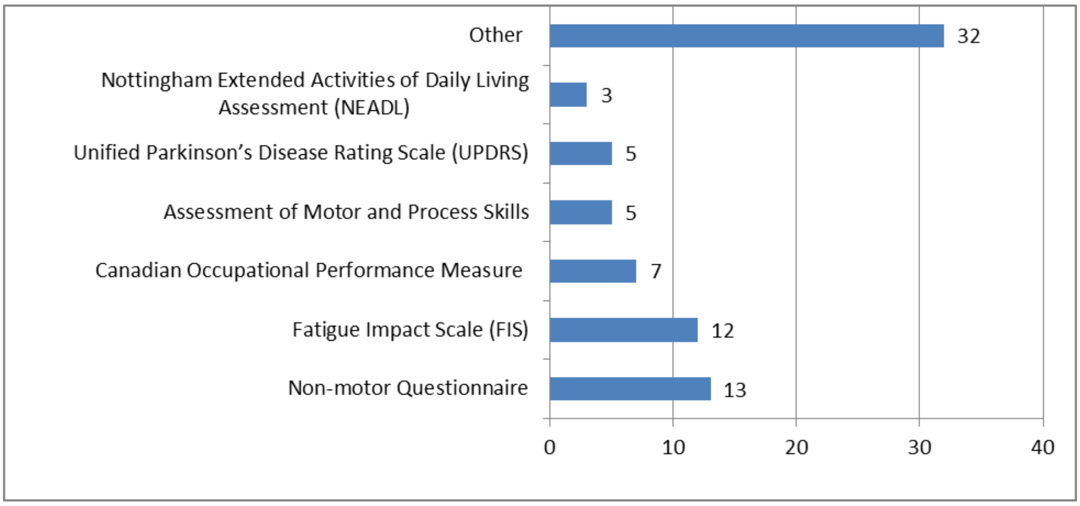


Table 41: Needs addressed through interventions

Needs addressed	Services
Domestic ADL	100.0%
Environmental issues to improve safety and motor function	100.0%
Improvement and maintenance of transfers and mobility	100.0%
Improvement of personal self-care activities, eg eating, drinking, washing and dressing	100.0%
Mental wellbeing, including cognition, emotional and/or neuropsychiatric problems	97.9%
Management of fatigue	95.7%
Social interaction/social support	93.6%
Leisure activities	89.4%
Maintenance of family roles	87.2%
Education	83.0%
Maintenance of work roles	80.9%
Other	12.8%
Number:	47

Table 42: Locations in which services provide interventions

Location of interventions	Services
Individual's home	57.4%
Day hospital/centre	31.9%
Inpatient hospital	10.6%
Number:	47

Evidence-based practice

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

Type of evidence	Services
Clinical experience	94.7%
Advice from colleague or supervisor	76.3%
Occupational Therapy for People with Parkinson's disease: Best Practice Guidelines [1]	78.8%
Information from Parkinson's UK website	72.4%
National Service Framework for Long Term Conditions (2005)[2]	64.7%
NICE Guidelines (2006)[3]	69.2%
Published evidence in a peer reviewed journal	35.1%
None	0.2%
Other	10.0%

Since the 2012 audit, there has been a significant increase (up to 78.8%) in the proportion of services using the *Occupational Therapy for People with Parkinson's: Best Practice Guidelines.*

Patient audit

Referral to OT

Referrals to OT are made by a wide variety of sources, with the majority triggered as a result of a medical review (59.6%) or following a previous OT referral (51.9%). Referred patients had a range of disease durations.

Table 44: Source of referral to OT

Source of referral	Patients
Neurologist	12.5%
Geriatrician	13.1%
Dietician	0.2%
Social care worker	2.7%
Self referral	3.9%
Other	59.2%
Unknown	0.9%
GP	7.5%
Number:	559

Table 45: Referrals triggered as a result of medical review

Referral triggered by medical review	Patients
Yes	59.6%
No	36.7%
Unknown	3.8%
Number:	559

Table 46: Reason for referral to OT

Reason for referral to OT	Patients
Improvement and maintenance of transfers and mobility	71.3%
Improvement of personal self-care activities, such as eating, drinking, washing and dressing	46.0%
Environmental issues to improve safety and motor function	43.0%
Domestic ADL	26.7%
Mental wellbeing, including cognition, emotional and/or neuropsychiatric problems	23.4%
Management of fatigue	15.5%
Leisure activities	13.4%
Maintenance of family roles	10.0%
Maintenance of work roles	5.7%
Other	13.2%
Number:	561

Table 47: Time between diagnosis and OT referral

Duration of disease	Patients
Less than 1 year	13.9%
1–2 years	17.2%
3–5 years	25.2%
6–10 years	25.2%
11–15 years	12.0%
16–20 years	4.8%
More than 20 years	1.7%
Number:	540

Over three-quarters of referrals had most of the information required for assessment and intervention. The majority of referrals were judged to have been made at the appropriate time.

Table 48: Information essential for OT assessment and intervention available on referral

Information available on referral	Patients
Yes, most of it	78.2%
Yes, some of it	16.5%
No	5.4%
Number:	559

Table 49: Outcomes reported back to referrer

Reports made	Patients
Yes	88.6%
No	11.3%
Other	0.2%
Number:	559

When considering the data in Table 49, it should be noted that many occupational therapists reported an issue with this question, suggesting that if the patient was still undergoing OT it was too soon to report back. Therefore, many were selecting ‘yes’ if this was the eventual intention, rather than if it had been done.

Table 50: Patient referred at an appropriate time according to the occupational therapist

Referral at appropriate time	Patients
Yes	89.4%
No	8.4%
Don't know	2.1%
Number:	559

Table 51: Person who identified the goals for optimising activities

Optimising activities	Patients
Client and carer	21.9%
Client and therapist	78.1%
Number:	556

Table 52: Person who identified the goals for supporting participation

Supporting participation	Patients
Client and carer	23.4%
Client and therapist	76.6%
Number:	552

Intervention strategies used

Occupational therapists typically work with people on an individual basis for an average of five or six sessions, using a wide range of interventions. When specific treatment strategies were not used, it was rarely due to lack of training or experience of the technique (less than 1% of audited cases).

Figure 8: Range of occupational therapy interventions used

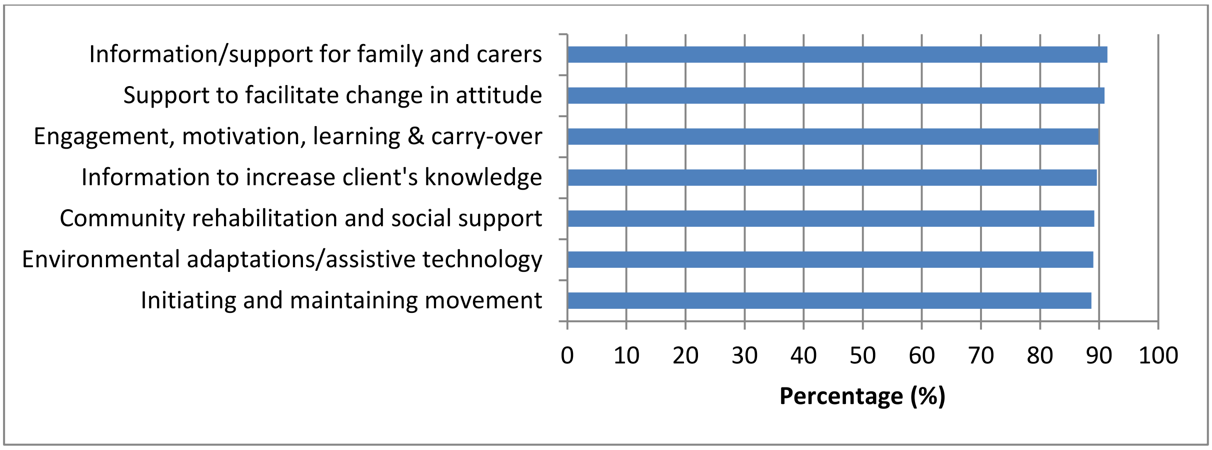


Table 53: Interventions used for initiating and maintaining movement

Intervention strategies used	Patients
Promoting functional ability throughout a typical day, taking account of medication	54.2%
Promoting functional ability throughout a typical day, taking account of fatigue	50.4%
Promoting functional abilities through trial of extrinsic cueing techniques	37.4%
Promoting functional abilities through trial of intrinsic cueing techniques	27.1%
None of the above treatment strategies applicable	18.5%
Number:	561

Table 54: Reasons for not using applicable treatment strategies for initiating and maintaining movement

Reason	Patients
Lack of training in the technique	0.4%
Lack of experience in the technique	1.1%
Lack of time/not a priority	3.1%
Lack of resources	0.7%
Other	6.0%
All specific applicable treatment strategies were used	88.7%
Number:	549

Table 55: Interventions used for engagement, motivation, learning and carry-over

Intervention strategies used	Patients
Promoting mental wellbeing	57.2%
Promoting new learning	43.1%
None of the treatment strategies applicable	23.4%
Number:	561

Table 56: Reasons for not using applicable treatment strategies for engagement, motivation, learning and carry-over

Reason	Patients
Lack of experience in the technique	0.2%
Lack of time/not a priority	3.8%
Lack of resources	0.5%
All specific applicable treatment strategies were used	89.9%
Other	5.5%
Number:	547

Table 57: Interventions that included assessment of environmental adaptations/assistive technology

Assessment	Patients
Small aids and adaptations	74.0%
Wheelchair and seating	14.3%
Assistive technology	10.5%
Major adaptations	8.4%
None of the treatment strategies applicable	18.9%
Number:	561

Table 58: Reasons for not using applicable treatment strategies for environmental adaptations or assistive technology

Reason	Patients
Lack of experience in the technique	0.5%
Lack of time/not a priority	1.8%
Lack of resources	0.5%
Other	8.0%
All specific applicable treatment strategies were used	89%
Number	547

Table 59: Services to which referrals were made to support community rehabilitation and social support

Referrals made	Patients
Other allied health professions	37.6%
Social services OT	15.5%
Social worker/carers	14.6%
Voluntary services	11.6%
Respite care	1.6%
Access to work	0.9%
None of the treatment strategies applicable	34.9%
Number:	561

Table 60: Reasons for not using applicable treatment strategies to support community rehabilitation and social support

Reason	Patients
Lack of experience in the technique	0.2%
Lack of time/not a priority	1.8%
Lack of resources	0.4%
Other	8.4%
All specific applicable treatment strategies were used	89.2%
Number:	548

Table 61: Information provided to increase patient’s knowledge

Information provided	Patients
Specific ADL techniques	65.4%
Fatigue management	33.9%
Cognitive strategies	29.8%
Relaxation/stress management	18.5%
Work advice and resources	5.3%
None of the treatment strategies applicable	17.3%
Number:	561

Table 62: Reasons for not using applicable treatment strategies to provide information to increase patient's knowledge

Reason	Patients
Lack of training in the technique	0.4%
Lack of experience in the technique	0.7%
Lack of time/not a priority	2.9%
Lack of resources	0.7%
Other	5.7%
All specific applicable treatment strategies were used	89.6%
Number:	547

Table 63: Information and support provided for family and carers

Information provided	Patients
Optimising function	52.4%
Safe moving and handling	40.8%
Support services	32.6%
Managing changes in mood, cognition or behaviour	21.2%
None of the treatment strategies applicable	22.5%
Number:	561

Table 64: Reasons for not using applicable treatment strategies to provide information and support for family and carers

Reason	Patients
Lack of training in the technique	0.0%
Lack of experience in the technique	0.4%
Lack of time/not a priority	1.5%
Lack of resources	0.0%
Other	6.8%
All specific applicable treatment strategies were used	91.4%
Number:	547

Table 65: Support provided to facilitate a change in attitude

Support provided	Patients
Developing self awareness/adjustment to limitations	51.0%
Increasing confidence	44.9%
Positive attitude/emotional set	34.4%
Explore new occupations	7.5%
None of the treatment strategies applicable	24.8%
Number:	561

Table 66: Reasons for not using applicable treatment strategies to facilitate a change in attitude

Reason	Patients
Lack of training in the technique	0.4%
Lack of experience in the technique	0.7%
Lack of time/not a priority	1.5%
Lack of resources	0.4%
Other	6.2%
All specific applicable treatment strategies were used	90.9%
Number:	547

Physiotherapy

Aims

The Physiotherapy audit intended to establish whether Physiotherapy services are currently providing quality services to people with Parkinson’s, taking into account recommendations from evidence-based guidelines and using standardised assessments. It allows local and national mapping of service provision, patient management and access to CPD. The Standards and Guidance document for Physiotherapy can be found at Appendix E.

Demographics

Physiotherapists in the 83 services registered for the audit reported on 1,263 people with Parkinson’s receiving Physiotherapy. Patients were aged between 39 and 95 years (mean age: 74.3 years; SD 9.0 years) and just 4.4% were living in residential or nursing homes. The majority were male (62.3%) and white British (85.7%). Audited patients had a mean disease duration of 5.7 years (SD 5.9 years, range 0–43 years). Among those receiving Physiotherapy, 15.7% were in the diagnostic phase, 48.9% in the maintenance phase, 33.4% in the complex phase and 2.1% in the palliative phase.

Table 67: Gender of Physiotherapy patients

Gender	Patients
Male	62.3%
Female	37.7%
Number:	1263

Table 68: Ethnicity of Physiotherapy patients

Ethnicity	Patients
White British	85.7%
Any other White background	1.8%
Black/Back British	2.1%
Asian/Asian British	3.3%
Mixed/multiple ethnic group	0.2%
Not stated	6.5%
Other ethnic group	0.4%
Number:	1263

Table 69: Settings in which Physiotherapy patients live

Home setting	Patients
Own home	93.6%
Residential care home	2.4%
Nursing home	2.0%
Other	2.1%
Number:	1263

Table 70: Health settings in which Physiotherapy patients are seen

Healthcare setting	Patients
NHS – inpatient	9.4%
NHS – outpatient	59.9%
NHS – community	20.3%
At home	6.8%
Other	3.6%
Number:	1263

Table 71: Parkinson’s phase of Physiotherapy patients

Phase	Patients
Diagnosis	15.7%
Maintenance	48.9%
Complex	33.4%
Palliative	2.1%
Number:	1263

Service audit

Model of service provision

Multidisciplinary assessment was offered in 52 services (62.7%), whereas 64 services (77.1%) offered only Physiotherapy assessment. However, some services offer both multidisciplinary and Physiotherapy assessments. Therefore, different assessment pathways are offered to people with Parkinson's, sometimes within the same service.

Group and individual therapy sessions were offered by 56.6% of the audited services.

Table 72: How patients with Parkinson's are usually seen

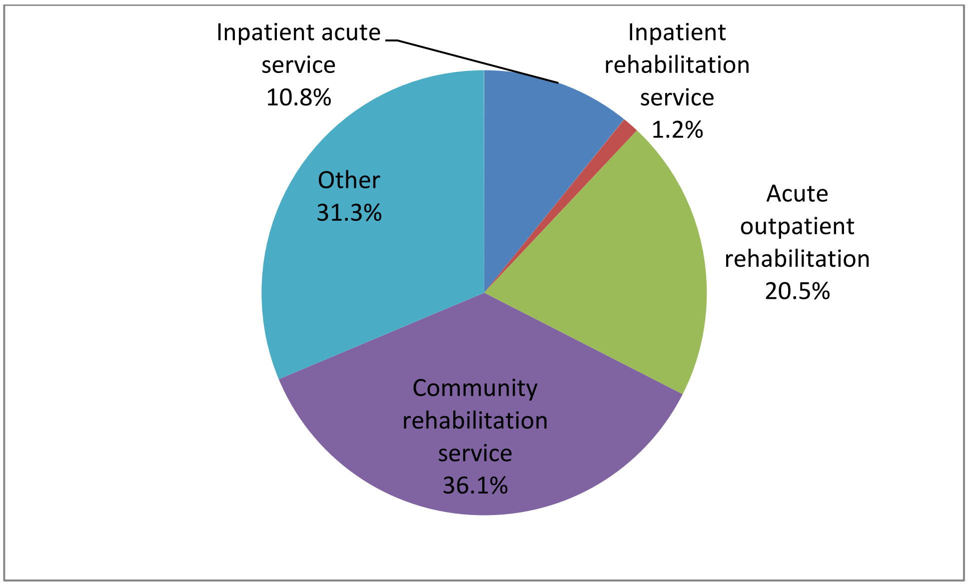
How patients seen	Services
Individually	43.4%
Individually and in groups	56.6%
In a group setting	0.0%
Number:	83

Group therapy focused on patient education (50.6%) or exercise (61.4%). Again, some services offer both education and exercise groups. Thirty-two services (38.6%) did not offer any groups.

Table 73: Needs addressed by group work

Needs addressed	Services
Education	50.6%
Exercise	61.4%
No group work	38.6%
Other	12.0%
Number:	83

Figure 9: The settings in which people with Parkinson's receive Physiotherapy



Some services reported that they specialised in the treatment of neurological conditions, which we can assume would include the management of Parkinson's. However, some services specifically reported specialising in both.

Table 74: Physiotherapy services specialising in the treatment of neurological conditions and Parkinson's

Service specialisation	Yes (%)	No (%)
Specialise in treatment of neurological conditions	68.7	31.3
Specialise in treatment of Parkinson's	57.8	42.2

Table 75: Percentage of people referred to the service annually with a diagnosis of Parkinson's

Percentage referred	Services
0–19%	39.8%
20–39%	31.3%
40–59%	14.5%
60–79%	2.4%
80–100%	12.0%
Number:	83

Table 76: Assessments offered to patients with Parkinson’s

Assessment	Services
MDT assessment	62.7%
Physiotherapy assessment	77.1%
Other	16.9%
Number:	83

Accessing Parkinson’s-related CPD

Although 88% of services offered access to Parkinson’s-related CPD, induction and support strategies were not available for new physiotherapists working with people with Parkinson’s in 39.8% of the 83 services. All services reported access to support for individual therapists of some kind.

Table 77: Access to Parkinson’s-related CPD at least yearly

Access to CPD yearly	Services
Yes	88.0%
No	12.0%
Number:	83

Table 78: Documented induction and support strategies for new physiotherapists working with people with Parkinson’s

Induction and support strategies	Services
Yes	60.2%
No	39.8%
Number:	83

Table 79: Support available to individual physiotherapists

Type of support	Services
Can consult any member of the Parkinson’s specialist MDT of which they are a member	44.6%
Can consult members of a general Neurology/Elderly Care specialist service of which they are a member	14.5%
Doesn't work directly in specialist Parkinson’s clinics, but has access to Parkinson’s specialist MDT/Parkinson’s nurse	34.9%
Doesn't work directly in a specialist clinic, but has access to advice from a specialist Neurology or Elderly Care MDT	6.0%
No access to more specialised advice	0.0%
Number:	83

Use of appropriate outcome measures by physiotherapists

A goal plan was included in the Physiotherapy notes of 89.8% of people with Parkinson's referred for treatment.

Table 80: Physiotherapy notes included a goal plan

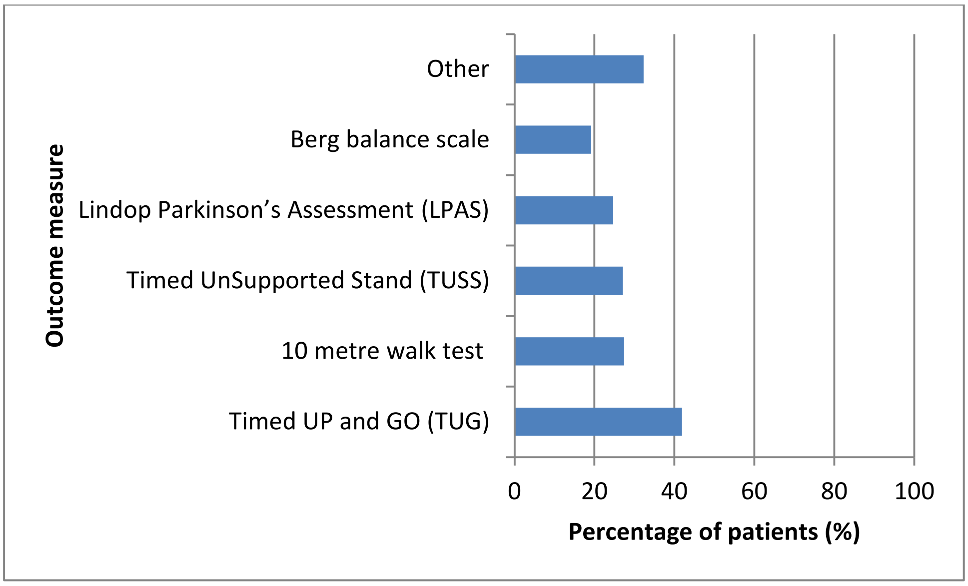
Goal plan included	Patients
Yes	89.8%
No	10.2%
Number:	1263

Outcome measures were reported as being used in 84.9% of patients (85.1% in 2012).

Table 81: Outcome measures used

Outcome measures used	Patients
Yes	84.9%
No	15.1%
Number:	1263

Figure 10: Most frequently used Physiotherapy outcome measures



For many patients, multiple outcome measures were used and in 32.3% of cases, use of "other" outcome measures that did not appear on the audit suggested list was reported. Some of these were not specific to Physiotherapy. For 15.4% of people with Parkinson's, the physiotherapist reported using no outcome measures. This finding is similar to the 2012 audit (14.9%) and reflects continuing poor practice.

Table 82: Outcome measures used to assess Physiotherapy patients

Outcome measure	Patients
Timed UP and GO (TUG)	41.9%
10 metre walk test	27.4%
Timed UnSupported Stand (TUSS)	27.1%
Lindop Parkinson’s Assessment (LPAS)	24.7%
Berg Balance Scale	19.2%
Tragus to wall	17.6%
Five times sit to stand test	7.4%
History of Falls Questionnaire	6.7%
Functional Gait Assessment	5.9%
Retropulsion Test	5.1%
Unified Parkinson’s Disease Rating Scale (UPDRS)	4.3%
The Falls Efficacy Scale – International (Short FES-I)	3.9%
Freezing of Gait Questionnaire	3.8%
Push and Release Test	3.6%
EQ-5D tool	3.3%
Parkinson’s Disease Questionnaire-39 (PDQ-39)	2.5%
Dynamic Gait Index	2.1%
Modified Parkinson’s Activity Scale (M-PAS) Chair	1.8%
Modified Parkinson’s Activity Scale (M-PAS) Gait	1.4%
Modified Parkinson’s Activity Scale (M-PAS) Bed	1.1%
Movement Disorder Society – UPDRS	0.7%
Six minute walk test	0.5%
Parkinson's Activity Scale (PAS)	0.4%
Borg Scale	0.2%
Snijders & Bloem Freezing of Gait Test	0.1%
Phone FITT	0.0%
General Practice Physical Activity Questionnaire (GPPAQ)	0.0%
Other (see below)	32.3%
Outcome measures were not used in this case	15.4%
Number:	1263

Outcome measures included in ‘Other’ category:

- 180 degree turn
- 360 degree turn
- Barthel or Modified Barthel

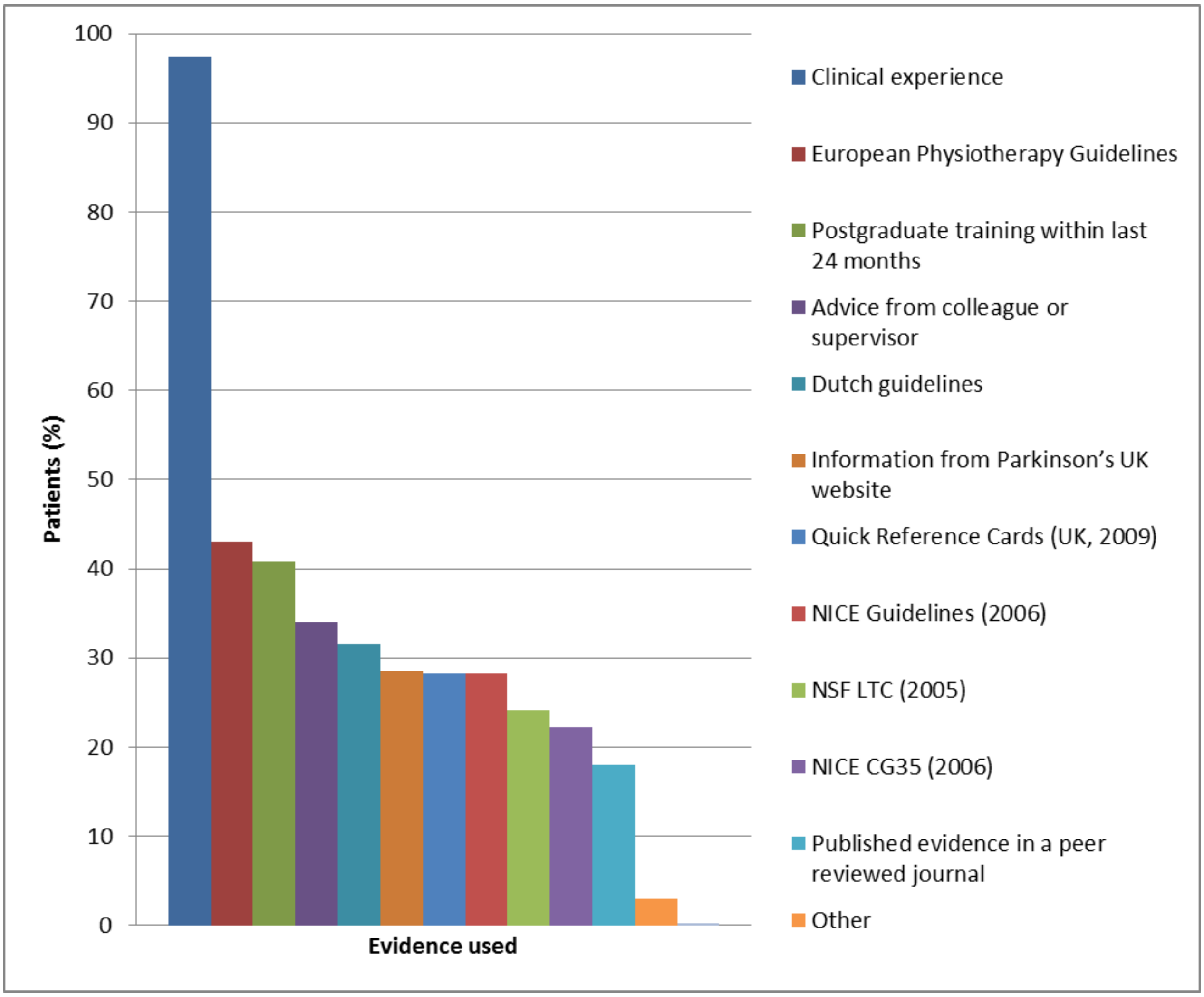
- Elderly Mobility Scale
- Goal Attainment Scale
- Visual Analogue Scale – for pain/gait confidence
- Tinetti Gait/Balance
- Assessment of Mobility Problems in Elderly Patients (POAM)
- Modified Falls Efficacy Scale (MFES)
- Falls rate
- Home Falls and Accidents Screening Tool (Homefast)
- Four Test Balance Scale
- Clinical Test of Sensory Interaction on Balance (CTSIB)
- Functional Reach
- Timed unsupported stand
- Single leg stance
- Tandem stand
- Activities-Specific Balance Confidence Scale (ABC)
- Six metre walk
- Functional gait assessment
- Three metre walk
- Three minute walk
- Modified Rivermead Mobility Index
- Sit to stand in one minute
- Three button tap test
- Five coins in and out of a box
- Parkinson’s disease tap test
- Timed fastening of three buttons
- Nine hole peg test
- Grip strength
- Muscle power
- Rhomberg’s test
- Active range of movement
- Canadian Occupational Performance Measure (COPM)
- Dual task timed up and go
- One Repetition Maximum Test (1 RM)
- Hospital Anxiety and Depression Scale (HAD)
- Abbreviated Mental Test (AMT)
- Montreal Cognitive Assessment (MOCA)
- Addenbrooke’s Cognitive Examination-Revised (ACE-R)

- General Practitioner Assessment of Cognition (CPCOG)
- Local tool
- Measure Yourself Medical Outcome Profile (MYMOP)
- Manual handling review
- Mini-Balance Evaluation Systems Test (Mini-BESTest)
- Modified functional grid
- Postural instability with falling (PIF)
- Oswestry Low Back Pain Scale
- Chest monitoring observations
- Patient Health Questionnaire (PHQ)
- Patient-Specific Functional Scale (PSFS)
- Physical Performance Test (PPT)
- Tragus to wall (included in suggested outcomes list but entered as “other” in some data)
- Heel to floor measurement
- Assessment of peripheral vestibulo-ocular reflex (VOR, up and down, timed)
- Webster Rating Scale for Parkinsonism
- Webster Dyskinesia Scale
- Falls diary
- Timed dexterity tasks
- Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS)
- Therapy Outcome Measures (TOMs)
- Timed supported stand with Zimmer frame and support of one person
- Transfer – steps for 180 degree transfer plus assistance of one

Evidence-based practice and training

The European Physiotherapy Guideline for Parkinson’s Disease[4] was used to inform clinical practice in the care of 43.0% of patients. Other guidelines used included the older Physiotherapy-specific guideline, The Royal Dutch Society for Physical Therapy in Patients with Parkinson’s Disease[5] (31.6% in 2015 compared with 41.3% in 2012) and the UK Quick Reference Cards from the Dutch Guidelines (28.3% in 2015 compared with 46.0% in 2012). NICE 2006 and NICE CG35 2006 are, in fact, the same document, but were inadvertently included as separate guidelines. In 79 cases, 'yes' was answered for both, and, overall, 558 of the 1263 cases (44.2%) answered 'yes' for one or both of them. Therefore 55.8% did not use the 2006 NICE Guidance as a component of their evidence base. In 40.9% of cases, the physiotherapist providing treatment had attended postgraduate training specific to Parkinson’s in the previous 24 months. However, it is unclear whether this training was specific to Physiotherapy.

Figure 11: Evidence used to inform physiotherapists' practice and to guide intervention



Patient audit

Referral to Physiotherapy

The time between diagnosis and referral to Physiotherapy ranged from under a year to over 20 years. A referral within two years of diagnosis was reported in 49.3% of patients.

Table 83: Time between diagnosis and Physiotherapy referral

Time between diagnosis and referral	Patients
Less than 1 year	27.0%
1–2 years	22.3%
3–5 years	20.2%
6–10 years	17.3%
11–15 years	7.7%
16–20 years	3.8%
More than 20 years	1.7%
Number:	1204

Of the patients receiving Physiotherapy, 40.5% had not previously been offered Physiotherapy for management of their Parkinson's. Most referrals were routine (88.9%) and met local standards. Most people with Parkinson's received Physiotherapy as outpatients, with only 9.4% receiving inpatient care.

Table 84: Routine or urgent referrals

Referral type	Patients
Urgent	10.8%
Routine	88.9%
Unknown	0.3%
Number:	1263

Table 85: Referrals that meet local standards for time between referral and initial assessment

Local standard met	Patients
Yes	75.6%
No	15.2%
No local standard	9.2%
Number:	1263

Table 86: Outcomes reported back to referrer

Reports made	Patients
Yes	81.8%
No	18.2%
Number:	1263%

When considering the data in Table 86, it should be noted that many physiotherapists reported an issue with this question, suggesting that if the patient was still undergoing Physiotherapy it was too soon to report back. Therefore, many were selecting 'yes' if this was the eventual intention, rather than if it had been done.

Speech and Language therapy

Aims

The Speech and Language therapy (SLT) audit intended to examine the models of service delivery, policies for reviewing patients and the seniority of practitioners operating in the field of Parkinson's SLT. It also identifies timings of referral, the types of assessment and interventions used, and whether practice adheres to national guidance. The Standards and Guidance document for SLT can be found at Appendix F.

Demographics

Speech and language therapists in 63 services registered for the audit reported on 820 people with Parkinson's. Patients were aged between 28 and 97 years (mean: 73.7 years; SD 9.7 years) and the majority were male (71.1%) and living in their own home (88.3%). Audited patients had a mean disease duration of 6.5 years (SD 5.8 years, range 0–39 years). Among those referred for SLT, the majority were in the maintenance (57.9%) or complex (18.3%) phase.

Table 87: Gender of SLT patients

Gender	Patients
Male	71.7%
Female	28.3%
Number:	820

Table 88: Ethnicity of SLT patients

Ethnicity	Patients
White British	88%
Any other White background	1.5%
Black/Black British	1.1%
Asian/Asian British	2.4%
Mixed/multiple ethnic group	0.4%
Not stated	5.4%
Other ethnic group	1.2%
Number:	820

Table 89: Settings in which SLT patients live

Home setting	Patients
Own home	88.3%
Residential care home	2.9%
Nursing home	6.7%
Other	2.1%
Number:	820

Table 90: Health settings in which SLT patients were seen

Healthcare setting	Patients
NHS – inpatient	6.1%
NHS – outpatient	40.7%
NHS – community	23.9%
At home	28.4%
Other	0.9%
Number:	820

Service audit

Model of service provision

The majority of SLT (76.3%) was offered to people with Parkinson’s within general adult acquired speech and language disorders services. Only five SLT services saw people with Parkinson’s in a specialist Parkinson’s clinic.

Figure 12: Settings in which people with Parkinson's received SLT

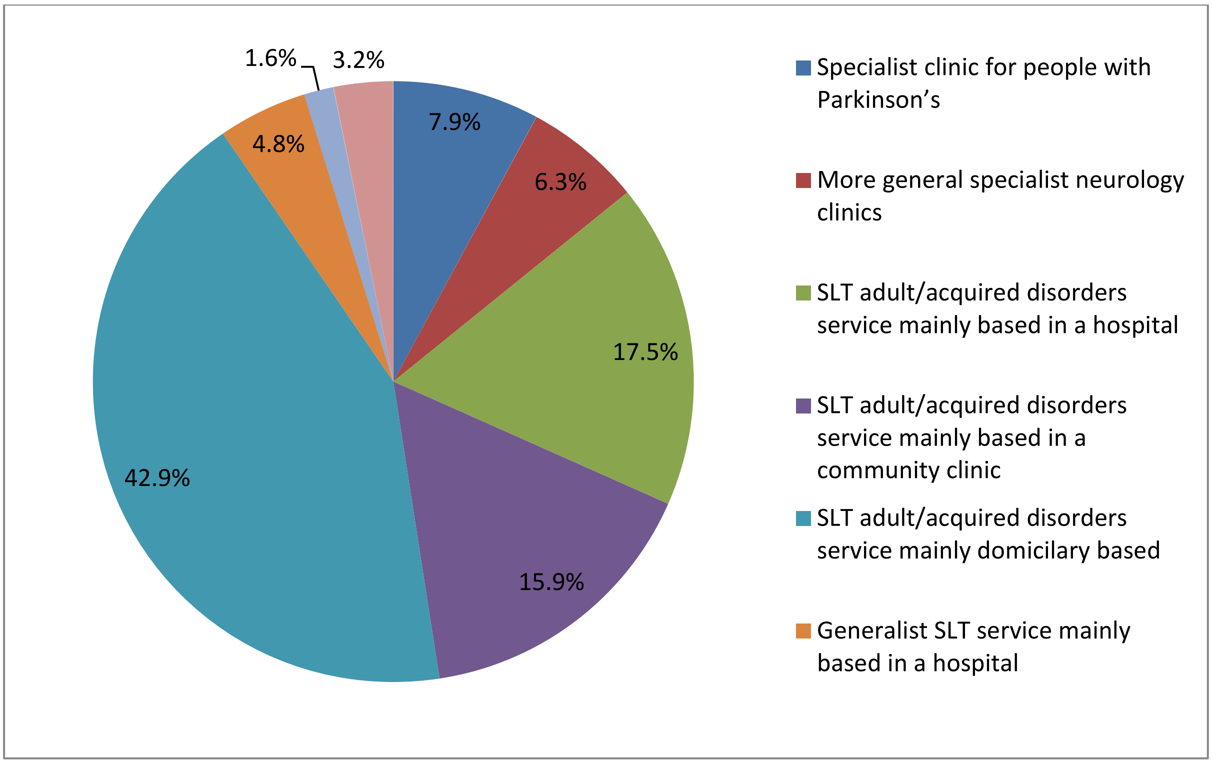


Table 91: Services specialising in treatment of people with neurological conditions

Specialising in neurological conditions	Services
Yes	76.2%
No	23.8%
Number:	63

Table 92: Services specialising in treatment of people with Parkinson's

Specialising in Parkinson's	Services
Yes	47.6%
No	52.4%
Number:	63

Most services (69.9%) were staffed with 1–3 full time equivalent speech and language therapists seeing people with Parkinson's, and therapists saw people with Parkinson's as part of a more general case mix. Parkinson's constituted less than 20% of annual referrals in 39 services (61.9%) and more than 80% of annual referrals in five services. People with

Parkinson's were mostly seen in either outpatient/community clinics (64.6%) or their homes (28.4%).

Referrals for SLT were received from Parkinson's nurses (34.0%), medical and allied health colleagues (34.6%) or other sources (26.0%). Only 3.2% were self-referrals.

Table 93: Source of referrals

Referral source	Patients
Elderly Care clinic	5.7%
General Neurology clinic	12.9%
Parkinson's nurse	34.0%
Allied health professions colleague	12.7%
SLT colleague	5.5%
Self/relative	3.2%
Other	26.0%
Number:	820

Accessing Parkinson's-related CPD

Of the audited services, 79.4% reported that Parkinson's-related CPD was available at least yearly.

Table 94: Access to Parkinson's-related CPD at least yearly

Access to CPD	Services
Yes	79.4%
No	20.6%
Number:	63

Table 95: Documented induction and support strategies for new therapists

Induction and support strategies	Services
Yes, specifically in relation to patients with Parkinson's	14.3%
Yes, as part of more general competencies	50.8%
No	34.9%
Number:	63

Table 96: Support available to therapists in the SLT service

Type of support	Services
Consult any member of the Parkinson’s specialist MDT of which they are a member	22.2%
Consult members of a general Neurology/Elderly Care specialist service of which they are a member	14.3%
Doesn't work directly in specialist Parkinson’s clinics, but has access to Parkinson’s specialist MDT/Parkinson’s nurse	50.8%
Doesn't work directly in a specialist clinic, but has access to advice from a specialist Neurology or Elderly Care MDT	11.1%
No access to more specialised advice	1.6%
Number:	63

Table 97: SLT assistants involved in the delivery of care

Involvement of SLT assistants	Services
Always	3.2%
Sometimes	55.6%
Never	41.3%
Number:	63

Availability of services for speech and swallowing changes

The majority of SLT services offered a full service for communication changes (90.5%) and for swallowing/drooling (93.7%).

Table 98: SLT 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	90.5%
Not full service, some patients not seen depending on their stage of Parkinson’s	3.2%
Not full service, restricted by number of hours assigned (eg patients can receive only 10 hours before discharge/re-referral/placed on review)	1.6%
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)	3.2%
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 SLT Parkinson’s service	0.0%
Not full service, some patients not seen depending on prioritization in overall SLT service	0.05%
No service	3.3%
Number:	63

Table 99: SLT available for people with Parkinson’s for eating/swallowing/drooling issues irrespective of Parkinson’s phase at referral

Service available for eating, swallowing and drooling	Services
Full service, all referrals seen	93.7%
Not full service, some patients not seen depending on stage of their Parkinson’s	0.0%
Not full service, restricted by number of hours assigned (eg patients can receive only 10 hours before discharge/re-referral/placed on review)	0.0%
Not full service, some patients not seen depending on postcode/area	0.0%
Not full service, some patients not seen depending on service (eg Neurology versus Elderly Care)	4.8%
Not full service, some patients not seen depending on issue (eg communication versus swallowing)	0.0%
Not full service, some patients not seen depending on prioritization in SLT Parkinson’s service	0.0%
Not full service, some patients not seen depending on prioritization in overall SLT service	1.6%
No service	0.0%
Number:	63

The Lee Silverman Voice Treatment (LSVT) programme was offered in full by 34.9% of services. It was not available to all potentially eligible people with Parkinson’s in 17.5% of services. A similar alternative programme to LSVT was offered by 27.0% of services. Only 3.2% of services had no one qualified to deliver LSVT.

Table 100: 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	34.9%
Not all eligible candidates able to receive full service	17.5%
Variant(s) of LSVT offered	27.0%
LSVT not offered due to lack of LSVT trained SLT	3.2%
LSVT not offered due to no service delivery decision	17.5%
Number:	63

Table 101: 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	31.7%
Yes, full access via other AAC service	17.5%
Restricted AAC service due to financial restrictions	42.9%
Restricted AAC service due to equipment range	4.8%
No service	3.2%
Number:	63

Review policy

Only eight SLT services (12.7%) operated a recommended regular review policy within 6–12 months.

Table 102: Review policies in SLT services

Review policy	**Services**
All patients in SLT service routinely reviewed every 6–12 months	12.7%
Some patients reviewed at request of wider MDT/Parkinson’s nurse	25.4%
Some patients reviewed according to local prioritisation	6.3%
Patients are not automatically reviewed	11.1%
No fixed time set for review	27.0%
Patients are discharged after a set number of treatment sessions/episodes of care	17.5%
Number:	63

Table 103: 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	9.5%
Selective range of formal speech/voice and/or language assessments	19.0%
Informal disease-specific assessment proforma	20.6%
No specific assessments stipulated	50.8%
Number:	63

Many speech and language therapists use only informal, non-standardised assessments, which may have low validity and reliability in charting status and change/outcomes, or do not assess all potential areas of change and do not record a justification for this.

Table 104: Swallowing measures specifically stipulated to be carried out at initial assessment and each review point

Initial swallowing assessment	Services
Standardised assessments of swallowing	14.3%
Selective range of formal assessments	11.1%
Informal disease-specific assessment proforma	22.2%
No specific assessments stipulated	52.4%
Number:	63

These figures suggest that people with Parkinson’s are not being assessed using validated clinical assessments (as opposed to videofluoroscopy/fiberscopic assessments), and there is a high use of informal or non-specific assessments.

Table 105: Saliva management included in the SLT assessment and treatment plan if required

Saliva management	Services
Yes	93.7%
No	6.3%
Number:	63

Patient audit

Table 106: Patients experiencing first episode of care within any SLT service

First episode of SLT care	Patients
Yes	65.5%
No	34.5%
Number:	820

Table 107: Stage of Parkinson’s at first referral to SLT

Parkinson’s stage	Patients
Diagnosis	14.1%
Maintenance	57.9%
Complex	18.3%
Palliative	1.7%
Not Known	7.9%
Number:	820

Table 108: Description of current episode of care

Current episode of care	Patients
Initial assessments only	24.1%
Review appointment only	16.6%
Group treatment only	2.1%
Individual treatment only	39.1%
Group and individual treatment	11.1%
Other	7%
Number:	820

Table 109: Referrals that meet target time between referral and first SLT appointment

Target met	Patients
Yes	85.4%
No, and no reason documented	8.3%
No, but reason documented (eg clinician leave)	6.3%
Number:	820

Table 110: Target met for waiting time between SLT intention-to-treat decision and first appointment

Target met	Patients
Yes	90.9%
No and no reason documented	4.0%
No, but reason documented (eg failed appointment)	5.1%
Number:	820

Referrals

In people with Parkinson’s referred for SLT, most (79.0%) were referred for assessment of specific aspects of their communication/swallowing.

Table 111: Reason for referral to the audited service

Referral reason	Patients
General assessment opinion	9.6%
Specific assessment opinion: breathing, voice, speech, swallowing, drooling or other	79.0%
Treatment	11.2%
Unknown	0.1%
Number:	820

On first referral, 92.8% of patients received a full communication assessment or if a full assessment was not made the reasons for this were documented. The equivalent figure for swallowing assessments on first referral was 93.4%.

Table 112: Full communication assessment carried out on first referral

Communication assessed	Patients
Yes	67.7%
No assessments documented	7.2%
No, but reasons why assessment was inappropriate documented	25.1%
Number:	820

Table 113: Full swallowing assessment carried out on first referral

Swallowing assessed	Patients
Yes	40.3%
No assessments documented	6.6%
No, but reasons why assessment was not appropriate documented	53.1%
Number:	818

It is important to consider these figures together with Tables 104 and 105 above. Together, the responses show that although assessments were conducted they were not necessarily the best suited assessments (ie there is a heavy reliance on informal, non-standardised procedures).

Table 114: Communication assessment carried out at each review

Communication assessment at review	Patients
Yes	56.9%
No assessments documented	9.5%
No, but reasons why assessment was inappropriate documented	33.6%
Number:	819

Table 115: Swallowing assessment carried out at each review

Swallowing assessment at review	Patients
Yes	44.5%
No assessments documented	9.2%
No, but reasons why assessment was inappropriate documented	46.3%
Number:	814

Table 116: Audio or video recording made at initial assessment and follow-up appointments, and recording available

Recording made	Patients
Yes and available	11.6%
Yes, but not available	5.9%
No, Trust or Board governance rules do not permit acquisition or storage of digital data	14.3%
No	68.3%
Number:	820

Assessments carried out

The key aspects of speech and loudness are routinely evaluated, while other areas of functioning (reading, writing, language, participation) are less well addressed in terms of routine assessment and use of standardised measures. Assessment of the key area of intelligibility is not neglected, but assessment appears to rest on nonstandard and informal assessments that have poor evidence for validity and reliability as accurate outcome measures. Assessment is not routinely documented in the context of overall impact of communication changes and effects of communication changes on participation in society. While swallowing is attended to in over 90% of cases, the absence of consistent, systematic, more objective monitoring of change using recognised methods is an area for improvement. Further, while the majority of assessments examine communication in one-to-one situations, just under a third assess multispeaker situations, where communication is likely to be more difficult.

Table 117: Assessment results available for all speech subsystems for the initial assessment and all review appointments

Assessment results available	Patients
Yes, subsystems assessed in both stimulated and unstimulated conditions	28.0%
Restricted range of subsystems and/or conditions assessed, justification documented	22.8%
Restricted range of subsystems and/or conditions assessed, justification not documented	15.1%
No assessments documented, but with justification documented	28.8%
No assessments and no justification documented	5.2%
Number:	820

Table 117 suggests that assessment was not necessarily comprehensive.

Table 118: Tasks/contents covered by assessment (in people not seen for swallowing only)

Task covered	Patients
Speaking	97.9%
Reading	36.9%
Writing	12.0%
One-to-one	83.4%
Group	31.5%
Number:	608

Table 119: Voice-respiration and prosody parameters assessed (in people not seen for swallowing only)

Parameter assessed	Patients
Loudness/amplitude level and variation	94.1%
Pitch, pitch range and variation	65.6%
Voice quality	77.9%
Speech/articulation rate	79.4%
Number:	608

Disappointingly only 10.5% employ a standardised intelligibility assessment, whilst 53.7% rely on less accurate and less sensitive informal (20.5%) or rating scale (33.2%) evaluations for intelligibility.

Table 120: Intelligibility assessed

Intelligibility assessed	Patients
Standardised diagnostic intelligibility test completed and score given	10.5%
Informal assessment, non-standardised tool/subsection of other test completed and score given	20.5%
Informal assessment (eg rating scale) completed	33.2%
No assessment/results documented but justification given	29.5%
No assessment documented and no justification given	6.3%
Number:	820

Around two-thirds assess communication participation (62.7%) and the impact of Parkinson’s on communication participation (63.5%). Given that these are main outcome targets, these represent low figures.

Documented assessment of communication strengths and needs

The full details of test scores and their interpretations regarding communication strengths and needs were documented in just over half of patients audited.

Figure 13: Percentage of SLT patients for whom communication strengths and needs were documented

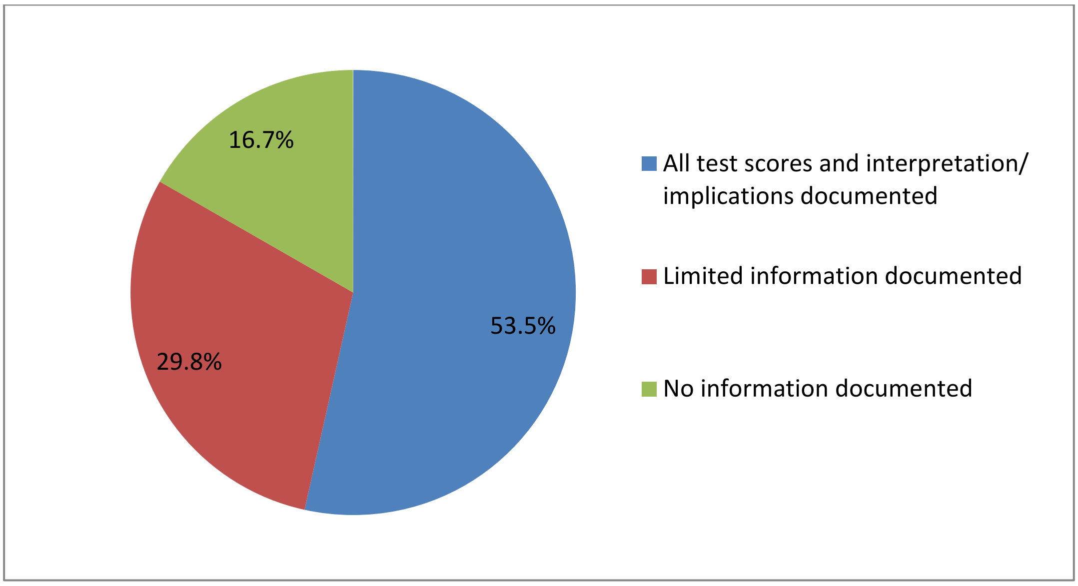


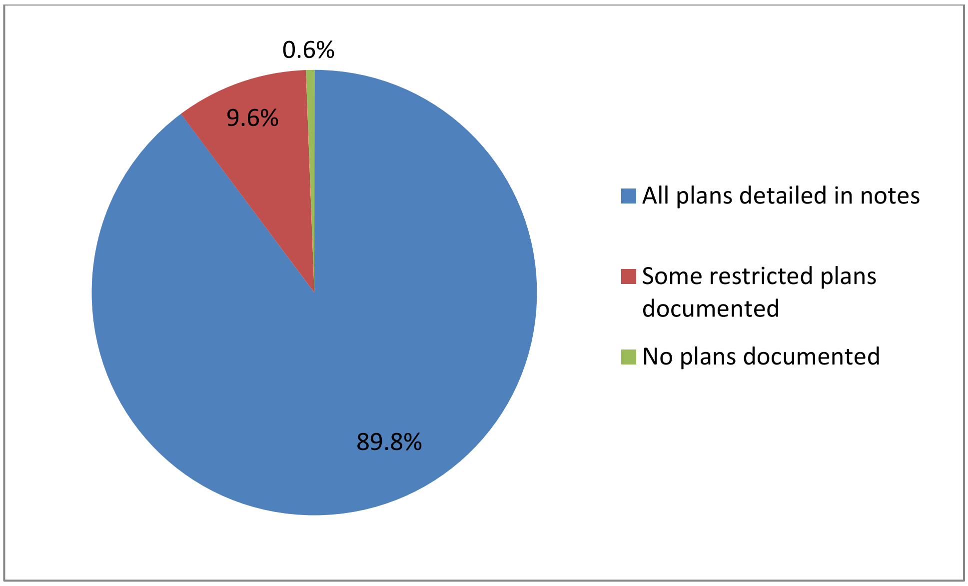
Table 121: Notes record whether assessments were carried out during 'on' or 'off' state

'On' or 'off' state recorded	Patients
Yes	31.8%
No	68.2%
Number:	820

Management plans based on assessment outcomes

Although full assessment results and patients' strengths and needs were often not documented, the majority of people with Parkinson's did have a clear management plan documented. A complete breakdown of what details were or were not documented in clinical notes is given below.

Figure 14: Percentage of SLT patients with a clear management plan based on assessment outcomes



Assessments

Table 122: AAC need identified and addressed

AAC need addressed	Patients
Yes, fully	4.0%
Yes, partially, awaiting action from outside AAC service	0.7%
Yes, partially, limited range of AAC devices available	1.7%
Not addressed as not indicated	93.2%
Indicated, but no action documented	0.4%
Number:	820

Table 123: Assessment includes communication participation

Communication participation assessed	Patients
Yes	62.7%
No	12.2%
N/A, swallowing only	25.1%
Number:	820

Table 124: Assessment includes the impact of Parkinson’s on communication

Impact on communication assessed	Patients
Yes	63.5%
No	11.3%
N/A, swallowing only	25.1%
Number:	820

Table 125: Assessment includes the impact of communication changes on partner/carer

Impact of communication changes assessed	Patients
Yes	45.0%
No	21.2%
No carer	8.7%
N/A, swallowing only	25.1%
Number:	820

Table 126: 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	92.2%
No explanation made/documented, but justification documented	2.8%
No explanation made/documented and no justification documented	5.0%
Number:	820

Table 127: Information supplied to enable informed decisions about care and treatment

Information supplied	Patients
Intervention specifically included education and advice on self-management, and was documented	90.2%
No explanation made/documented, but justification documented	3.8%
No explanation made/documented and no justification documented	6.0%
Number:	820

Table 128: Onward referrals (eg ENT, video fluoroscopy) made where recommended in notes

Onward referrals	Patients
Yes	32.0%
None, reasons documented	3.3%
None, reasons not documented	1.1%
No onward referrals recommended	63.7%
Number:	820

Interventions

Table 129: Prophylactic and anticipative interventions used, not just symptomatic

Prophylactic and anticipative interventions used	Patients
Yes, education/planning for upcoming issues included	83.8%
No, no prophylactic component indicated	16.2%
Number:	820

Table 130: Indication of preparation during an earlier phase for patients in later stages

Preparation for later stages	Patients
Yes	16.7%
No	6.3%
Not referred in early stages	17.4%
Patient not in later stages	59.5%
Number:	820

Table 131: Targets of intervention (where patient not seen for swallowing only)

Intervention target	Patients
Pitch	40.7%
Prosody	32.1%
Loudness	81.4%
Intelligibility	75.9%
Number:	608

Although intelligibility and loudness were major intervention targets, as expected, very few speech and language therapists conducted a standardised or objective measure of these. Therefore it remained unclear whether intervention targets had been achieved.

Table 132: Interventions targeting features outside direct speech/voice work

Intervention	Patients
Patient education/advice	82.2%
Managing patient participation	49.3%
Managing patient impact	46.4%
Managing generalisation outside clinic	50.5%
Carer education/advice	44.6%
Managing work/occupational impact	11.7%
Other	11.2%
Number:	819

Table 133: Final outcomes reported back to referrer or other key people at the conclusion of intervention (or interim reports where treatment lasts longer)

Reports made	Patients
Yes	87.4%
No	12.6%
Number:	818

Table 134: Reports detail the intervention, duration, frequency, effects and expected prognosis, and provide assessment results

Details included in reports	Patients
Yes	69.8%
No	30.2%
Number:	818

Table 135: Referral letters to other agencies include relevant history

Relevant history included	Patients
No onward referrals recommended	*64.0%*
Yes	87.4%
No	12.6%
Number:	818

Table 136: Referral letters to other agencies include questions the referrer wishes to have answered

Questions included	Patients
No onward referrals recommended	*64.0%*
Yes	22.4%
No	13.6%
Number:	816

Table 137: Referral letters to other agencies include type of referral requested (eg single consultation for advice or initiation of treatment)

Type of referral included	Patients
No onward referrals recommended	*64.0%*
Yes	21.6%
No	14.5%
Number:	816

Patient Reported Experience Measure (PREM)

Aims

The PREM questionnaire gathered views from people with Parkinson's and their carers about their Parkinson's service. Of the 432 services that submitted clinical data to the audit, 52.1% also took part in the PREM. This provided questionnaires from 5,834 people with Parkinson's and their carers. The PREM questionnaire can be found at Appendix G.

Demographics

The majority of PREM questionnaires (72.4%) were completed by a person with Parkinson's rather than a carer.

Table 138: Individual completing the PREM questionnaire

Individual completing questionnaire	
Patient	72.4%
Carer	22.2%
Not answered	5.4%
Number:	5834

The majority of people with Parkinson's represented were male (57.7%) and white British (92.0%).

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

Ethnicity	
White British	92.0%
Asian/Asian British	2.8%
Other white background	2.0%
Black/black British	1.0%
Not stated	1.0%
Other ethnic group	1.0%
Mixed race	0.2%
Number:	5834

Table 140: Age of people with Parkinson's represented in the PREM

Age	
20–29	0.1%
30–39	0.3%
40–49	1.6%
50–59	5.8%
60–69	22.8%
70–79	43.1%
80–89	24.3%
90+	1.6%
Not answered	0.4%
Number:	5834

Less than 4% of people with Parkinson's represented lived in a care home, and 19.6% lived alone.

Table 141: Percentage of people with Parkinson's represented who live alone

Lives alone	
No	76.1%
Yes	19.6%
No, care home	3.9%
Not answered	0.4%
Number:	5834

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

Table 142: Duration of Parkinson’s

Parkinson’s duration	
Less than 1 year	6.7%
1–2 years	16.7%
3–5 years	30.5%
6–10 years	25.6%
11–20 years	16.0%
Over 20 years	2.8%
Not answered	1.7%
Number:	5834

The demographics of the people with Parkinson’s represented in the PREM questionnaire were comparable to those seen in the audit data.

Table 143: Duration of attendance at current Parkinson’s service

Duration of service attendance	
Less than 1 year	15.4%
1–2 years	20.9%
3–5 years	30.1%
Over 5 years	31.5%
Not answered	2.1%
Number:	5834

Findings

Frequency of review by consultant or Parkinson’s nurse

The majority of respondents (73.3%) felt that the number of reviews carried out by their consultant met their needs, while 67.5% felt this was true for their Parkinson’s nurse. Some respondents felt that they were reviewed less than was needed by either their consultant (13.2%) or Parkinson’s nurse (10.2%).

Table 144: Number of face-to-face or telephone reviews by consultant meets needs

Meets needs (consultant)	
Yes	73.3%
Less than needed	13.2%
Not answered	10.1%
No	1.6%
More than needed	1.5%
No access	0.2%
Number:	5834

Table 145: Number of face-to-face or telephone reviews by Parkinson’s nurse (if individual has one) meets needs

Meets needs (Parkinson’s nurse)	
Yes	67.5%
Not answered	17.4%
Less than needed	10.2%
No	3.1%
More than needed	1.4%
No access	0.3%
Number:	5834

Contacting Parkinson’s service between reviews

Respondents to the PREM reported whether they feel able to contact their Parkinson's service for advice in between scheduled reviews. The tables below give figures for the different professionals and service areas.

Table 146: Access to service co-ordinator

Service co-ordinator access	
No access	3.3%
Not answered	31.7%
Not aware	11.8%
Not needed	8.7%
Not sure	13.0%
Yes	31.5%
Number:	5834

Table 147: Access to Parkinson’s nurse

Parkinson’s Nurse access	
No access	3.2%
Not answered	10.1%
Not aware	2.6%
Not needed	3.0%
Not sure	6.4%
Yes	74.6%
Number:	5834

Table 148: Access to OT

OT access	
No access	5.0%
Not answered	36.5%
Not aware	6.7%
Not needed	15.9%
Not sure	11.7%
Yes	24.2%
Number:	5834

Table 149: Access to Physiotherapy

Physiotherapy access	
No access	5.9%
Not answered	33.7%
Not aware	5.2%
Not needed	13.1%
Not sure	10.9%
Yes	31.2%
Number:	5834

Table 150: Access to SLT

SLT access	
No access	5.3%
Not answered	35.8%
Not aware	5.9%
Not needed	21.1%
Not sure	10.1%
Yes	21.7%
Number:	5834

Quality of services provided within a Parkinson's service

Figure 15: Quality of service offered by consultant or doctor

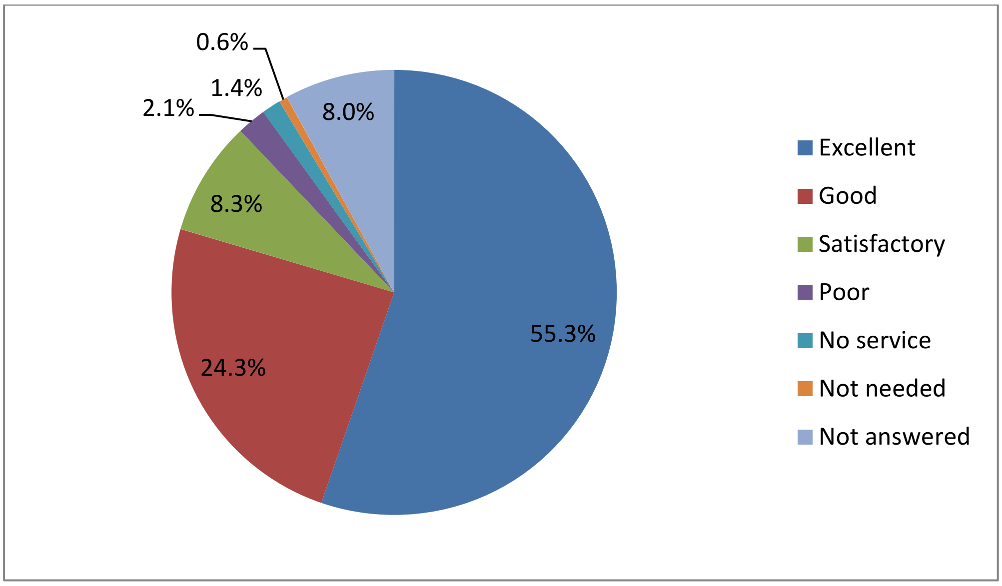


Figure 16: Quality of service offered by Parkinson's nurse

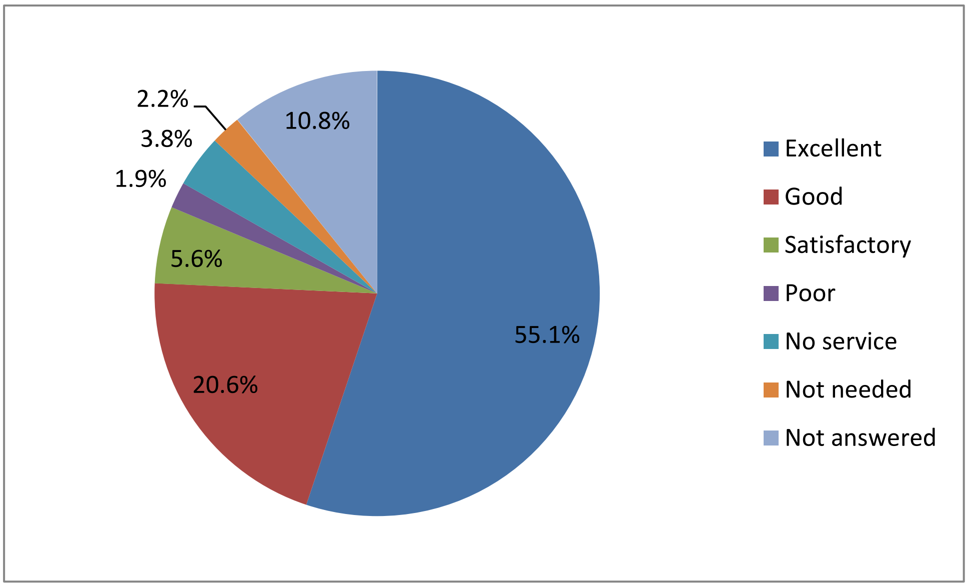


Figure 17: Quality of service offered by occupational therapists

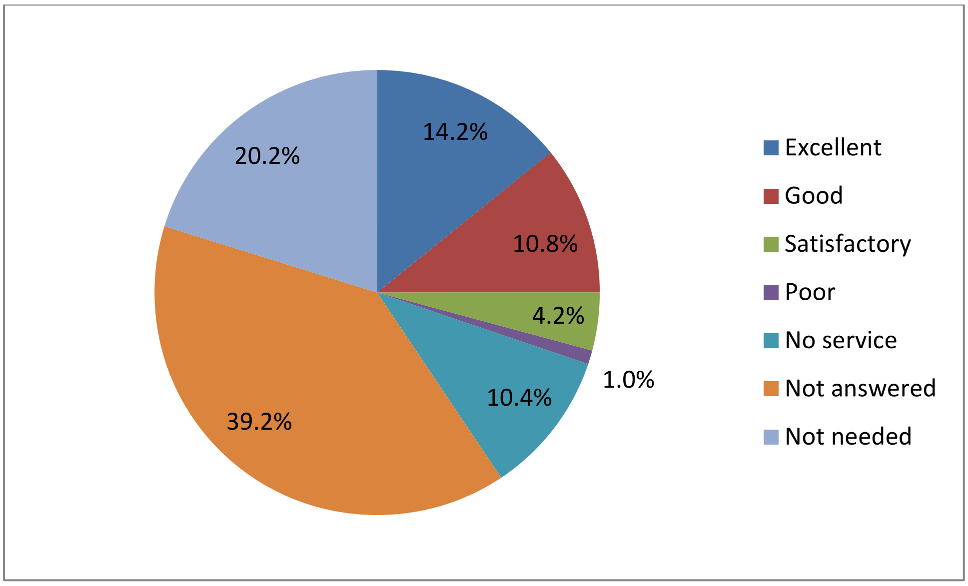


Figure 18: Quality of service offered by physiotherapists

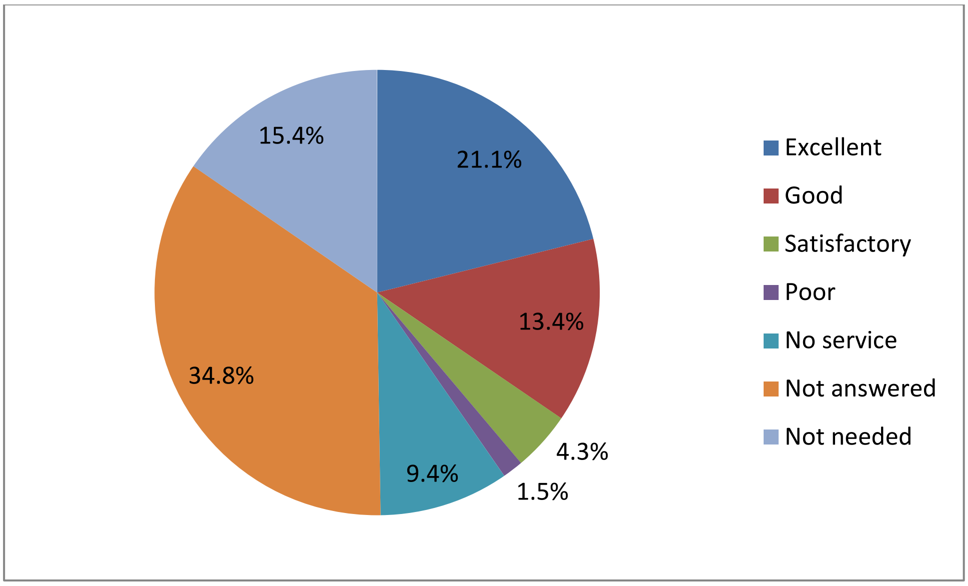
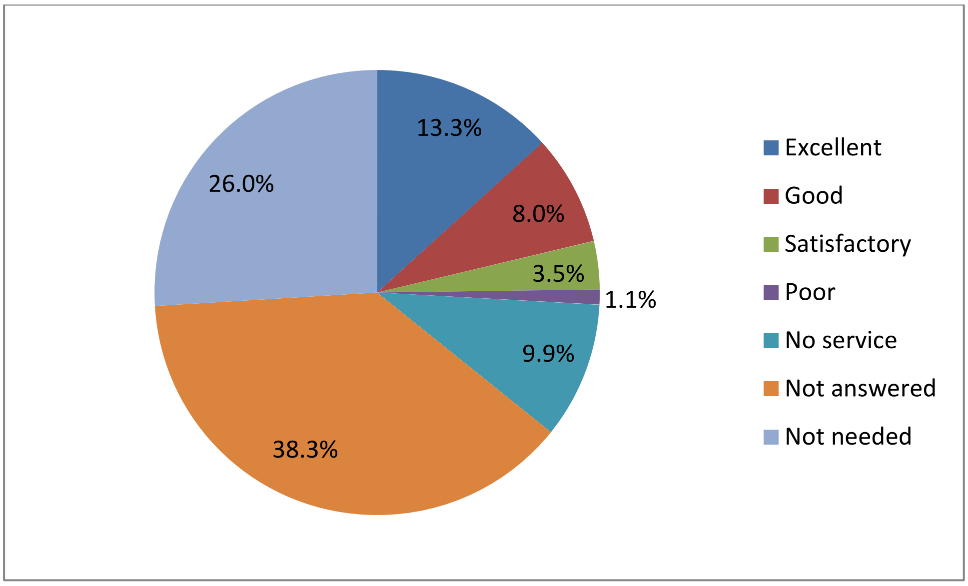


Figure 19: Quality of service offered by speech and language therapists



Information provided by Parkinson's service

Although the majority of respondents (64.9%) said they had received enough information about Parkinson's at diagnosis, there was still a significant number who had not or were not sure.

Figure 20: People with Parkinson's who received enough information about Parkinson's on diagnosis (%)

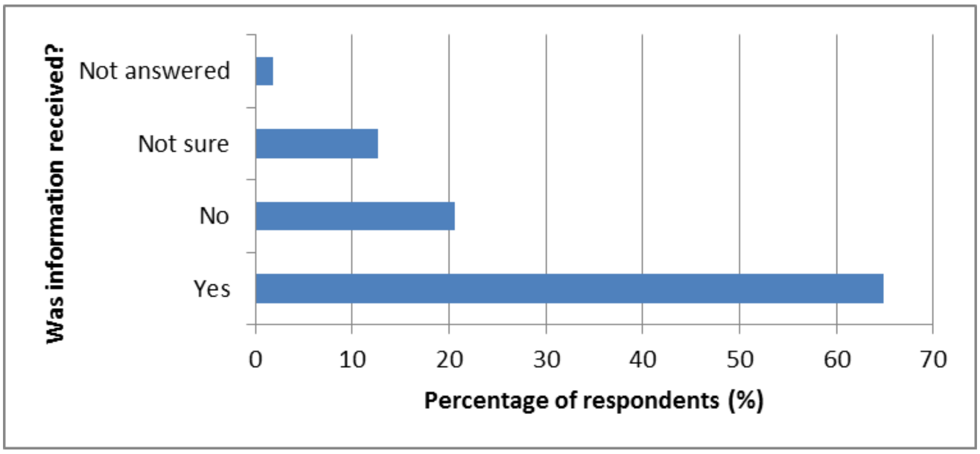


Table 156: People with Parkinson’s who received enough information about Parkinson's at diagnosis

Enough information received at diagnosis	
Yes	64.9%
No	20.6%
Not sure	12.7%
Not answered	1.8%
Number:	5834

Table 157: People with Parkinson’s given enough information about new medication, including potential side effects

Information provided about new medication	
Yes	62.8%
Not sure/no new medication started	17.9%
No	17.2%
Not answered	2.1%
Number:	5834

Table 158: Services providing information about how to access the range of support and information available from Parkinson's UK

Information provided about Parkinson’s UK	
Yes	63.1%
Not sure	17.2%
No	14.9%
Not answered	4.8%
Number:	5834

Table 159: Services providing information about the role of social work for people with Parkinson’s and their carers

Information provided about social work	
Yes	32.8%
Not sure	25.2%
No	22.7%
Not answered	19.3%
Number:	5834

Table 160: Services providing information about support for carers

Information provided about carer support	
Not answered	35.3%
Yes	23.2%
Not sure	23.2%
No	18.3%
Number:	5834

Advice given to drivers about contacting the DVLA or DVA and car insurance company

Of people with Parkinson’s who answered this question, 26.5% either had not been given information regarding contacting the DVLA (or DVA) or their insurance company or were not sure whether they had.

Table 161: Drivers given verbal and/or written advice about contacting the DVLA (or DVA) and car insurance company

Advice given	
Yes	73.4%
No	23.0%
Not sure	3.5%
Number:	3502

Medicines management in hospital

In the last year, 22.7% of people with Parkinson’s represented had been in hospital.

Table 162: People with Parkinson’s admitted to hospital in the last year

Hospital admission	
No	74.3%
Yes	22.7%
Not answered	2.9%
Number:	5834

Delayed or missed Parkinson's medications in hospital impacts on mobility and recovery and is one of the reasons that people with Parkinson's stay longer in hospital than those of the same age without Parkinson's (on average spending 7 days longer[6]). Parkinson's UK created the Get It On Time Campaign in 2007 to promote better practice in hospital care of people with Parkinson's. This is not yet a focus of the National Audit, but was raised in the PREM questionnaire.

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

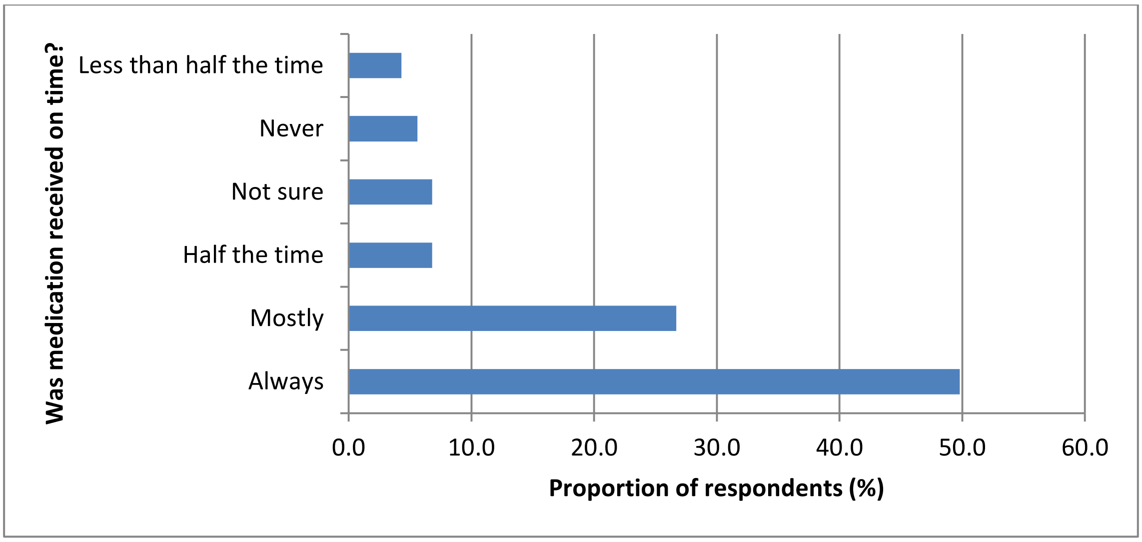


Table 163: Percentage of people with Parkinson's who received their Parkinson's medication on time while in hospital

Medication on time	
Always	49.8%
Mostly	26.7%
Half the time	6.8%
Not sure	6.8%
Never	5.6%
Less than half the time	4.3%
Number:	1581

Of those who did not always receive their medication on time, 38.5% said this had a negative or significantly negative effect, 37.3% were unsure if it had an effect, 18.4% said it had no effect and 5.9% said it had a positive effect.

Table 164: Effect experienced after receiving Parkinson’s medication late while in hospital

Effect experienced	
Not sure	37.3%
Significant negative effect	19.3%
Negative effect	19.2%
No effect	18.4%
Positive effect	5.9%
Number:	902

In some cases, hospitals will allow a patient to self-medicate, which ensures they take their medication on time every time. Of our respondents, 69.6% wanted to take their own medication and 53.7% were able to. However, 32.3% were unable to self-medicate and 14.0% were not sure if they were able to.

Table 165: Percentage of people with Parkinson’s who wanted to take their own medication in hospital

Wanted to self-medicate	
Yes	69.6%
No	30.4%
Number:	1327

Table 166: Percentage of people with Parkinson’s who were able to self-medicate in hospital

Able to self-medicate	
Yes	53.7%
No	32.3%
Not sure	14.0%
Number:	1142

Overall service quality

Figure 22: Percentage of people with Parkinson’s who feel listened to by their Parkinson’s service

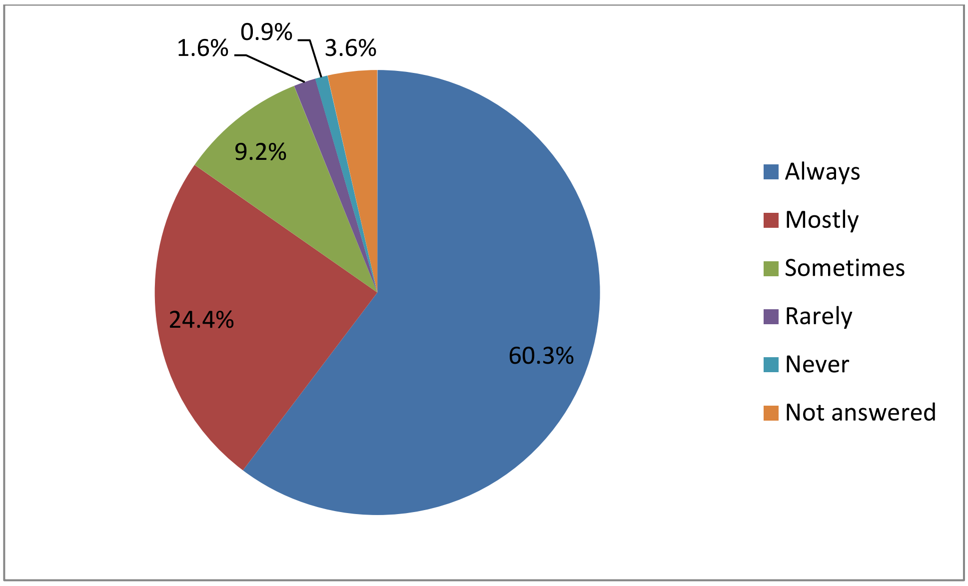


Table 167: Percentage of people with Parkinson’s who feel listened to by their Parkinson’s service

Feel listened to	
Always	60.3%
Mostly	24.4%
Sometimes	9.2%
Not answered	3.6%
Rarely	1.6%
Never	0.9%
Number:	5834

Figure 23: Percentage of people with Parkinson's who feel involved by their Parkinson's service in decisions about their care

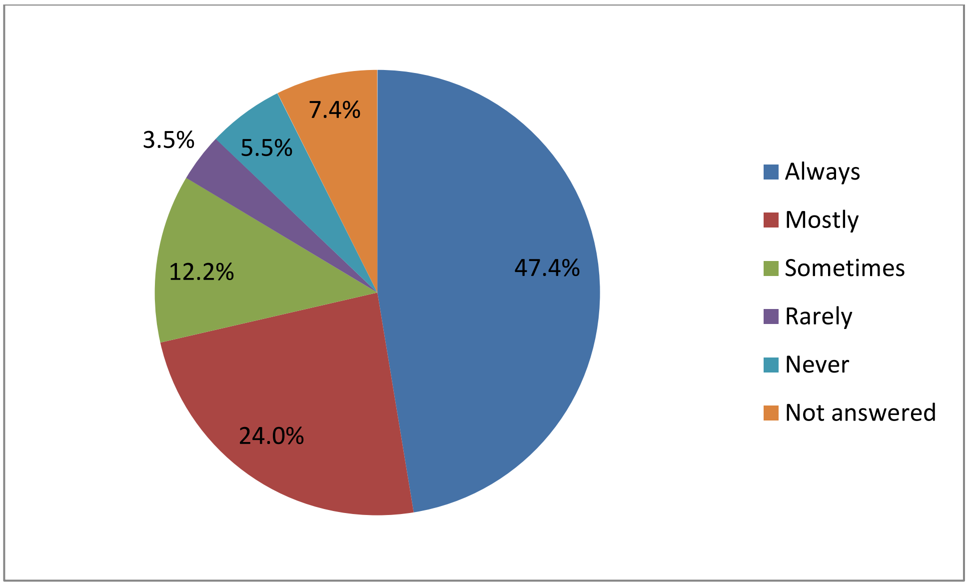


Table 168: Percentage of people with Parkinson's who feel involved by their Parkinson's service in decisions about their care

Involved in decisions about care	
Always	47.4%
Mostly	24.0%
Sometimes	12.2%
Not answered	7.4%
Never	5.5%
Rarely	3.5%
Number:	5834

Table 169: Percentage of people with Parkinson's who feel treated as a whole person (including other conditions they may have) rather than only as a Parkinson's patient

Treated as a whole person	
Always	61.9%
Mostly	19.5%
Not answered	7.7%
Sometimes	6.6%
Never	2.2%
Rarely	2.0%
Number:	5834

Table 170: Percentage of people with Parkinson’s who feel their service is improving or getting worse

Service improving or getting worse	
Improving	45.9%
Same	44.1%
Not answered	7.8%
Getting worse	2.2%
Number:	5834

Free text comments

Over 1,800 comments were collected from the PREM questionnaires, covering a wide range of issues for people with Parkinson’s and their carers. Over 70% of those responding reported a high level of satisfaction with their service, with many saying that a high value is placed on multidisciplinary input.

However, not all comments were positive. Roughly 7% said they had significant concerns regarding timing and delays within services, and a further 7% felt there was a lack of information and communication regarding Parkinson’s. The reliance of people with Parkinson’s on their Parkinson’s nurse was apparent. This was mostly highlighted by very appreciative comments, but many people commented on the difficulties faced if a Parkinson’s nurse was not available.

A qualitative report on the free-text comments is available at Appendix H.

Actions indicated by the audit findings

Elderly Care and Neurology

Overall, services for patients managed by both Elderly Care and Neurology services appear to have improved since the 2012 audit. Patient satisfaction with their local services is also high. However, there are some clear areas where improvements need to be made.

Firstly, there is a general lack of integrated clinics in both Elderly Care and Neurology, despite evidence to indicate that this provides the highest standard of care to people with Parkinson’s. We need to better understand the obstacles preventing the use of integrated clinics. This knowledge can inform service providers and commissioners planning services.

Secondly, several non-motor symptoms are often not being assessed in many people with Parkinson’s. In particular, excessive daytime sleepiness, postural hypotension, malnutrition, pain and saliva management are often not asked about. In services that have a lack of recorded questioning in these areas, the non-motor symptoms (NMS) questionnaire or an alternative form could be used. Healthcare professionals, people with Parkinson’s and their carer could then use these to prioritise the impact of the symptoms experienced, highlighting which non-motor symptoms are most important to each patient. Blood pressure and nutrition screening appear to be particularly lacking in neurology clinics. This could easily be improved by using a system in which the clinic nurse checks postural blood pressure and weight for every patient on arrival.

Medico-legal advice, eg about potential impulse control disorders or the impact of excessive daytime sleepiness on driving, must be recorded for all relevant patients. Adapting clinic record systems could highlight these issues and encourage them to be explored with patients and then documented.

Falls and fractures have a major impact on people with Parkinson’s and so it is vital that services consider how bone health may be adequately addressed within the clinic setting. The Parkinson’s Excellence Network is developing structures to support improved management of bone health in Parkinson’s. These improvements will hopefully be reflected in future audits.

Many people with Parkinson’s will receive constant support throughout their journey with Parkinson’s from their Parkinson’s clinic and specialist team. It is therefore likely that these teams are best placed to discuss advanced care planning, eg Lasting Power of Attorney and Anticipatory Care Plans, with their patients. Services should ensure that sensitive written information is routinely available, and consider creating prompts in clinic documentation for clinicians to invite discussion in this important area.

Occupational therapy

The audit results suggest that OT services and their commissioners should ensure wider use of standardised assessments to obtain clear outcome measures for people with Parkinson‘s. Evidence for the impact of OT interventions in Parkinson’s will provide a clearer evidence base that can help develop more effective services.

Physiotherapy

There has been an improvement in the time people with Parkinson’s wait for a Physiotherapy referral following initial diagnosis. But, referral within the first year should continue to be encouraged to enable education and uptake or maintenance of exercise, and to provide advice and support.

Physiotherapists working with people with Parkinson's should also be encouraged to use recognised, validated and appropriate outcome measures. Parkinson's specific education, including signposting to evidence-based guidelines, should be available for every physiotherapist working with people with Parkinson's.

Speech and Language therapy

The audit highlighted several areas for improvement in SLT services. First, services should aim for earlier referral to SLT to provide education and preventive interventions even if no direct work is required on speech or voice. Second, validated and reliable assessments should be used to measures changes in communication in Parkinson's. Third, change should be monitored by documenting outcomes in clinical notes. Finally, there should be improvements in review policies reflecting recommended practice. This will ensure that people with Parkinson's receive timely help for any current or emerging difficulties.

Conclusion

The 2015 audit is the largest to date, including a higher number of services than any previous audit. We therefore believe our findings are robust and have considerable external validity for UK Parkinson's services. Several areas of good practice and improvements since previous audits have been identified. Nonetheless, as this report shows, there are a number of shortcomings still to be addressed.

The Parkinson's Excellence Network will provide the vehicle to close the audit loop by highlighting national and local priorities for improvement and the development of service improvement plans. The latter will address several of the shortcomings listed above, but will also focus upon regionally specific issues. Support for the development of these plans will be provided by Parkinson's UK.

The next audit round is scheduled for 2017. We hope that more services will participate again next time, and by adopting a broadly similar methodology we will be able to directly compare data with the current findings.

References

1. Occupational Therapy for People with Parkinson’s – Best practice guidelines. Aragon and Jill Kings on behalf of the College of Occupational Therapists Specialist Section – Neurological Practice, Parkinson’s UK and College of Occupational Therapists (2010)
2. National Service Framework for Long Term Conditions, Department of Health (2005)
3. NICE guideline for Parkinson's disease: National clinical guideline for diagnosis and management in primary and secondary care (CG35), Department of Health (2006)
4. The European Physiotherapy Guideline for Parkinson’s Disease, Keus SHJ, Munneke M, Graziano M, et al, KNGF/ParkinsonNet (2014)
5. The Royal Dutch Society for Physical Therapy in Patients with Parkinson’s Disease, Royal Dutch Society for Physical Therapy (2006)
6. Measuring the burden and mortality of hospitalisation in Parkinson's disease: A cross-sectional analysis of the English Hospital Episodes Statistics database 2009-2013; Low et al, Parkinsonism and Related Disorders 21 (2015) 449-454

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Appendix A
Definition of phases of Parkinson's

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).

UK PARKINSON'S Excellence Network

Appendix B
Participating services

2015 UK Parkinson’s Audit – Participating services

England

Elderly Care		
1	Aintree University Hospitals NHS Foundation Trust	Aintree University Hospital
2	Airedale NHS Foundation Trust	Airedale General Hospital
3	Ashford & St Peter’s Hospitals NHS Foundation Trust	St Peter's Hospital, Chertsey
4	Birmingham Community Healthcare NHS Trust	Moseley Hall Hospital, Birmingham
5	Brighton and Sussex University Hospitals NHS Trust	Princess Royal Hospital, Haywards Heath
6	Buckinghamshire Healthcare NHS Trust	Stoke Mandeville Hospital
7	Cambridgeshire & Peterborough NHS Foundation Trust	City Care Centre, Peterborough
8	Central London Community Healthcare NHS Trust	Edgware Community Hospital
9	Central Manchester University Hospital NHS Foundation Trust	Manchester Royal Infirmary
10	Central Manchester University Hospitals NHS Foundation Trust	Trafford General Hospital
11	Cheshire and Wirral Partnership NHS Foundation Trust	Stanney Lane Clinic, Ellesmere Port
12	Chesterfield Royal Hospital NHS Foundation Trust	Chesterfield Royal Hospital
13	County Durham and Darlington NHS Foundation Trust	Memorial Hospital, Darlington
14	Croydon Health Services NHS Trust	Croydon University Hospital
15	Dartford & Gravesham NHS Trust	Darent Valley Hospital
16	Derby Hospitals NHS Foundation Trust	London Road Community Hospital, Derby
17	Derbyshire Community Health Services	Ripley Hospital
18	Derbyshire Community Health Services NHS Foundation Trust	Walton Hospital, Chesterfield
19	Doncaster and Bassetlaw NHS Foundation Trust	Doncaster Royal Infirmary
20	Dorset County Hospital NHS Foundation Trust	Dorset County Hospital
21	Dudley Group NHS Foundation Trust	Russells Hall Hospital
22	East and North Herts NHS Trust	Lister Hospital, Stevenage
23	East Kent Hospitals University NHS Foundation Trust	Kent & Canterbury Hospital
24	Epsom and St Helier University Hospitals NHS Trust	St Helier Hospital
25	First Community Health and Care	Oxted Therapies Unit
26	Frimley Health NHS Foundation Trust	Frimley Park Hospital
27	Gloucestershire Hospitals NHS Foundation Trust	Gloucester Royal Hospital
28	Guy's and St Thomas' NHS Foundation Trust	St Thomas' Hospital

29	Hampshire Hospitals NHS Foundation Trust	Royal Hampshire County Hospital
30	Hampshire Hospitals NHS Foundation Trust	Basingstoke & North Hampshire Hospital
31	Heart of England NHS Foundation Trust	Birmingham Heartlands Hospital
32	Hinchingbrooke Healthcare NHS Trust	Hinchingbrooke Hospital
33	Isle of Man Department of Health & Social Care	Community Health Centre
34	Kettering General Hospital NHS Foundation Trust	Kettering General Hospital
35	Kettering General Hospital NHS Foundation Trust	Kettering General Hospital
36	King's College Hospital NHS Foundation Trust	Princess Royal University Hospital
37	King's College Hospital NHS Foundation Trust	Kings College Hospital, London
38	Luton and Dunstable University Hospital NHS Foundation Trust	Luton & Dunstable University Hospital
39	Maidstone and Tunbridge Wells NHS Trust	Tunbridge Wells Hospital
40	Maidstone and Tunbridge Wells NHS Trust	Maidstone Hospital
41	Newcastle Upon Tyne Hospitals NHS Foundation Trust	Belsay Unit, Campus for Ageing and Vitality, Newcastle
42	Newcastle Upon Tyne Hospitals NHS Foundation Trust	Freeman Hospital, Newcastle upon Tyne
43	Norfolk and Norwich University Hospitals NHS Foundation Trust	Norfolk and Norwich University Hospital
44	North Bristol NHS Trust	Cossham Hospital, Bristol
45	North Cumbria University Hospitals NHS Trust	Cumberland Infirmary
46	North Devon Healthcare NHS Trust	Exmouth Community Hospital
47	North East London NHS Foundation Trust	The Long Term Conditions Centre, Harold Wood
48	North Tees and Hartlepool NHS Foundation Trust	University Hospital of North Tees
49	Northampton General Hospital NHS Trust	Northampton General Hospital
50	Northern Lincolnshire and Goole NHS Foundation Trust	Diana Princess of Wales Hospital, Grimsby
51	Northumbria Healthcare NHS Foundation Trust	North Tyneside General Hospital
52	Nottingham University Hospitals NHS Trust	Nottingham City Hospital
53	Nottingham University Hospitals NHS Trust	NUH Rehabilitation Unit
54	Oxford University Hospitals NHS Foundation Trust	John Radcliffe Hospital
55	Peninsula Community Health	Camborne Redruth Community Hospital
56	Pennine Acute Hospitals NHS Trust	Fairfield General Hospital
57	Peterborough and Stamford NHS Trust	Peterborough City Hospital
58	Plymouth Community Trust	Mount Gould Hospital, Plymouth
59	Poole Hospital NHS Foundation Trust	Poole Hospital NHS Foundation Trust
60	Portsmouth Hospitals NHS Trust & Southern Health NHS Foundation Trust	Laurel Assessment Unit, Petersfield
61	Royal Berkshire NHS Foundation Trust	Royal Berkshire NHS Foundation Trust
62	Royal Bolton Hospital Foundation Trust	Royal Bolton Hospital
63	Royal Devon and Exeter NHS Foundation Trust	Royal Devon and Exeter Hospital
64	Royal Free London NHS Trust	The Royal Free Hospital
65	Royal Liverpool and Broadgreen University	Clinical Gerontology Outpatient Dept,

	Hospitals NHS Trust	Broadgreen Hospital
66	Royal Surrey County Hospital NHS Foundation Trust	Royal Surrey County Hospital
67	Royal United Hospitals Bath NHS Foundation Trust	Royal United Hospital, Bath (Bath and North East Somerset service)
68	Royal United Hospitals Bath NHS Foundation Trust	Royal United Hospital, Bath (Wiltshire service)
69	Salford Royal NHS Foundation Trust	Salford Royal Hospital
70	Salisbury NHS Foundation Trust	Salisbury Hospital
71	Sandwell and West Birmingham Hospitals NHS Trust	City Hospital, Birmingham
72	SEQOL & Great Western Hospitals NHS Foundation Trust	Great Western Hospital, Swindon
73	Sheffield Teaching Hospitals NHS Trust	Northern General Hospital
74	Sherwood Forest Hospitals NHS Foundation Trust	Newark Hospital
75	Solent NHS Foundation Trust	Southampton General Hospital
76	Solent NHS Foundation Trust	Southampton General Hospital
77	Solent NHS Foundation Trust & Portsmouth Hospitals NHS Trust	Amulree Assessment and Treatment Unit
78	South Warwickshire NHS Foundation Trust	Warwick Hospital
79	Southern Health & Portsmouth Hospitals NHS Trust	Oak Park Community Hospital, Havant
80	Southern Health NHS Foundation Trust	Longterm Condition Centre, Pikes Hill
81	Southern Health NHS Foundation Trust	Gosport War Memorial Hospital
82	Southern Health NHS Foundation Trust	Gosport War Memorial Hospital
83	Southport and Ormskirk Hospital NHS Trust	Southport District General Hospital
84	St Helens and Knowsley Teaching Hospitals NHS Trust	Allen Day Unit, St Helens Hospital
85	Surrey and Sussex Healthcare NHS Trust	East Surrey Hospital
86	Taunton and Somerset NHS Foundation Trust	Musgrove Park Hospital
87	The Ipswich Hospital NHS Trust	Ipswich Hospital
88	The Rotherham NHS Foundation Trust	Rotherham General Hospital
89	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Royal Bournemouth Hospital
90	United Lincolnshire Hospitals NHS Trust	Lincoln County Hospital
91	University Hospital of South Manchester NHS Foundation Trust	Day Hospital, Buccleuch Lodge, Manchester
92	University Hospitals Bristol NHS Foundation Trust	Bristol Royal Infirmary
93	University Hospitals of Leicester NHS Trust	Leicester General Hospital
94	Walsall Healthcare NHS Trust	Shortheath Clinic, Willenhall
95	Warrington and Halton Hospitals NHS Foundation Trust	Warrington and Halton Hospital
96	West Hertfordshire Hospitals NHS Trust	Watford General Hospital
97	Weston Area Health NHS Trust	Weston General Hospital
98	Whittington Health	The Whittington Hospital
99	Wirral Community NHS Trust	Civic Medical Centre, Wirral
100	Wirral University Teaching Hospital NHS Foundation Trust	Wirral University Teaching Hospital

101	Wrightington, Wigan and Leigh NHS Foundation Trust	Leigh Infirmary
102	Wye Valley NHS Trust	Hereford County Hospital
103	Yeovil District Hospital NHS Foundation Trust	Yeovil District Hospital
104	York Teaching Hospitals NHS Foundation Trust	Scarborough Hospital
Neurology		
1	Airedale NHS Foundation Trust	Airedale General Hospital
2	Airedale NHS Foundation Trust	Community Services Specialist Nurses
3	Barking Havering and Redbridge University Hospitals NHS Trust	Queen's Hospital, Romford
4	Barking Havering and Redbridge University Hospitals NHS Trust	Queen's Hospital, Romford
5	Barts Health NHS Trust	The Royal London Hospital
6	Barts Health NHS Trust	Whipps Cross Hospital
7	Bradford Teaching Hospitals NHS Foundation Trust	St Luke's Hospital, Bradford
8	Bridgewater Community NHS Trust	Orford Jubilee Park Health Centre
9	Buckinghamshire Healthcare NHS Trust	Stoke Mandeville Hospital
10	Burton Hospitals NHS Foundation Trust	Queen's Hospital, Burton on Trent
11	Calderdale and Huddersfield NHS Foundation Trust	Calderdale Royal Hospital & Huddersfield Royal Infirmary
12	Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital
13	Central and Northwest London NHS Foundation Trust	Laurel Lodge Clinic, Hillingdon
14	Chelsea and Westminster Healthcare NHS Foundation Trust	Chelsea & Westminster Hospital
15	City Hospitals Sunderland NHS Foundation Trust	Sunderland Royal Hospital
16	Dartford and Gravesham NHS Trust	Darent Valley Hospital
17	Derby Hospitals NHS Foundation Trust	Royal Derby Hospital
18	Dorset County Hospital NHS Foundation Trust	Dorset County Hospital
19	Dorset Healthcare University Foundation Trust	Blandford Community Hospital
20	Dudley Group NHS Foundation Trust	Russells Hall Hospital
21	East and North Herts NHS Trust	Lister Hospital, Stevenage
22	East Cheshire NHS Trust	Macclesfield District General Hospital
23	East Coast Community Healthcare	Northgate Hospital, Great Yarmouth
24	East Sussex Healthcare NHS Trust	Eastbourne Hospital
25	Frimley Health NHS Foundation Trust	Wexham Park Hospital, Slough
26	Frimley Health NHS Foundation Trust	Frimley Park Hospital
27	Guy's and St Thomas' NHS Foundation Trust	St Thomas' Hospital, London
28	Hampshire Hospitals NHS Foundation Trust	Royal Hampshire County Hospital
29	Hampshire Hospitals NHS Foundation Trust	Basingstoke & North Hampshire Hospital
30	Harrogate and District NHS Foundation Trust	Harrogate & District NHS Foundation Trust
31	Hinchingbrooke Healthcare NHS Trust	Hinchingbrooke Hospital

32	Homerton University Hospital NHS Foundation Trust	Adult Community Rehabilitation Team
33	Hounslow and Richmond Community Healthcare NHS Trust	Community Neuro Rehabilitation
34	Imperial College Healthcare NHS Trust	Charing Cross Hospital
35	Isle of Wight NHS Trust	St Mary's Hospital, Isle of Wight
36	Kings College Hospital NHS Foundation Trust	King's College Hospital
37	Kings College Hospital NHS Foundation Trust	Princess Royal University Hospital
38	Kingston Hospital NHS Foundation Trust	Kingston Hospital
39	Lancashire Teaching Hospitals NHS Foundation Trust	Royal Preston Hospital
40	Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary
41	Lewisham and Greenwich NHS Trust	University Hospital Lewisham
42	London North West Healthcare NHS Trust	Northwick Park Hospital
43	London North West Healthcare NHS Trust	Central Middlesex Hospital
44	Maidstone and Tunbridge Wells NHS Trust	Tunbridge Wells Hospital
45	Maidstone and Tunbridge Wells NHS Trust	Maidstone Hospital
46	Medway NHS Foundation Trust	Medway Maritime Hospital
47	Mid Essex Hospital Services NHS Trust	Broomfield Hospital, Chelmsford
48	Milton Keynes University Hospital NHS Foundation Trust; Central and North West London NHS Foundation Trust	Bletchley Community Hospital
49	Newcastle Upon Tyne Hospitals NHS Foundation Trust	Clinical Ageing Research Unit
50	North East London NHS Foundation Trust	Phoenix House, Basildon
51	North Lincolnshire & Goole NHS Foundation Trust	Diana Princess of Wales Hospital, Grimsby
52	Northampton General Hospital NHS Trust	Northampton General Hospital
53	Nottingham Citycare	Community Neurology Team, Sherwood Rise Health Centre
54	Nottingham University Hospitals NHS Trust	Queen's Medical Centre, Nottingham
55	Oxford University Hospitals NHS Foundation Trust	John Radcliffe Hospital
56	Peninsula Community Health	Camborne Redruth Community Hospital
57	Plymouth Hospitals NHS Trust	Derriford Hospital, Plymouth
58	Poole Hospital NHS Foundation Trust	Poole Hospital NHS Foundation Trust
59	Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	Queen Elizabeth Hospital
60	Royal Berkshire NHS Foundation Trust	Royal Berkshire Hospital
61	Royal Free London NHS Foundation Trust	The Royal Free Hospital, London
62	Royal Free London NHS Foundation Trust	The Royal Free Hospital
63	Royal United Hospitals Bath NHS Foundation Trust	Royal United Hospital
64	Royal Wolverhampton Hospitals NHS Trust	New Cross Hospital, Wolverhampton
65	Salford Royal NHS Foundation Trust	Salford Royal NHS Foundation Trust
66	Salford Royal NHS Foundation Trust	Leigh Infirmary
67	Salisbury NHS Foundation Trust	Salisbury District Hospital

68	Sandwell & West Birmingham Hospitals NHS Trust	City Hospital, Birmingham
69	SEPT Community Health Services Bedfordshire	SEPT Community Health Services
70	Sheffield Teaching Hospitals NHS Foundation Trust	Royal Hallamshire Hospital
71	South Essex Partnership Trust (SEPT) - West Essex	Latton Bush Centre, Harlow
72	South Tees Hospitals NHS Foundation Trust	James Cook University Hospital, Middlesbrough
73	South West Yorkshire Partnership NHS Foundation Trust	Apollo Court Medical Centre, Dodworth
74	Southampton University Hospital NHS Foundation Trust	Queen Alexandra Hospital, Portsmouth
75	St George's University Hospitals NHS Foundation Trust	St George's Hospital, London
76	Staffordshire and Stoke on Trent Partnership NHS Trust	Adult Ability Team, Burton on Trent
77	Staffordshire and Stoke on Trent Partnership NHS Trust	Stonydelph Health Centre, Tamworth
78	Stepping Hill Hospital NHS Foundation Trust	Stepping Hill Hospital, Stockport
79	Suffolk Community Healthcare	West Suffolk Disability Resource Centre, Bury St Edmunds
80	Taunton and Somerset NHS Foundation Trust	Musgrove Park Hospital, Taunton
81	The Ipswich Hospital NHS Trust	Ipswich Hospital
82	United Lincolnshire Hospitals NHS Trust	Grantham and District Hospital
83	University College London Hospitals NHS Foundation Trust	National Hospital for Neurology, London
84	University Hospitals Coventry and Warwickshire NHS Trust	George Eliot Hospital, Nuneaton
85	University Hospitals Coventry and Warwickshire NHS Trust	University Hospital Coventry
86	University Hospitals Coventry and Warwickshire NHS Trust	Hospital of St Cross Rugby
87	University Hospitals Coventry and Warwickshire NHS Trust	University Hospital Coventry
88	University Hospitals Coventry and Warwickshire NHS Trust	Warwick Hospital
89	University Hospitals Coventry and Warwickshire NHS Trust	University Hospital Coventry
90	University Hospitals Coventry and Warwickshire NHS Trust	University Hospital Coventry
91	University Hospital of North Midlands	County Hospital, Stafford
92	University Hospitals Birmingham NHS Foundation Trust	New Queen Elizabeth Hospital, Birmingham
93	University Hospitals of Morecambe Bay NHS Foundation Trust	North and South Lakes area
94	Walsall Healthcare NHS Trust	Shortheath Clinic, Willenhall
95	West Middlesex University Hospital NHS Trust	West Middlesex University Hospital
96	Western Sussex Hospitals NHS Foundation	St Richard's Hospital, Chichester

	Trust	
97	Whittington Hospital NHS Trust	The Whittington Hospital
98	Worcestershire Acute Hospitals NHS Trust	Worcestershire Royal Hospital
99	York Teaching Hospital NHS Foundation Trust	York Hospital
Occupational Therapy		
1	Barts Health NHS Trust	Central Community Health Team
2	Birmingham Community Healthcare NHS Trust	Moseley Hall Hospital, Birmingham
3	Bristol Community Health	Knowle Clinic, Bristol
4	Calderdale and Huddersfield NHS Foundation Trust	Huddersfield Royal Infirmary
5	Central and North West London NHS Foundation Trust	Camden Neurological & Stroke Service
6	Central London Community Healthcare NHS Trust	Community Rehabilitation
7	Central London Community Healthcare NHS Trust	Edgware Community Hospital
8	County Durham & Darlington NHS Foundation Trust	Chester le Street Community Hospital
9	Derby Hospital NHS Foundation Trust	London Road Community Hospital
10	Derbyshire Community Health Care Services NHS Foundation Trust	Walton Hospital, Chesterfield
11	Derbyshire Community Health Services NHS Foundation Trust	Ripley Hospital
12	East Lancashire Hospital NHS Trust	Royal Blackburn Hospital
13	East Sussex Healthcare NHS Trust	Joint Community Rehabilitation Service, Eastbourne
14	Gloucestershire Care Services NHS Trust	Gloucestershire service
15	Hampshire Hospital NHS Foundation Trust	Basingstoke and North Hampshire Hospital
16	Harrogate and District NHS Foundation Trust	Harrogate and District NHS Foundation Trust
17	Herts Community NHS Trust	Herts Neuro Service - West
18	Imperial College Healthcare NHS Trust	St Mary's Hospital, London
19	Isle of Man Dept of Health and Social Care	Nobles Hospital
20	King's College Hospital NHS Foundation Trust	Ruskin Wing, Kings College Hospital
21	Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary
22	Norfolk and Norwich University Hospitals NHS Foundation Trust	MFE Outpatients Department
23	Northern Lincolnshire & Goole NHS Foundation Trust	Diana Princess of Wales Hospital, Grimsby
24	Oxleas NHS Foundation Trust	Community Rehab Team, Memorial Hospital, London
25	Plymouth Community Trust	Mount Gould Hospital, Plymouth
26	Royal Berkshire Hospital NHS Foundation Trust	Royal Berkshire Hospital
27	SEQOL	SEQOL
28	Sheffield Health and Social Care NHS Trust	Neurological Enablement Service

		(Community Team)
29	Sheffield Teaching Hospitals NHS Foudnation Trust	Michael Carlisle Centre, Sheffield
30	Sirona Care and Health	St Martin's Hospital, Bath
31	South Essex Partnership Trust (SEPT)	Community Occupational Therapy Team
32	South Staffordshire and Stoke on Trent Partnership NHS Trust	Adult Ability Team, Burton on Trent
33	South Tees NHS Foundation Trust	Redcar Primary Care Hospital
34	Sussex Community NHS Trust	Community Neurological Rehabilitation Team, Worthing
35	Sussex Community NHS Trust	Community Neurological Rehabilitation Team (North)
36	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Royal Bournemouth Hospital
37	University Hospitals Bristol NHS Foundation Trust	South Bristol Community Hospital
38	Walsall Healthcare NHS Trust	Shortheath Clinic, Willenhall
39	Warrington and Halton Hospitals NHS Foundation Trust	Warrington and Halton Hospitals
40	Wye Valley NHS Trust	Hereford County Hospital
41	York Teaching Hospital NHS Foundation Trust	York Hospital
Physiotherapy		
1	Airedale NHS Foundation Trust	Airedale General Hospital
2	Barts Health NHS Trust	Whipps Cross Hospital
3	Birmingham Community Healthcare NHS Trust	Moseley Hall Hospital
4	Blackpool Teaching Hospitals NHS Foundation Trust	Assessment & Rehabilitation Centre, Blackpool
5	Bristol Community Health	Knowle Clinic, Bristol
6	Brighton and Sussex University Hospitals NHS Trust	Princess Royal Hospital, Haywards Heath
7	Central and North West London - Hillingdon Community Health	Laurel Lodge Clinic, Hillingdon
8	Central and North West London NHS Foundation Trust	Camden Neurological & Stroke Services
9	Central London Community Healthcare NHS Trust	Edgware Day Hospital
10	Central London Community Healthcare NHS Trust	Central London Community Healthcare
11	County Durham and Darlington NHS Foundation Trust	Chester-le-Street Community Hospital
12	Cumbria Partnership NHS Foundation Trust	Dent View Rehabilitation Centre, West Cumberland Hospital
13	Department of Health and Social Care	Nobles Hospital, Isle of Man
14	Derby Hospitals NHS Foundation Trust	London Road Community Hospital, Derby
15	Derbyshire Community Health Services NHS Foundation Trust	Ripley Hospital
16	Derbyshire Community Health Services NHS	Walton Hospital, Chesterfield

	Foundation Trust	
17	Derbyshire Community Health Services NHS Foundation Trust	Bolsover Hospital, Chesterfield
18	East Coast Community Healthcare	Northgate Hospital, Great Yarmouth
19	East Sussex Healthcare NHS Trust	Eastbourne Hospital
20	George Eliot Hospital NHS Trust	George Eliot Hospital, Nuneaton
21	Gloucestershire Care Services NHS Trust	Redwood House, Stroud
22	Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire Royal Hospital
23	Guy's and St Thomas' NHS Foundation Trust	St Thomas' Hospital, London
24	Hampshire Hospitals NHS Foundation Trust	Basingstoke & North Hampshire Hospital
25	Harrogate and District NHS Foundation Trust	Harrogate & District NHS Foundation Trust
26	Herts Community NHS Trust	Herts Neuro Service - East & North
27	Homerton University Hospital NHS Foundation Trust	Adult Community Rehabilitation Team, St Leonard's Hospital, London
28	Hull and East Yorkshire Hospitals NHS Trust	Hull Royal Infirmary
29	Imperial College Healthcare NHS Trust	St Mary's Hospital, London
30	King's College Hospital NHS Foundation Trust	King's College Hospital, London
31	Lancashire Care NHS Foundation Trust	Minerva Health Centre, Preston
32	Leeds Teaching Hospitals NHS Trust	Chapel Allerton Hospital, Leeds
33	Lewisham and Greenwich NHS Trust	University Hospital Lewisham
34	London North West Healthcare NHS Trust	Northwick Park Hospital
35	Maidstone & Tunbridge Wells NHS Trust	Tunbridge Wells Hospital
36	Norfolk and Norwich University Hospitals NHS Foundation Trust	MFE Outpatients Dept, Norfolk & Norwich University Hospital
37	North Tees & Hartlepool NHS Foundation Trust	University Hospital of North Tees
38	Northern Lincolnshire and Goole NHS Foundation Trust	Diana Princess of Wales Hospital, Grimsby
39	Nottingham University Hospitals NHS Trust	Nottingham University Hospital
40	Oxleas NHS Foundation Trust	Memorial Hospital, London
41	Peninsula Community Health	Camborne and Redruth Community Hospital
42	Plymouth Community Trust	Mount Gould Hospital
43	Royal Berkshire Hospital NHS Foundation Trust	Royal Berkshire Hospital
44	Royal Free London NHS Foundation Trust	Royal Free Hospital, London
45	Royal Free London NHS Foundation Trust	Woodlands Unit, Barnet Hospital
46	Sandwell & West Birmingham Hospitals NHS Trust	City Hospital, Birmingham
47	SEQOL (Care & Support Partnership)	SEQOL, Swindon
48	Sheffield Health & Social Care Trust	Neurological Enablement Service (Community Team), Sheffield
49	Sheffield Teaching Hospitals NHS Foundation Trust	Royal Hallamshire Hospital, Sheffield
50	Sheffield Teaching Hospitals NHS Foundation Trust	Royal Hallamshire Hospital, Sheffield
51	Sheffield Teaching Hospitals NHS Foundation Trust	Michael Carlisle Centre, Sheffield

52	Sirona Health and Care	St Martins Hospital, Bath
53	Solent NHS Trust	St Mary's Community Health Campus
54	Solent NHS Trust	Turner Centre, St James Hospital, Portsmouth
55	South Tees Hospitals NHS Foundation Trust	Rehab Centre, James Cook University Hospital
56	Southern Health NHS Foundation Trust	Petersfield Hospital
57	Staffordshire and Stoke on Trent Partnership NHS Trust	Adult Ability Team, Burton-on-Trent
58	Stockport NHS Foundation Trust	Stepping Hill Hospital, Stockpot
59	Sussex Community NHS Trust	Community Neurological Rehabilitation Team
60	Sussex Community NHS Trust	Community Neurological Rehabilitation Team (North)
61	Sutton & Merton Community Services	The Nelson Health Centre, London
Speech and Language Therapy		
1	Airedale NHS Foundation Trust	Airedale General Hospital
2	Anglian Community Enterprise (ACE)	Community Speech & Language Therapy, Colchester
3	Barts Health NHS Trust	Mile End Hospital
4	Bristol Community Health	Knowle Clinic, Bristol
5	Cambridge and Peterborough NHS Foundation Trust	City Care Centre, Peterborough
6	Central and North West London NHS Foundation Trust	Camden Neurological & Stroke Service
7	Central and North West London NHS Foundation Trust	Mount Vernon Hospital
8	Central London Community Healthcare NHS Trust	St Charles Centre for Health & Wellbeing, London
9	Central London Community Healthcare NHS Trust	Edgware Day Hospital
10	County Durham and Darlington NHS Foundation Trust	University Hospital of North Durham
11	Cumbria Partnership NHS Foundation Trust	Ashton Community Care Centre, Lancaster
12	Derby Hospitals NHS Foundation Trust	London Road Community Hospital, Derby
13	East Lancashire Hospitals NHS Trust	Burnley General Hospital
14	East Sussex Healthcare NHS Trust	Speech & Language Therapy Dept, Eastbourne
15	Gloucestershire Care Services NHS Trust	Gloucestershire Royal Hospital
16	Hampshire Hospitals NHS Foundation Trust	Basingstoke & North Hampshire Hospital
17	Hampshire Hospitals NHS Foundation Trust	Royal Hampshire County Hospital
18	Harrogate and District NHS Foundation Trust	Harrogate & District5 NHS Foundation Trust
19	Kent Community Health NHS Foundation Trust	Adult Speech and Language Therapy, Sandwich
20	Kings College Hospital NHS Foundation Trust	King's College Hospital

21	Leeds Community Healthcare NHS Trust	Speech & Swallowing Team, Halton Health Centre, Leeds
22	Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary
23	Lewisham and Greenwich NHS Trust	Waterloo Block, University Hospital Lewisham
24	London North West Healthcare NHS Trust	Northwick Park Hospital
25	Maidstone & Tunbridge Wells NHS Trust	Tunbridge Wells Hospital
26	Norfolk and Norwich University Hospitals NHS Foundation Trust	MFE Outpatients Dept, Norfolk and Norwich University Hospital
27	North Bristol NHS Trust	Southmead Hospital, Bristol
28	North East London NHS Foundation Trust	Orsett Hospital
29	North Tees and Hartlepool NHS Foundation Trust	University Hospital of North Tees
30	Northern Lincolnshire and Goole NHS Foundation Trust	Diana Princess of Wales Hospital, Grimsby
31	Northumbria Healthcare NHS Trust	Wallsend Health Centre
32	Nottinghamshire Healthcare NHS Trust	Queens Medical Centre, Nottingham
33	Oxleas NHS Foundation Trust	Community Rehab Team, Memorial Hospital, London
34	Peninsula Community Health	Bellair Health Office, Penzance
35	Plymouth Community Trust	Mount Gould Hospital, Plymouth
36	Sheffield Health & Social Care Trust	Neurological Enablement Service (Community Team), Sheffield
37	Sheffield Teaching Hospitals NHS Foundation Trust	Michael Carlisle Centre, Sheffield
38	Sirona Care and Health	Clara Cross Centre, St Martin's Hospital, Bath
39	South Essex Partnership Trust (SEPT)	Hadleigh Clinic, Hadleigh
40	South Essex Partnership Trust (SEPT)	Luton and Dunstable Hospital
41	South Essex Partnership Trust (West Essex)	Speech & Language Office - Epping Forest Unit
42	Southend University Hospital NHS Foundation Trust	Southend University Hospital
43	Sussex Community NHS Foundation Trust	Bognor Regis War Memorial Hospital
44	Sussex Community NHS Foundation Trust	Community Neurological Rehabilitation Team (North)
45	Sussex Community NHS Foundation Trust	Community Neurological Rehabilitation Team, Worthing
46	Sussex Community NHS Foundation Trust	Hove Polyclinic
47	The Rotherham NHS Foundation Trust	The Rotherham NHS Foundation Trust
48	University Hospitals Bristol NHS Foundation Trust	Bristol Royal Infirmary
49	University Hospitals Bristol NHS Foundation Trust	South Bristol Community Hospital
50	Walsall Healthcare HNS Trust	Shortheath Clinic, Willenhall
51	Warrington and Halton Hospitals NHS Foundation Trust	Warrington and Halton Hospitals
52	Wye Valley NHS Trust	Hereford County Hospital

53	York Teaching Hospital NHS Foundation Trust	York Hospital

Scotland

Elderly Care		
1	NHS Ayrshire and Arran	Crosshouse Hospital, Kilmarnock
2	NHS Dumfries and Galloway	Dumfries and Galloway Royal Infirmary
3	NHS Grampian	Woodend Hospital, Aberdeen
4	NHS Greater Glasgow and Clyde	Glasgow Royal Infirmary
5	NHS Greater Glasgow and Clyde	Southern General Hospital, Glasgow
6	NHS Greater Glasgow and Clyde	Drumchapel Hospital, Glasgow
7	NHS Greater Glasgow and Clyde	Lightburn Hospital, Glasgow
8	NHS Lanarkshire	Hairmyres Hospital, East Kilbride
9	NHS Lothian	Assessment & Rehabilitation Centre, Western General Hospital
10	NHS Tayside	Perth Royal Infirmary
11	NHS Tayside	Whitehill Hospital, Forfar
12	NHS Tayside	Arbroath Infirmary
Neurology		
1	NHS Borders	Borders General Hospital, Melrose
2	NHS Borders	Borders General Hospital, Melrose
3	NHS Borders	Borders General Hospital, Melrose
4	NHS Grampian	Aberdeen Royal Infirmary
5	NHS Grampian	Aberdeen Royal Infirmary
6	NHS Grampian	Aberdeen Royal Infirmary
7	NHS Greater Glasgow and Clyde	South Glasgow University Hospital (Southern General)
8	NHS Greater Glasgow and Clyde	South Glasgow University Hospital (Southern General)
9	NHS Greater Glasgow and Clyde	South Glasgow University Hospital (Southern General)
10	NHS Lothian	Western General Hospital, Edinburgh
11	NHS Lothian	Western General Hospital, Edinburgh
12	NHS Lothian	Western General Hospital, Edinburgh
Occupational Therapy		
1	NHS Fife	Queen Margaret Hospital, Dunfermline
2	NHS Greater Glasgow and Clyde	Stobhill Hospital, Glasgow
3	NHS Greater Glasgow and Clyde	New Victoria Hospital, Glasgow
4	NHS Greater Glasgow and Clyde	Queen Elizabeth University Hospital, Glasgow
Physiotherapy		
1	NHS Fife	Whitefield Day Hospital, Dunfermline
2	NHS Greater Glasgow & Clyde	New Victoria Hospital, Glasgow
3	NHS Greater Glasgow and Clyde	Southern General Hospital, Glasgow
4	NHS Greater Glasgow and Clyde	Stobhill Day Hospital, Glasgow

5	NHS Greater Glasgow and Clyde	Lightburn Day Hospital, Glasgow
6	NHS Highland	Royal Northern Infirmary, Inverness
Speech and Language Therapy		
1	NHS Greater Glasgow and Clyde	Southern General Hospital, Glasgow

Wales

Elderly Care		
1	Abertawe Bro Morgannwg University Health Board	Pendre Day Hospital, Bridgend
2	Aneurin Bevan University Health Board	Nevill Hall Hospital, Abergavenny
3	Aneurin Bevan University Health Board	St Woolos Hospital, Newport
4	Aneurin Bevan University Health Board	Ysbyty Ystrad Fawr, Hengoed
5	Betsi Cadwaladr University Health Board: West	Ysbyty Gwynedd, Bangor
6	Cwm Taf University Health Board	Dewi Sant Hospital,Pontypridd
Neurology		
1	Abertawe Bro Morgannwg University Health Board	Gorseinon Hospital, Swansea
2	Aneurin Bevan University Health Board	Royal Gwent Hospital, Newport
Occupational Therapy		
1	Abertawe Bro Morgannwg University Health Board	Pendre Day Hospital, Bridgend
Physiotherapy		
1	Abertawe Bro Morgannwg University Health Board	Gorseinon Hospital, Swansea
2	Abertawe Bro Morgannwg University Health Board	Pendre Day Hospital, Bridgend
3	Betsi Cadwaladr University Health Board	Ysbyty Eryri, Caernarfon
Speech and Language Therapy		
1	Abertawe Bro Morgannwg University Health Board	Morriston Hospital, Swansea
2	Cardiff and Vale University Health Board	University Hospital Llandough
3	Cwm Taf University Health Board	Dewi Sant Hospital, Pontypridd
4	Powys Teaching Health Board	Brecon Hospital

Northern Ireland

Elderly Care		
1	Belfast Health and Social Care Trust	Musgrave Park Hospital, Belfast
2	Northern Health and Social Care Trust	Antrim Hospital
3	Southern Health and Social Care Trust	Lurgan Hospital

4	Western Health and Social Care Trust	Limavady Health Centre
5	Western Health and Social Care Trust (Southern sector)	South West Acute Hospital, Enniskillen
Neurology		
1	Belfast Health and Social Care Trust	Royal Hosptials, Belfast
2	Belfast Health and Social Care Trust	Belfast City Hospital
3	Western Health and Social Care Trust	Limavady Health Centre
4	Western Health and Social Care Trust (Southern Sector)	South West Acute Hospital
Occupational Therapy		
No services		
Physiotherapy		
1	Belfast Health and Social Care Trust	Musgrave Park Hospital, Belfast
2	South Eastern Health and Social Care Trust	Thompson House Hospital, Lisburn
Speech and Language Therapy		
1	Northern Health and Social Care Trust	Whiteabbey Hospital, Newtownabbey & Moyle
2	Northern Health and Social Care Trust	Mid Ulster Hospital, Magherafelt
3	Northern Health and Social Care Trust	Causeway Hospital, Coleraine
4	Northern Health and Social Care Trust	Antrim Area Hospital

Channel Islands

Elderly Care		
1	Guernsey Health and Social Services	Princess Elizabeth Hospital, Guernsey
Neurology		
1	States of Jersey	Jersey General Hospital
Occupational Therapy		
1	States of Jersey	Jersey General Hospital
Physiotherapy		
1	States of Jersey	Jersey General Hospital
Speech and Language Therapy		
1	States of Jersey	Jersey General Hospital

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Appendix C

Elderly Care and Neurology standards and guidance

UK Parkinson's Audit 2015 – patient management standards and guidelines

Audit of national standards relating to patient management for people with Parkinson's, incorporating the NICE Guideline for Parkinson's and quality standards from the National Service Framework for Long-term Neurological Conditions.

Background

127,000 people in the UK are living with the disabling effects of Parkinson's. The diagnosis has profound implications for the individual and their family as well as major cost implications for health and social services.

A multi-professional steering group (including the 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 and the British and Irish Neurologists Movement Disorder Section) 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 Parkinson's Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (NICE, 2006),[1] referred to as 'NICE CG35' throughout this document, but incorporate other national guidance relevant to Parkinson's care, in particular the *National Service Framework for Long-term Neurological Conditions* (NSF LTNC)[2] and the SIGN guidelines.[3]

In 2012 the patient audit focused on auditing patients with an established Parkinson's diagnosis, to capture how they have been managed over the previous year. This will be continued in 2015. A Question Review Group was convened in 2014, and the audit questions have been refined with their guidance.

This round of the audit includes a Patient Reported Experience Measure (PREM) for the first time to include the views of people with Parkinson's about their services.

Aim

The objective of the patient management audit is to examine if the assessment/management of patients with an established diagnosis of Parkinson's complies with national guidelines, including NICE CG35 and NSF LTNC.

Objectives

- 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.

- To identify areas of good practice and areas where improvements need to be made, leading to action plans to improve quality of care.

- To establish baseline audit data to allow:
    - national mapping of variations in quality of care
    - local and national 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, including the early treatment, maintenance, complex care and palliative care phase. It incorporates monitoring the physical status and current needs for support and, as appropriate, making referrals and providing treatment, education and support and coordination of services among care providers and the patient and carer. The audit excludes people newly referred to the service for purposes of diagnosis.

Methodology

It is recognised that it is not always necessary or practical to undertake a full assessment of activities of daily living (ADL) function, social care, motor and non-motor problems at every visit. For example, when there has been a recent in-depth assessment and the patient is attending for brief review of a medication change. For this reason, the Parkinson's patient management audit is designed to examine how the patient has been managed/assessed over the previous year rather than on a single visit. Although this complicates data collection, it will be more representative of actual patient care. For most patients, this will capture two–three assessments over a year, if the service complies with NICE CG35 requirement for at least six-12 monthly reviews.

A process flow chart (*How do I take part?*) can be found on page 7 of this document. Please note the importance of logging your participation in this national clinical audit with your audit department and notifying your local Caldicott Guardian.

Definition of an audit site

We are aware there is considerable variation in how Parkinson's services are organised and delivered throughout the country. There is, in addition, an ongoing reconfiguration of services and how they are commissioned.

An audit site is roughly defined as a service provided by consultants with (or without) a Parkinson's nurse specialist 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:

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

The service as described will then be allocated an audit service number. If the consultant and Parkinson's nurse specialist 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:

- 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 specialist input and cover the same geographical area.
- Discrete services should be logged as separate audit sites and separate data submitted.
- Parkinson's nurse specialists should conduct the audit in collaboration with their patients' consultant service(s) – and vice versa.
- The audit can be completed purely from the medical input received only in services without Parkinson's nurse specialist cover.
- Clinicians working across more than one discrete service – for example, a consultant working with different Parkinson's nurse specialists in different commissioning/geographical areas – should return separate audits for each service.

Patient sample

The minimum audit sample size is 20 consecutive Parkinson's patients seen during the audit data collection period, which runs from 30 April 2015 to 30 September 2015. You should 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 entry 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', – for example a Parkinson's nurse specialist auditing both neurology and elderly care patients, or a consultant who may work with different Parkinson's nurse specialists 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. This only needs to be completed 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

For audit sites without a Parkinson's nurse specialist, audit data from medical notes can be entered directly into the data entry tool either at the end of the clinic, or in batches at a later date when convenient. Appendix A (see page 27) is a version of the patient questions that you can print and use to record data in your clinics if this would be useful.

Audit sites with Parkinson's nurse specialist provision using integrated medical/Parkinson's nurse specialist notes can enter audit data from integrated notes described on page 3. Services with separate medical and Parkinson's nurse specialist notes can either:

- collect a list of patient names and enter audit data at later date when both sets of notes are available
- **or** use a paper version of the tool to answer what they can from one set of the notes and mark questions still to be completed from other notes, entering the data into the audit tool when this is complete

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

A user guide for the data entry tool, available at **parkinsons.org.uk/audit**, provides full instructions and information.

All data must be submitted by 15 October 2015. 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. 'No, but…' answers can be removed from calculations of compliance.

Confidentiality

A. Patients

Patients' confidentiality must be protected. Please ensure that any information you submit for the audit does not include any personally identifiable information about your patients. Identifiable information can be described as, "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, 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.** 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.

B. Employers

In order to comply with *Healthcare Quality Improvement Partnership (HQIP) Principles of Quality in National Clinical Audit* guidelines (**http://bit.ly/1Gy1e9o**), the summary report on the audit findings will list all participating organisations and include data from identified individual services. This means that your employer's confidentiality will not be protected. **It is therefore vital that your employer is aware of, and agrees to, your participation in the audit, and to the submission of your final data.**

C. Participants

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

Data security

The audit tool, which is available for download from **parkinsons.org.uk/audit**, is 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 dataset, we also advise you to save and use your spreadsheet on a secure computer at work and not on your personal computer at home. We ask you to comply with your trust/board/local health board'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 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 staff working directly on analysis. Raw data will not be available 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 (PREM)

All services participating in the audit can opt to participate in the PREM. The PREM is a short paper questionnaire to be distributed to up to 50 consecutive patients between 30 April 2015 and 30 September 2015. 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 a few 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 an 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 a large postage-paid envelope provided.

Each service will receive the following resources:

- 50 x copies of a paper questionnaire
- 50 x sealable envelopes
- 50 x patient information leaflets
- an A3 laminated poster (on request)
- 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 as a national summary report and an individual report for each service. This will benchmark the results of individual services against the national average for each audit question.

The national summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. This full audit report will also include a list of all participating services and some data from identified individual services. A bespoke patient version of the audit summary report will also be produced.

The national summary report will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The report will also be made available on 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 such as NICE CG35 and the NSF LTNC. Therefore, this data will provide valuable information about priority areas within the existing health care 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.

UK Parkinson's Audit 2015 – 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 (30 April to 30 September 2015) for your data to be included in the audit.

How do I take part if I am eligible?

Register your service

Download the registration form from **parkinsons.org.uk/audit**, add your details and return to **pdaudit@parkinsons.org.uk** by **30 March 2015**. At this stage you can also opt in to the Patient Reported Experience Measure (PREM) part of the audit. You will then be emailed a service number and a password for the data entry tool – you will need these to enter your audit data.

Inform your audit department

Please log your participation in this clinical audit with your audit department and notify your local Caldicott Guardian.

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 entry tool from **parkinsons.org.uk/audit** from mid-April 2015, along with a user guide. Data entry begins on 30 April 2015.

1. Enter brief details about your service (the Service Audit).
2. Enter details of consecutive patients seen during the audit period 30 April 2015 to 30 September 2015 (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.

Table 1: Patient management service audit – questions, data items/answer options and help notes

No.	Question	Data items/answer options	Help notes
Your details			
1.1	Did this service take part in the Parkinson's Audit 2012?	• 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	List 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 Parkinson's nurse specialist works in clinics with the consultant but with AHPs located elsewhere. • Integrated clinics – multidisciplinary team working: neurologist or care of the elderly specialist, Parkinson's nurse specialist 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: • an identified lead clinician for training, service development and specialist opinion **and** • 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.

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 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

Consultants

3	Consultant details	3.1 Lead consultant name 3.2 Specialty 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	What percentage of consultants providing medical input to this service have attended movement disorder-specific external CME in the last 12 months?	Free text	Provide the percentage. The question refers to external CME, ie regional, national or international education updates, relevant to Parkinson’s. Use the number of consultants (headcount) and not the whole-time equivalents they represent.

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, ie regional, national or international education updates, relevant to Parkinson's.
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. Omit this question if there is no Parkinson's nurse specialist service for neurology patients.

Table 2: Patient management patient audit – questions, data items/answer options and help notes

No.	Question	Data items/answer options	Help notes
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 British • Any other white background • Black/Black British • Asian/Asian British • Mixed race • Not stated • Other ethnic group	
1.4	Year of birth	Free text	
1.5	Year of Parkinson’s diagnosis	Free text	

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 on medication four or less doses/day • Stable medication (changes needed less than every three months) • Absence of postural instability Complex • Drugs – five 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 (changes needed more often than every three months) • 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 medicines reconciliation?	• Yes • No	**Resources** Medicine reconciliation standards: • *Keeping Patients Safe When They Transfer Between Care Providers – Getting the Medicines Right: Good Practice Guidance for Healthcare Professions* (Royal Pharmaceutical Society, 2011) (**http://bit.ly/1dk1jld**) • HIS Clinical Standards for Neurological Health Services 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.' • *Safer Use of Medicines Reconciliation* (The Scottish Government, 2013) (**http://bit.ly/1CrGZL5**)

<table>
<tr><td colspan="4">Specialist review</td></tr>
<tr><td colspan="4">Standard A: 100% of people with Parkinson’s must be reviewed at six-12 monthly intervals. (NICE CG35, R12, R77; NSF LNTC: QR2; HIS Clinical Standard 19.3)</td></tr>
<tr><td>2.1</td><td>Has the patient been reviewed by a specialist within the last year? (This can be doctor or Parkinson’s nurse specialist)</td><td>• Yes
• No</td><td></td></tr>
<tr><td>2.2</td><td>Time since most recent medical review (by doctor or Parkinson’s nurse specialist)</td><td>• Less than six months
• Six-12 months
• More than one year
• More than two years
• Never</td><td></td></tr>
<tr><td colspan="4">New or recent Parkinson’s medication</td></tr>
<tr><td colspan="4">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. (NICE CG35, R3; HIS Clinical Guidelines 1.3 & 1.4)</td></tr>
<tr><td>3.1</td><td>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?</td><td>• Yes
• No
• Not applicable – patient not started on Parkinson’s medication for the first time during the previous year</td><td>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
• <i>Drug treatments for Parkinson’s</i> (Parkinson’s UK, 2012) (http://bit.ly/1M4iGJz)</td></tr>
</table>

Specific adverse effect monitoring

Standard B: 100% of people with Parkinson's who have sudden onset of sleep should be advised not to drive and to consider any occupational hazards. (NICE CG35, R72)

Standard D: 100% of patients on dopaminagic therapies are monitored for impulse control behaviours including dopamine dysregulation syndrome. (NICE CG35, 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. (NICE CG35 R30, R40; 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, such as MAOI, levodopa or dopamine agonists. **Resources** • Weintraub D et al. (2010) 'Impulse Control Disorders in Parkinson Disease.' *Archives of neurology*; 67(5):589-95

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. **Resources** • Weintraub D et al. (2010) ‘Impulse Control Disorders in Parkinson Disease.’ *Archives of neurology*; 67(5):589-95
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 Parkinson’s service directly or letter sent asking GP to arrange during the previous year.

Advanced 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. (NICE CG35, 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. (NICE CG35, R83)

5.1	Are there markers of advanced disease eg dementia, increasing frailty, impaired swallowing, nursing home level of care required?	• Yes • No – skip to Section 6	A diagnosis of Parkinson’s dementia or significant problems with swallow should be regarded as markers of the need to consider end-of-life issues. NICE CG35 recommends that end-of-life care requirements should be considered throughout the illness. This audit only examines this standard in relation to patients with markers of advanced disease as many discussions early in the illness are poorly documented and the timing of when the patient is ready to discuss these matters is individual.

5.2	Are there any documented discussions regarding end-of-life care issues/care plans?	• Yes • No	**Resources** • *Capacity, Care Planning and Advance Care Planning in Life Limiting Illness* (NHS, 2014) (**http://bit.ly/1CRDuxV**) • Scottish Palliative Care Guidelines, (NHSScotland, 2014) (**http://bit.ly/1CRDVYZ**) • *Together for Health: Delivering End of Life Care* (NHS Wales, 2013) (**http://bit.ly/1Bt73S2**) • *Preparing for end of life* (Parkinson's UK, 2012) (**http://bit.ly/1CrNopD**)
5.3	Is there evidence the patient/carer has been offered information about, or has set up a Lasting Power of Attorney?	• Yes • No	**Resources** • Lasting power of attorney information from www.gov.uk (**http://bit.ly/PelJDd**) • *A Guide to Making a Power of Attorney* (Office of the Public Guardian (Scotland), 2013) (**http://bit.ly/1CrNDRj**)

Parkinson’s assessment and care planning process scores (complete from medical and Parkinson’s nurse specialist notes)

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

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

Domain 3: Education and multidisciplinary involvement during the previous year (Maximum points = 10)

Total process score: 34
These assessments underpin achieving compliance with NICE CG35 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 recognised 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)

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	• 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 (maximum score = 12)			
1	Evidence of enquiry re 'on/off' fluctuations	• Yes • No • No, but not yet on treatment • No, but less than three 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 (eg getting in/out of bed, moving/rolling from side to side once in bed)	• Yes • No	
6	Evidence of enquiry re problems with transfers (eg 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 a care home	
9	Evidence of enquiry re problems with hygiene (eg washing/bathing/hair/nails)	• Yes • No • No, but in a nursing home	
10	Evidence of enquiry re difficulty eating and drinking (ie 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 a 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 multidisciplinary involvement during the previous year (maximum points = 10)			
1	Evidence of referral/input from Parkinson’s nurse specialist	• 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	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.
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	The option ‘No but clear documentation no therapy need’ can 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.

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.
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	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.

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	**Resources** • Work and money for people with Parkinson’s (Parkinson’s UK) (**http://bit.ly/1CCekms**) • Financial help and support for carers (Parkinson’s UK) (**http://bit.ly/190Aljb**)
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 an information support worker	• Yes • No • Yes, but declined	
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	

Appendix A: Patient audit question sheet

This sheet can be printed out and used to collect patient data, which can be entered on the data entry tool at a later date.

No.	Question	Data items/answer options
Demographics		
1.1	Patient identifier	This can be used by you to identify audited patients.
1.2	Gender	• Male • Female
1.3	Ethnicity	• White British • Any other white background • Black/Black British • Asian/Asian British • Mixed race • Not stated • Other ethnic group
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 medicines reconciliation?	• Yes • No
Specialist review		
2.1	Has the patient been reviewed by a specialist within the last year? (This can be doctor or Parkinson's nurse specialist)	• Yes • No
2.2	Time since most recent medical review (by doctor or Parkinson's nurse specialist)	• Less than six months • Six-12 months • More than one year • More than two years • Never

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
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 adverse effects	• Yes • No • Not applicable – not on ergot dopamine agonists
Advanced care planning		
5.1	Are there markers of advanced disease eg dementia, increasing frailty, impaired swallowing, nursing home level of care required?	• Yes • No – skip to Section 6
5.2	Are there any documented discussions regarding end-of- life care issues/care plans?	• Yes • No
5.3	Is there evidence the patient/carer has been offered information about, or has set up a Lasting Power of Attorney?	• Yes • No

Parkinson's assessment and care planning process scores (complete from medical and Parkinson's nurse specialist 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	• 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		
1	Evidence of enquiry re 'on/off' fluctuations	• Yes • No • No, but not yet on treatment • No, but less than three 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 no falling and no concern re balance
5	Evidence of enquiry re problems with bed mobility (eg getting in/out of bed, moving/rolling from side to side once in bed)	• Yes • No
6	Evidence of enquiry re problems with transfers (eg 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 a care home
9	Evidence of enquiry re problems with hygiene (eg washing/ bathing/hair/nails)	• Yes • No • No, but in a nursing home
10	Evidence of enquiry re difficulty eating and drinking (ie 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 a 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 multidisciplinary involvement during the previous year		
1	Evidence of referral/input from Parkinson’s nurse specialist	• 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 needed • No, but no acheivable 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
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 declined
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

References

1. National Institute of Health and Clinical Excellence. *Parkinson's Dsease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (2006) **http://guidance.nice.org.uk/CG35/NICEGuidance/pdf/English**

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

3. Scottish Intercollegiate Guidelines Network. *Diagnosis and Pharmacological Management of Parkinson's Disease: A National Clinical Guideline 113* (2010) **www.sign.ac.uk/guidelines/fulltext/113/index.html**

4. Health Professionals Council. *Confidentiality – Guidance for Registrants.* (2012) **www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf**

UK PARKINSON'S
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Appendix D

Occupational Therapy standards and guidance

UK Parkinson's Audit 2015 – occupational therapy standards and guidelines

Audit of national standards relating to occupational therapy for people with Parkinson's, incorporating the NICE Guideline for Parkinson's and quality standards from the National Service Framework for Long-term Neurological Conditions.

Background

Continuous monitoring of an organisation and delivery of a service is a way of ensuring that what should be happening is happening. If not, it can identify where changes can or need to be implemented and what those changes might be. Through this, services can improve patient care, financial efficiencies and working practices. Audit and service development is especially enhanced when it can be conducted against explicit, nationally agreed criteria.

This occupational therapy audit is part of the UK Parkinson's Audit. This is the third round in which occupational therapists will be able to take part, along with physiotherapists and speech and language therapists. The occupational therapy audit has received research governance approval by the College of Occupational Therapists. A Question Review Group was convened in 2014, and the audit questions for this round of the audit have been refined with their guidance.

The 2015 audit includes a Patient Reported Experience Measure (PREM) for the first time to ensure that the views of people with Parkinson's about their services are included.

The occupational therapy audit has been structured according to *Occupational Therapy for People with Parkinson's: Best Practice Guidelines*[1] (referred to as 'OT Best Practice Guidelines' throughout), and *The National Service Framework for Long-term Neurological Conditions* (NST LTNC).[2] It has also been structured according to principles of occupational therapy for Parkinson's, as outlined in *The Parkinson's Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (NICE, 2006).[3] This guideline will be referred to as 'NICE CG35' throughout this document.

The principles of occupational therapy for Parkinson's include:[4]

- 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 CG35 states that occupational therapy should be available for people with Parkinson's, and that particular consideration should be given to:[5]

- 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

Aim

The aim of the occupational therapy audit is to establish if occupational therapy services are currently providing quality services for people with Parkinson's, taking into account recommendations made in OT Best Practice Guidelines, NICE CG35 and NSF LTNC.

Objectives

- To evaluate if occupational therapy services are currently providing assessment and interventions appropriate to the needs of people with Parkinson's.

- To highlight areas of good and poor practice to inform local discussions, leading to action plans to improve quality of care.

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

Methodology

This audit is open to all occupational therapy services and individual occupational therapists that work with people with Parkinson's in the UK.

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) (page 7) and Table 2 (Patient audit) (page 11).

A process flow chart (*How do I take part?*) can be found on page 6. Please note the importance of logging your participation in this national clinical audit with your audit department, and notifying your local Caldicott Guardian.

Patient sample

The minimum audit sample size is 10 consecutive Parkinson's patients seen during the audit data collection period, which runs from 30 April 2015 to 30 September 2015. You should 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 entry tool will have the capacity to capture as many consecutive patients as therapists wish to audit.

Data collection and entry

The audit tool contains three sections:

- a **'service audit'** section, which consists of some general questions about your service. This 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

Patient data can be entered on the data entry tool, saved on your computer 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 (see page 24) 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 entry tool, available at **parkinsons.org.uk/audit**, provides full instructions and information.

All data must be submitted by 15 October 2015. 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. 'No, but...' answers can be removed from calculations of compliance.

Confidentiality

A. Patients

Patients' confidentiality must be protected. Please ensure that any information you submit for the audit does not include any personally identifiable information about your patients. Identifiable information can be described as, "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, 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.** 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.

B. Employers

In order to comply with *Healthcare Quality Improvement Partnership (HQIP) Principles of Quality in National Clinical Audit* guidelines (**http://bit.ly/1Gy1e9o**), the summary report on the audit findings will list all participating organisations and include data from identified individual services. This means that your employer's confidentiality will not be protected. **It is therefore vital that your employer is aware of, and agrees to, your participation in the audit, and to the submission of your final data.**

C. Participants

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

Data security

The audit tool, which is available for download from **parkinsons.org.uk/audit**, is 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 dataset, we also advise you to save and use your spreadsheet on a secure computer at work and not on your personal computer at home. We ask you to comply with your trust/board/local health board'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 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 staff working directly on analysis. Raw data will not be available 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 (PREM)

All services participating in the audit can opt to participate in the PREM. The PREM is a short paper questionnaire to be distributed to up to 50 consecutive patients between 30 April 2015 and 30 September 2015. 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 a few minutes to complete. If a carer has accompanied the patient on their clinic visit, they may help the patient to complete 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 an 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 a large postage-paid envelope provided.

Each service will receive the following resources:

- 50 x copies of a paper questionnaire
- 50 x sealable envelopes
- 50 x patient information leaflets

- an A3 laminated poster (on request)
- 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 as a national summary report and an individual report for each service. This will benchmark the results of individual services against the national average for each audit question.

The national summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. This full audit report will also include a list of all participating services and some data from identified individual services. A bespoke patient version of the audit summary report will also be produced.

The national summary report will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The report will also be made available on 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 such as NICE CG35 and the NSF LTNC. Therefore, this data will provide valuable information about priority areas within the existing health care 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.

UK Parkinson's Audit 2015 – 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 (30 April to 30 September 2015) for your data to be included in the audit.

How do I take part if I am eligible?

Register your service

Download the registration form from **parkinsons.org.uk/audit**, add your details and return to **pdaudit@parkinsons.org.uk** by **30 March 2015**. At this stage you can also opt in to the Patient Reported Experience Measure (PREM) part of the audit. You will then be emailed a service number and a password for the data entry tool – you will need these to enter your audit data.

Inform your audit department

Please log your participation in this clinical audit with your audit department and notify your local Caldicott Guardian.

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 entry tool from **parkinsons.org.uk/audit** from mid-April 2015, along with a user guide. Data entry begins on 30 April 2015.

1. Enter brief details about your service (the Service Audit).
2. Enter details of consecutive patients seen during the audit period 30 April 2015 to 30 September 2015 (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.

Table 1: Occupational 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	
Service description			
2.1	Describe the setting in which you usually see individuals with Parkinson's.	• Integrated medical and therapy Parkinson's clinic • Inpatient acute service • Inpatient rehabilitation service • Community rehabilitation service, eg intermediate care • Social services, including reablement • Outpatient/day hospital • Other (please specify)	
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	
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	How many full-time equivalent occupational therapists work with individuals with Parkinson's patients in your service?	Free text	
4.2	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 and conferences.
4.3	Are there any documented induction and support strategies for new occupational therapists working with individuals with Parkinson's?	• Yes • No	
4.4	What support (eg 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	

Clinical practice			
5.1	How does your service approach assessment of an individual with Parkinson's?	• MDT assessment • Interview with patient 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	
5.2a	Number of sessions in an intervention period.	Free text	
5.3	Please list the standardised assessments that you use.	• Assessment of Motor and Process Skills • Canadian Occupational Performance Measure (Law et al, 2005) • Nottingham Extended Activities of Daily Living Assessment (NEADL) (Nouri and Lincoln, 1987) • Fatigue Impact Scale (FIS) (Whitehead, 2009) • Unified Parkinson's Disease Rating Scale (UPDRS) • Model of Human Occupation Screening Tool (MOHOST) • Non-motor Questionnaire • Other (please specify)	

5.4	What needs are addressed through your interventions?	• Maintenance of work roles • Maintenance of family roles • Domestic activities of daily living • 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 • Mental wellbeing, including cognition, emotional and/or neuro-psychiatric problems • Management of fatigue • Education • Social interaction/social support • Other (please specify)	
5.5	Where do you carry out the intervention?	• Individual's home • Day hospital/centre • Inpatient hospital	

Table 2: Occupational therapy patient audit – questions, data items/answer options and help notes

No.	Question	Data items/answer options	Help notes
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 British • Any other white background • Black/Black British • Asian/Asian British • Mixed race • Not stated • Other ethnic group	
1.4	Year of birth	Free text	
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 specify)	

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 on medication four or less doses/day • Stable medication for >3/12 • Absence of postural instability Complex • Drugs – five 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)

Referral

Standard A: Occupational therapy should be available and considered at diagnosis and during each regular reviews for people with Parkinson's. (NICE CG35, R12, R80)

Standard B: Occupational therapists reviewing people with Parkinson's should give particular consideration to: (NICE CG35, 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 staff have access to all relevant records and background information about the person's condition, test results and previous consultations. (NSF LTNC, QR1)

2.1	Who made the referral to OT?	• Neurologist • Geriatrician • GP • Dietician • Social care worker • Self-referral • Other • Unknown	
2.2	Year of Parkinson's diagnosis	Free text	
2.3	Date of referral letter to this episode	(dd/mm/yyyy)	
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	

2.6	If yes, how many episodes of OT has s/he received for Parkinson's related problems, prior to this referral?	Free text	
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?	• Maintenance of work roles • Maintenance of family roles • Domestic activities of daily living • 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 • 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	**Resources** • NSF LTNC, 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 a long-term condition. The most effective support is provide, when local health and social services teams communicate, have access to up-to-date case notes and patient-held records, and work together to provide a co-ordinated service.
2.10	If 'no', what information was missing?	Free text	
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 in interim reports where treatment lasts a longer time)?	• Yes • No	

Referral

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 CG35, R5)

Principle 3: Development of goals in collaboration with the individual and carer with regular review (OT Best Practice Guidelines)

3.1	What goals, amenable to occupational therapy intervention, were identified and by whom?		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.'[7] 'Goal setting: Goals identified by the patient, in partnership with the therapist.'[8] **Resources** • OT Best Practice Guidelines (page references can be provided for each sub-section) • *Falls: Assessment and Prevention of Falls in Older People Clinical Guideline 161* (NICE, 2013) (**http://bit.ly/1OrPj2j**) • *Up and About – Pathways for the prevention and management of falls and fragility fractures* (NHS Quality Improvement Scotland, 2010) (**http://bit.ly/1Ci0OPY**)

3.1a	Optimising activities	• Patient and carer • Patient and therapist	
3.1b	Supporting participation	• Patient and carer • Patient and therapist	
3.1c	End-of-life care	• Patient and carer • Patient and therapist	

Intervention strategies used			
4.1	Initiating and maintaining movement.	• Promoting functional 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. • For example, imagining action to be carried out in detail before starting movement. • For example, 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 specify)	
4.2	Engagement, motivation, learning and carry-over.	• Promoting mental wellbeing • Promoting new learning • None of the above strategies applicable	Tick all that apply. • For example, intervention to address emotional, cognitive and/or neuropsychiatric impairment. • For example, 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 specify)	
4.3	Environmental adaptations/assistive technology – did intervention include assessment for:	• Small aids and adaptations • Wheelchair and seating • Major adaptations • Assistive technology • None of the above treatment strategies applicable	Tick all that apply. • For example, grab rails, perching stool, adaptive cutlery • For example, telecare
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 specify)	
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 specify) • None of the above treatment strategies available	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 specify)	
4.5	Providing information to increase patient's knowledge.	• 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 specify)	
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 • 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 specify)	

4.7	Providing support to facilitate a change in attitude.	• Positive attitude/emotional set • Developing self awareness/adjustment to limitations • Increasing confidence • Explore new occupations • 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 specify)	

About the occupational therapist			
5.1	What is the NHS banding/social service grade of the person who assessed this person?	• Band 5 • Band 6 • Band 7 • Band 8a • Band 8b • Band 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	

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 in OT Best Practice Guidelines (2010) • Information from Parkinson's UK website • NSF LTNC (2005) • NICE CG35 (2006) • Published evidence in a peer-reviewed journal • None • Other (please specify)	

Appendix A: Patient audit question sheet

This sheet can be printed out and used to collect patient data, which can be entered on the data entry tool at a later date.

No.	Question	Data items/answer options
Demographics		
1.1	Patient identifier	This can be used by you to identify audited patients.
1.2	Gender	• Male • Female
1.3	Ethnicity	• White British • Any other white background • Black/Black British • Asian/Asian British • Mixed race • Not stated • Other ethnic group
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 clinic • At home • Other (please specify)
1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative
Referral		
2.1	Who made the referral to OT?	• Neurologist • Geriatrician • GP • Dietician • Social care worker • Self-referral • Other • Unknown
2.2	Year of Parkinson's diagnosis	
2.3	Date of referral letter to this episode (dd/mm/yyyy)	

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
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)	• Maintenance of work roles • Maintenance of family roles • Domestic activities of daily living • 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 • 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?	• Yes • No • Unknown
2.11	As an occupational therapist, do you feel that the patient was referred at an appropriate time?	• Yes • No • Unknown
2.12	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

Goals identified		
3.1	What goals, amenable to occupational therapy intervention, were identified and by whom?	• Optimising activities – Patient and carer – Patient and therapist • Supporting participation – Patient and carer – Patient and therapist • End-of-life care – Patient and carer – Patient and therapist

Intervention strategies used		
4.1	Initiating and maintaining movement (Tick all that apply)	• Promoting functional 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 specify)
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 specify)
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 • 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 specify)

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 specify) • None of the above treatment strategies available
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 specify)
4.5	Providing information to increase patient's knowledge (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 specify)
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 • 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 specify)
4.7	Providing support to facilitate a change in attitude (Tick all that apply)	• Positive attitude/emotional set • Developing self awareness/adjustment to limitations • Increasing confidence • Explore new occupations • 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 specify)

About the occupational therapist

5.1	What is the NHS banding/social service grade of the person who assessed this person?	• Band 5 • Band 6 • Band 7 • Band 8a • Band 8b • Band 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

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 (2010) • Information from Parkinson's UK website • NSF LTNC (2005) • NICE CG35 (2006) • Published evidence in a peer-reviewed journal • None • Other (please specify)

References

1. Aragon A, Kings J (2010) *Occupational Therapy for People with Parkinson's Disease: Best Practice Guidelines.* College of Occupational Therapists, in partnership with Parkinson's UK. **www.cot.co.uk/sites/default/files/publications/public/OT-People-Parkinsons.pdf**

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

3. National Institute of Health and Clinical Excellence. *Parkinson's Dsease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (2006) **http://guidance.nice.org.uk/CG35/NICEGuidance/pdf/English**

4. National Institute of Health and Clinical Excellence. *Parkinson's Dsease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (2006), p142 **http://guidance.nice.org.uk/CG35/NICEGuidance/pdf/English**

5. National Institute of Health and Clinical Excellence. *Parkinson's Dsease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (2006), p16 **http://guidance.nice.org.uk/CG35/NICEGuidance/pdf/English**

6. Health Professionals Council. *Confidentiality – Guidance for Registrants.* (2012) **www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf**

7. Aragon A, Kings J (2010) *Occupational Therapy for People with Parkinson's Disease: Best Practice Guidelines.* College of Occupational Therapists, in partnership with Parkinson's UK, p16 **www.cot.co.uk/sites/default/files/publications/public/OT-People-Parkinsons.pdf**

8. Jain et al, 'The variety of occupational therapy interventions used to change skills, knowledge and attitude with people with Parkinson's and support their care givers' in Aragon A, Kings J (2010) *Occupational Therapy for People with Parkinson's Disease: Best Practice Guidelines.* College of Occupational Therapists, in partnership with Parkinson's UK. p18 **www.cot.co.uk/sites/default/files/publications/public/OT-People-Parkinsons.pdf**

Appendix E
Physiotherapy standards and guidance

UK Parkinson's Audit 2015 – physiotherapy standards and guidelines

Audit of national standards relating to physiotherapy for people with Parkinson's, incorporating the NICE Guideline for Parkinson's and quality standards from the National Service Framework for Long-term Neurological Conditions.

Background

Continuous monitoring of an organisation and delivery of a service is a way of ensuring that what should be happening is happening. If not, it can identify where changes can or need to be implemented and what those changes might be. Through this, services can improve patient care, financial efficiencies and working practices. Audit and service development is especially enhanced when it can be conducted against explicit, nationally agreed criteria.

The Parkinson's Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35 [1] (NICE, 2006), referred to as 'NICE CG35' throughout this document, state 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[2] (Department of Health, 2005) 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. Throughout this document, the framework will be referred to as the 'NSF LTNC'.

A group of key clinical, academic and research physiotherapists undertook work to adapt the *Quick Reference Cards*,[3] based on the *Dutch Guidelines for Physical Therapy in Patients with Parkinson's Disease*, 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 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 third round in which physiotherapists will be able to take part, along with occupational therapists and speech and language therapists. A Question Review Group was convened in 2014, and the audit questions for this round of the audit have been refined with their guidance.

The 2015 audit includes a Patient Reported Experience Measure (PREM) for the first time to ensure that the views of people with Parkinson's about their services are included.

Aim

The aim of the physiotherapy audit is to establish if physiotherapy services are currently providing quality services for people with Parkinson's, taking into account recommendations made in the evidence-based guidelines listed on page 1.

Objectives

- 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 NICE CG35 and the NSF LTNC.

- To highlight areas of good and poor practice to inform local discussions, leading to action plans to improve quality of care.

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

Methodology

This audit is open to all physiotherapy services and individual physiotherapists that work with people with Parkinson's in the UK.

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) (page 7) and Table 2 (Patient audit) (page 10).

A process flow chart (*How do I take part?*) can be found on page 6. Please note the importance of logging your participation in this national clinical audit with your audit department, and notifying your local Caldicott Guardian.

Patient sample

The minimum audit sample size is 10 consecutive Parkinson's patients seen during the audit data collection period, which runs from 30 April 2015 to 30 September 2015. You should 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 entry tool will have the capacity to capture as many consecutive patients as therapists wish to audit.

Data collection and entry

The audit tool contains three sections:

- a **'service audit'** section, which consists of some general questions about your service. This 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 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 entry tool, saved on your computer 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 (see page 17) 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 entry tool, available at **parkinsons.org.uk/audit**, provides full instructions and information.

All data must be submitted by 15 October 2015. 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 . 'No, but...' answers can be removed from calculations of compliance.

Confidentiality

A. Patients

Patients' confidentiality must be protected. Please ensure that any information you submit for the audit does not include any personally identifiable information about your patients. Identifiable information can be described as, "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, 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.** 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.

B. Employers

In order to comply with *Healthcare Quality Improvement Partnership (HQIP) Principles of Quality in National Clinical Audit* guidelines (**http://bit.ly/1Gy1e9o**), the summary report on the audit findings will list all participating organisations and include data from identified individual services. This means that your employer's confidentiality will not be protected. **It is therefore vital that your employer is aware of, and agrees to, your participation in the audit, and to the submission of your final data.**

C. Participants

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

Data security

The audit tool, which is available for download from **parkinsons.org.uk/audit**, is 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 dataset, we also advise you to save and use your spreadsheet on a secure computer at work and not on your personal computer at home. We ask you to comply with your trust/board/local health board'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 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 staff working directly on analysis. Raw data will not be available 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 (PREM)

All services participating in the audit can opt to participate in the PREM. The PREM is a short paper questionnaire to be distributed to up to 50 consecutive patients between 30 April 2015 and 30 September 2015. 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 only take a few minutes to complete. If a carer has accompanied the patient on their clinic visit, they may help the patient to complete 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 an envelope provided. These envelopes will 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 a large postage-paid envelope provided.

Each service will receive the following resources:

- 50 x copies of a paper questionnaire
- 50 x sealable envelopes
- 50 x patient information leaflets
- an A3 laminated poster (on request)
- 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 as a national summary report and an individual report for each service. This will benchmark the results of individual services against the national average for each audit question.

The national summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. This full audit report will also include a list of all participating services and some data from identified individual services. A bespoke patient version of the audit summary report will also be produced.

The national summary report will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The report will also be made available on 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 such as NICE CG35 and the NSF LTNC. Therefore, this data will provide valuable information about priority areas within the existing health care 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 data from the physiotherapy audit will also enable individual services to assess how well their service complies with the guidance and whether physiotherapists working within that service are using appropriate outcome measures and treatment strategies. Moreover, it will provide important information about access to training in Parkinson's-related physiotherapy.

UK Parkinson's Audit 2015 – 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 (30 April to 30 September 2015) for your data to be included in the audit.

How do I take part if I am eligible?

Register your service

Download the registration form from **parkinsons.org.uk/audit**, add your details and return to **pdaudit@parkinsons.org.uk** by **30 March 2015**. At this stage you can also opt in to the Patient Reported Experience Measure (PREM) part of the audit. You will then be emailed a service number and a password for the data entry tool – you will need these to enter your audit data.

▼

Inform your audit department

Please log your participation in this clinical audit with your audit department and notify your local Caldicott Guardian.

▼

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 entry tool from **parkinsons.org.uk/audit** from mid-April 2015, along with a user guide. Data entry begins on 30 April 2015.

1. Enter brief details about your service (the Service Audit).
2. Enter details of consecutive patients seen during the audit period 30 April 2015 to 30 September 2015 (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.

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.	• Inpatient acute service • Inpatient rehabilitation service • Acute outpatient rehabilitation • Community rehabilitation service • Social services • Other (please specify)	
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	
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	How many full-time equivalent physiotherapists work with individuals with Parkinson's patients in your service?	Free text	
4.2	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 and conferences.
4.3	Are there any documented induction and support strategies for new physiotherapists working with individuals with Parkinson's?	• Yes • No	
4.4	What support (eg 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	

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	Data items/answer options	Help notes
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 British • Any other white background • Black/Black British • Asian/Asian British • Mixed race • Not stated • Other ethnic group	
1.4	Year of birth	Free text	
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 specify)	

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 on medication four or less doses/day • Stable medication for >3/12 • Absence of postural instability Complex • Drugs – five 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)

Referral			
2.1	Year of Parkinson’s diagnosis.	Free text	
2.2	Has the person received previous physiotherapy specifically for Parkinson’s?	• Yes, please go to Q2.3 • No, please skip to Q3 • 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 if known.	(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 – 01/07/2007 for July 2007, for example. If not known at all, please leave blank. Please do not enter 00/00/0000.

Time from referral to initial assessment			
3.1	Date of referral letter to this episode.	(dd/mm/yyyy)	This is the date the letter was written. If the actual date is not known, please give the estimated year of that initial referral in the following format – 01/07/2007 for July 2007, for example. If not known at all, please leave blank. Please do not enter 00/00/0000.
3.2	Was the referral routine or urgent?	• Urgent • Routine • Unknown	Urgent or routine may be stated on referral letter, or the physiotherapy department or physiotherapist may have decided whether to treat as urgent or routine according todetails in the letter.
3.3	Date of initial physiotherapy assessment.	(dd/mm/yyyy)	If the actual date is not known, please give the estimated year of that initial assessment in the following format – 01/07/2007 for July 2007, for example. If not known at all, please leave blank. Please do not enter 00/00/0000.
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 physiotherapy department or physiotherapist may have a local standard of seeing people with Parkinson's within a certain time frame. For example, four 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	

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

Implementation of national recommendations			
4.1	Do the physiotherapy notes include a 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 test • 10-metre walk test • Time Up and Go (TUG) • Time UnSupported Stand (TUSS) • Parkinson's Activity Scale (PAS) • Modified Parkinson's Activity Scale (M-PAS) Gait • Modified Parkinson's Activity Scale (M-PAS) Chair • Modified Parkinson's Activity Scale (M-PAS) Bed • Retropulsion Test • Push and Release Test • Tragus to wall • Five times sit to stand test • Dynamic Gait index • Functional Gait Assessment • Freezing of Gait Questionnaire • Snijders and Bloem Freezing of Gait Test • Borg Scale • History of Falls Questionnaire • PDQ39 • Phone FITT • General Practice Physical Activity Questionnaire (GPPAQ) • The Falls Efficacy Scale – International (Short FES-I) • EQ-5D tool • Other (please specify)	

About the physiotherapist			
5.1	What band (grade) is the physiotherapist who assessed this person?	• 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	

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 • Recommendations given in *Dutch Guidelines for Physical Therapy in Patients with Parkinson's Disease* (2006) • *Quick Reference Cards* (2009) • Information from Parkinson's UK website • NSF LTNC (2005) • NICE CG35 (2006) • *European Physiotherapy Guideline for Parkinson's Disease* (2013) • Published evidence in a peer reviewed journal (read within last 12 months) • Postgraduate training (eg attending courses/lectures specific to Parkinson's) within last 24 months • Other (please specify) • None	

Appendix A: Patient audit question sheet

This sheet can be printed out and used to collect patient data, which can then be entered on the data entry tool at a later date.

No.	Question	Data items/answer options
Demographics		
1.1	Patient identifier	This can be used by you to identify audited patients.
1.2	Gender	• Male • Female
1.3	Ethnicity	• White British • Any other white background • Black/Black British • Asian/Asian British • Mixed race • Not stated • Other ethnic group
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 specify)
1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative
Referral		
2.1	Year of Parkinson's diagnosis	
2.2	Has the person received previous physiotherapy specifically for Parkinson's?	• Yes, please go to Q2.3 • No, please skip to Q3 • Offered, but declined • Unknown
2.3	Date of the first referral letter if known (dd/mm/yyyy)	

Time from referral to initial assessment

3.1	Date of referral letter to this episode (dd/mm/yyyy)	
3.2	Was the referral routine or urgent?	• Urgent • Routine • Unknown
3.3	Date of initial physiotherapy assessment (dd/mm/yyyy)	
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

Implementation of national recommendations

4.1	Do the physiotherapy notes include a 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 test • 10-metre walk test • Time Up and Go (TUG) • Time UnSupported Stand (TUSS) • Parkinson's Activity Scale (PAS) • Modified Parkinson's Activity Scale (M-PAS) Gait • Modified Parkinson's Activity Scale (M-PAS) Chair • Modified Parkinson's Activity Scale (M-PAS) Bed • Retropulsion Test • Push and Release Test • Tragus to wall • Five times sit to stand test • Dynamic Gait index • Functional Gait Assessment • Freezing of Gait Questionnaire • Snijders and Bloem Freezing of Gait Test

Options continued on the next page.

		• Borg Scale • History of Falls Questionnaire • PDQ39 • Phone FITT • General Practice Physical Activity Questionnaire (GPPAQ) • The Falls Efficacy Scale – International (Short FES-I) • EQ-5D tool • Other (please specify)
About the physiotherapist		
5.1	What band (grade) is the physiotherapist who assessed this person?	• Band 5 • Band 6 • Band 7 • Band 8a • Band 8b • Band 8c • Other (please specify)
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
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 • Recommendations given in *Dutch Guidelines for Physical Therapy in Patients with Parkinson's Disease* (2006) • *Quick Reference Cards* (2009) • Information from Parkinson's UK website • NSF LTNC (2005) • NICE CG35 (2006) • *European Physiotherapy Guideline for Parkinson's Disease* (2013) • Published evidence in a peer-reviewed journal (read within last 12 months) • Postgraduate training (eg attending courses/lectures specific to Parkinson's) within last 24 months • Other (please specify) • None

References

1. National Institute of Health and Clinical Excellence. *Parkinson's Dsease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (2006) **http://guidance.nice.org.uk/CG35/NICEGuidance/pdf/English**

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

3. Keus S et al. (2004) 'Guidelines for physical therapy in patients with Parkinson's disease.' *Dutch Journal of Physiotherapy*. 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) **www.parkinsons.org.uk/content/quick-reference-cards-uk-physiotherapists**

5. Health Professionals Council. *Confidentiality – Guidance for Registrants.* (2012) **www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf**

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Appendix F

Speech and Language therapy standards and guidance

UK Parkinson's Audit 2015 – speech and language therapy standards and guidelines

Audit of national standards relating to speech and language therapy for people with Parkinson's, incorporating the NICE Guideline for Parkinson's and quality standards from the National Service Framework for Long-term Neurological Conditions.

Background

Continuous monitoring of an organisation and delivery of a service is a way of ensuring that what should be happening is happening. If not, it can identify where changes can or need to be implemented and what those changes might be. Through this, services can improve patient care, financial efficiencies and working practices. Audit and service development is especially enhanced when it can be conducted against explicit, nationally agreed criteria.

Various guidelines published in recent years offer recommendations for speech language therapists in the management of people with Parkinson's. These include in particular *Parkinson's Disease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (NICE, 2006)[1] and sections/quality requirements of the *National Service Framework for Long-term Neurological Conditions* (Department of Health, 2005).[2] Throughout this document, these two sets of guidelines will be referred to as NICE CG35 and NSF LTNC.

The Royal College of Speech and Language Therapists (RCSLT) has also published guidelines pertinent to Parkinson's in their *Clinical Guidelines (Dysarthria)*[3] and *Communicating Quality 3*[4] (referred to as RCSLT CQ3 in this document). The Dutch speech and language therapy organisation, in conjunction with the Parkinson Net organisation, has also published detailed speech and language therapy guidelines for Parkinson's.[5]

National surveys[6,7] indicate that speech and language provision for people with Parkinson's is highly variable across the UK, with potential for improvement in many areas. This audit will allow speech and language services to be audited in relation to NICE CG35, NSF LTNC and other key national and international guidelines, and enable speech and language managers to compare their service with the national pattern of all responding speech and language 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.

This speech and language therapy audit is part of the UK Parkinson's Audit. This is the third round in which speech and language therapists will be able to take part, along with physiotherapists and occupational therapists. A Question Review Group was convened in 2014, and the audit questions for this round of the audit have been refined with their guidance.

The 2015 audit includes a Patient Reported Experience Measure (PREM) for the first time to ensure that the views of people with Parkinson's about their services are included.

Aim

The aim of the speech and language therapy audit is to establish if speech and language therapy services are currently providing quality services for people with Parkinson's, taking into account recommendations made in NICE CG35, the NSF LTNC, RCSLT CQ3 and *RCSLT Clinical Guidelines (Dysarthria)* standards for motor speech disorders and progressive neurological conditions.

The audit focuses on the early and maintenance phases of the pathway of care for people with Parkinson's (although several questions look at the longer-term care perspective and preparing the ground for later stage changes). It incorporates items around assessing the status and current needs for support from speech and language therapy for people newly referred to a service with Parkinson's, or those identified at a review as needing support, and initiating treatments.

Objectives

- 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 the guidelines listed on page 1.

- To identify areas of good practice and areas where improvements need to be made, leading to action plans to improve quality of care.

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

Methodology

This audit is open to all speech and language therapy and individual speech and language therapy that work with people with Parkinson's in the UK.

Standards agreed to be pertinent to occupational therapy have been transformed into a set of audit standards and statements reviewed by specialist speech and language therapy. The full list of questions is given in Table 1 (Service audit) (page 7) and Table 2 (Patient audit) (page 13).

A process flow chart (*How do I take part?*) can be found on page 6. Please note the importance of logging your participation in this national clinical audit with your audit department, and notifying your local Caldicott Guardian.

Patient sample

The minimum audit sample size is 10 consecutive Parkinson's patients seen during the audit data collection period, which runs from 30 April 2015 to 30 September 2015. You should 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 entry 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:
- patients who are currently receiving active intervention (including education/counselling) at the start of the audit period
- 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
- 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. This 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. The patient audit may be carried out by a designated colleague (with permission from participating therapists) or individual therapists responsible for their own notes. This part of the audit is completed on the basis of individual patient records
- 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 entry tool, saved on your computer 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 (see page 24) 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 entry tool, available at **parkinsons.org.uk/audit**, provides full instructions and information.

All data must be submitted by 15 October 2015. 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. 'No, but...' answers can be removed from calculations of compliance.

Confidentiality

A. Patients

Patients' confidentiality must be protected. Please ensure that any information you submit for the audit does not include any personally identifiable information about your patients. Identifiable information can be described as, "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."[8]

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, 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.** 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.

B. Employers

In order to comply with *Healthcare Quality Improvement Partnership (HQIP) Principles of Quality in National Clinical Audit* guidelines (**http://bit.ly/1Gy1e9o**), the summary report on the audit findings will list all participating organisations and include data from identified individual services. This means that your employer's confidentiality will not be protected. **It is therefore vital that your employer is aware of, and agrees to, your participation in the audit, and to the submission of your final data.**

C. Participants

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

Data security

The audit tool, which is available for download from **parkinsons.org.uk/audit**, is 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 dataset, we also advise you to save and use your spreadsheet on a secure computer at work and not on your personal computer at home. We ask you to comply with your trust/board/local health board'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 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 staff working directly on analysis. Raw data will not be available 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 (PREM)

All services participating in the audit can opt to participate in the PREM. The PREM is a short paper questionnaire to be distributed to up to 50 consecutive patients between 30 April 2015 and 30 September 2015. 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 a few 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 an 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 a large postage-paid envelope provided.

Each service will receive the following resources:

- 50 x copies of a paper questionnaire
- 50 x sealable envelopes
- 50 x patient information leaflets
- an A3 laminated poster (on request)
- 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 as a national summary report and an individual report for each service. This will benchmark the results of individual services against the national average for each audit question.

The national summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. This full audit report will also include a list of all participating services and some data from identified individual services. A bespoke patient version of the audit summary report will also be produced.

The national summary report will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The report will also be made available on 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 such as NICE CG35 and the NSF LTNC. Therefore, this data will provide valuable information about priority areas within the existing health care 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.

UK Parkinson's Audit 2015 – 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 (30 April to 30 September 2015) for your data to be included in the audit.

How do I take part if I am eligible?

Register your service

Download the registration form from **parkinsons.org.uk/audit**, add your details and return to **pdaudit@parkinsons.org.uk** by **30 March 2015**. At this stage you can also opt in to the Patient Reported Experience Measure (PREM) part of the audit. You will then be emailed a service number and a password for the data entry tool – you will need these to enter your audit data.

Inform your audit department

Please log your participation in this clinical audit with your audit department and notify your local Caldicott Guardian.

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 entry tool from **parkinsons.org.uk/audit** from mid-April 2015, along with a user guide. Data entry begins on 30 April 2015.

1. Enter brief details about your service (the Service Audit).
2. Enter details of consecutive patients seen during the audit period 30 April 2015 to 30 September 2015 (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.

Table 1: Speech and 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 specialist neurology clinics • 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 domiciliary based • In generalist SLT service mainly based in a hospital • In generalist SLT service mainly based in a community clinic • In generalist SLT service mainly domiciliary based • No contact with patients with Parkinson's	
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 (eg 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 (eg neurology vs elderly care) • Not full service, some patients not seen depending on issue (eg communication vs swallowing) • Not full service, some patients not seen depending on prioritisation in SLT Parkinson's service • Not full service, some patients not seen depending on prioritisation in overall SLT service • No service	Tick all that apply.

2.6	Is SLT available for all individuals with Parkinson's for issues with eating/swallowing/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 (eg 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 (eg neurology vs elderly care) • Not full service, some patients not seen depending on issue (eg communication vs swallowing) • Not full service, some patients not seen depending on prioritisation in SLT Parkinson's service • Not full service, some patients not seen depending on prioritisation in overall SLT service • No service	Tick all that apply.
2.7	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 • 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	Enter total number.
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	How many full-time equivalent SLTs work with individuals with Parkinson's patients in your service?	Free text	Enter total full-time equivalents.
4.2	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 and conferences.
4.3	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	
4.4	What support (eg 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	
4.5	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 six-12 monthly intervals?	• All patients in SLT service routinely reviewed within six-12 months • Some patients reviewed at request of wider MDT/ Parkinson's nurse specialist • Some patients reviewed according to local prioritisation • 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?	• 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 • Swallowing: – Standardised assessments of swallowing – Selective range of formal assessments – Disease-specific informal assessment proforma used – No specific assessments stipulated • Saliva management: – Is saliva management included in the SLT assessment and treatment plan if required?	

Table 2: Speech and langauge therapy patient audit – questions, data items/answer options and help notes

No.	Question	Data items/answer options	Help notes
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 British • Any other white background • Black/Black British • Asian/Asian British • Mixed race • Not stated • Other ethnic group	
1.4	Year of birth	Free text	
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 specify)	

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 on medication four or less doses/day • Stable medication for >3/12 • Absence of postural instability Complex • Drugs – five 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)

Referral			
Standard A: 100% of people with Parkinson’s must be reviewed at six-12 monthly intervals. (NICE CG35, R12, R77 and NSF LNTC,QR2)			
2.1	Year of Parkinson’s diagnosis	Free text	
2.2	Date of first referral to SLT service involved in the current audit.	(dd/mm/yyyy)	If the actual date is not known, please give the estimated year of diagnosis in the following format – 01/07/2007 for July 2007, for example. If not known at all, please leave blank. Please do not enter 00/00/0000.
2.3	Referred by?	• Elderly care clinic • General neurology clinic • Parkinson’s nurse specialist • 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	
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 (eg clinician leave)	
2.9	Was SLT intention to treat decision to first appointment wait time target met?	• Yes • No, and no reason documented for why • No, but reason documented (eg failed appointment)	

Assessments

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

- 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

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: (RCSLT Clinical Guidelines)

- 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

3.1	Full assessment carried out on a first referral for: • communication? • swallowing?	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented	
3.2	Assessment carried out at each review for communication?	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented	

3.3	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	
3.4	Assessment notes record whether assessment was in ‘off’ or ‘on’ state?	• Yes • No	
3.5	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	
3.6	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)			
3.7	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	

3.8	What tasks/contexts does assessment cover?	• Speaking • Reading • Writing • One to one context • Group context	Tick all that apply.
3.9	Which voice-respiration and prosody parameters were assessed?	• Loudness/amplitude level and variation • Pitch, pitch range and variation • Voice quality • Speech/articulation rate	Tick all that apply.
3.10	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 (eg 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)			
3.11	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	
3.12	Does assessment cover: • communication participation? • the impact of Parkinson's on communication? • the impact of communication changes on partner/carer?	• Yes/no • Yes/no • Yes/no/no carer	

Results of assessment			
3.13	Were results and rationale for resulting actions (eg 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	
3.14	Was information supplied to 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	
3.15	Where notes recommend onward referrals (eg ENT, video fluoroscopy), have these been made?	• Yes • None and reasons documented • None and reasons not documented • No onward referrals recommended	

Interventions

Standard H: Speech and language therapists should give particular attention to improvement of vocal loudness, pitch range and intelligibility. (NICE CG35, 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?	• Pitch (range) • Prosody • Improvement of vocal loudness • Strategies to optimise intelligibility	Tick all that apply.
4.4	Does intervention target features outside of direct speech/voice work?	• Patient education/advice • Managing patient participation • Managing patient impact • Managing generalisation outside clinic • Carer education/advice • Managing career impact • Other (please specify)	Tick all that apply.
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	

4.6	Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?	• Yes • No	
4.7	Do referral letters to other agencies contain the following?	• Relevant history • Question(s) that the referrer wishes to have answered • Type of referral requested (eg single consultation for advice/initiation of treatment)	
About the speech and language therapist			
5.1	What is the NHS banding/social service grade of the person who assessed this person?	• Band 5 • Band 6 • Band 7 • Band 8a • Band 8b • Band 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	

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 • RCSLT CQ3 • NICE CG35 • NSF LTNC • Published evidence in a peer-reviewed journal • None • Other (please specify)	

Appendix A: Patient audit question sheet

This sheet can be printed out and used to collect patient data, which can be entered on the data entry tool at a later date.

No.	Question	Data items/answer options
Demographics		
1.1	Patient identifier	This can be used by you to identify audited patients.
1.2	Gender	• Male • Female
1.3	Ethnicity	• White British • Any other white background • Black/Black British • Asian/Asian British • Mixed race • Not stated • Other ethnic group
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 clinic • At home • Other (please specify)
1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative
Referral		
2.1	Year of Parkinson's diagnosis	
2.2	Date of first referral to SLT service involved in the current audit (dd/mm/yyyy)	
2.3	Referred by?	• Elderly care clinic • General neurology clinic • Parkinson's nurse specialist • 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
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 (eg clinician leave)
2.9	Was SLT intention to treat decision to first appointment wait time target met?	• Yes • No, and no reason documented for why • No, but reason documented (eg failed appointment)
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 • Swallowing – Yes – No reference to assessments documented – No, but reasons for not appropriate to access documented
3.2	Assessment carried out at each review for:	• Communication – Yes – No reference to assessments documented – No, but reasons for not appropriate to assess documented • Swallowing – Yes – No reference to assessments documented – No, but reasons for not appropriate to access documented

3.3	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
3.4	Assessment notes record whether assessment was in 'off' or 'on' state?	• Yes • No
3.5	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
3.6	Is there a clear plan of management based on assessment outcomes?	• All plans detailed in notes • Some restricted plans documented • No plans documented
3.7	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
3.8	What tasks/contexts does assessment cover? (Tick all that apply)	• Speaking • Reading • Writing • One to one context • Group context
3.9	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
3.10	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 (eg rating scale) completed • No assessment/results documented, but justification given • No assessment documented and no justification given

3.11	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
3.12	Does assessment cover: • communication participation? • the impact of Parkinson's on communication? • the impact of communication changes on partner/carer?	 • Yes/no • Yes/no • Yes/no/no carer
3.13	Were results and rationale for resulting actions (eg 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
3.14	Was information supplied to 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
3.15	Where notes recommend onward referrals (eg ENT, video fluoroscopy), have these been made?	• Yes • None and reasons documented • None and reasons not documented • No onward referrals recommended
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
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
4.6	Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?	• Yes • No
4.7	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 (eg single consultation for advice/initiation of treatment)
About the speech and language therapist		
5.1	What is the NHS banding/social service grade of the person who assessed this person?	• Band 5 • Band 6 • Band 7 • Band 8a • Band 8b • Band 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
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 • RCSLT CQ3 • NICE CG35 • NSF LTNC • Published evidence in a peer reviewed journal • None • Other (please specify)

References

1. National Institute of Health and Clinical Excellence. *Parkinson's Dsease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35* (2006) **http://guidance.nice.org.uk/CG35/NICEGuidance/pdf/English**

2. Department of Health. *National Service Framework for Long-term Neurological Conditions.* (2005) **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 Guidlines (Dysarthria)* (2012)

4. Royal College of Speech and Language Therapists. *Royal College of Speech and Language Therapists Communicating Quality 3* (2006)

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

6. 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

7. 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

8. Health Professionals Council. *Confidentiality – Guidance for Registrants.* (2012) **www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf**

Appendix G

Patient Reported Experience Measure (PREM) questionnaire

UK PARKINSON'S
Excellence
Network

UK Parkinson's Audit 2015 – patient reported experience measure (PREM) questionnaire

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About the patient

I am the **patient** ☐

I am the **patient's carer** ☐ (If so, please complete on the patient's behalf)

1. Age

20 – 29 ☐	40 – 49 ☐	60 – 69 ☐	80 – 89 ☐
30 – 39 ☐	50 – 59 ☐	70 – 79 ☐	Over 90 ☐

2. Gender

Male ☐

Female ☐

3. Ethnicity

White British	☐	Mixed race	☐
Other white background	☐	Not stated	☐
Black/Black British	☐	Other ethnic group	☐
Asian/Asian British	☐	If other (please specify)	________________

4. Do you live alone?

Yes	☐	No, in a care home	☐
No	☐	Other (please specify)	________________

5. Approximately how long have you had Parkinson's?

Less than 1 year	☐	3 – 5 years	☐	11 – 20 years	☐
1 – 2 years	☐	6 – 10 years	☐	More than 20 years	☐

6. Approximately how long have you been attending your current Parkinson's service?

Less than 1 year	☐	3 – 5 years	☐
1 – 2 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, either 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	☐	☐	☐	☐

8. Do you feel able to contact your Parkinson’s service for advice in between scheduled reviews?

	Yes	Not sure	No – no access	Not aware of service	Not needed
Service co-ordinator/helpline	☐	☐	☐	☐	☐
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	Satisfactory	Poor	No service	Not needed
Consultant	☐	☐	☐	☐	☐	☐
Parkinson’s nurse	☐	☐	☐	☐	☐	☐
Occupational therapist	☐	☐	☐	☐	☐	☐
Physiotherapist	☐	☐	☐	☐	☐	☐
Speech and language therapist	☐	☐	☐	☐	☐	☐

10a. Do you feel you were given enough information about Parkinson’s when you were diagnosed?

Yes ☐
No ☐
Not sure ☐

10b. Do you feel that you are given enough information about any new medication, including potential side effects?

Yes ☐
No ☐
Not sure/no new medication started ☐

11. Does your Parkinson’s service give you information about:

	Yes	No	Not sure
how to access the range of support and information available from Parkinson’s UK?	☐	☐	☐
the role of social work for people with Parkinson’s and their carers?	☐	☐	☐
support for carers?	☐	☐	☐

12. Has your Parkinson's service ever checked any of the following issues with you and acted on them where necessary? (Please tick all that apply)

	Checked	Acted on	No action needed
Thinking or memory problems	☐	☐	☐
Hallucinations	☐	☐	☐
Mood	☐	☐	☐
Compulsive disorders	☐	☐	☐
Communication difficulties	☐	☐	☐
Swallowing problems	☐	☐	☐
Saliva problems	☐	☐	☐
Bladder problems	☐	☐	☐
Bowel problems	☐	☐	☐
Pain	☐	☐	☐
Sleep problems	☐	☐	☐
Daytime sleepiness	☐	☐	☐
Falls	☐	☐	☐
Tremor	☐	☐	☐
Mobility (walking)	☐	☐	☐
Mobility (getting off bed/chair)	☐	☐	☐
On/off fluctuations and wearing off	☐	☐	☐
Involuntary movements (dyskinesia)	☐	☐	☐
Issues with cooking and cleaning	☐	☐	☐
Issues with washing and dressing	☐	☐	☐
Issues with eating and drinking	☐	☐	☐
Issues with function at work	☐	☐	☐

13. If you are a driver, have you been given verbal and/or written advice by your Parkinson's service about contacting the DVLA or DVA and your car insurance company?
(If you do not drive, go to question 14)

Yes ☐
No ☐
Not sure ☐

14a. Do you feel your Parkinson's service involves you in decisions about your care?

Always ☐ Sometimes ☐ Never ☐
Mostly ☐ Rarely ☐

14b. Do you feel listened to?

Always ☐ Sometimes ☐ Never ☐
Mostly ☐ Rarely ☐

15. Have you been admitted to hospital in the last year?

Yes ☐
No ☐ (If no, please go to question 16)

15b. If yes, how often did you receive your Parkinson's medication at the correct time?

Always ☐
Mostly ☐
Half the time ☐
Less than half the time ☐
Never ☐
Not sure ☐

15c. 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 ☐

15d. Did you want to take your own Parkinson's medication in hospital?

Yes ☐
No ☐ (If no, go to question 16)

15e. Was it possible to take your own Parkinson's medication in hospital?

Yes ☐
No ☐
Not sure ☐

16. When you are seen by your Parkinson's service, are you treated as a whole person (including other conditions you may have) rather than only as a Parkinson's patient?

Always ☐
Mostly ☐
Sometimes ☐
Rarely ☐
Never ☐

17. Do you feel that your Parkinson's service is:

Improving ☐
Staying the same ☐
Getting worse ☐

18. 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.

UK PARKINSON'S
Excellence
Network

Appendix H

PREM – Qualitative report on free-text comments

2015 UK Parkinson’s Audit – Patient Reported Experience Measure (PREM) - Qualitative report on free-text comments

7. Do you feel the amount of times you see your consultant or Parkinson’s nurse (if you have one) for a review, either at a face-to-face appointment or by telephone, meets your needs?

A total of 110 patients commented on the frequency at which they were able to see their consultant and/or Parkinson’s nurse. Although a majority of these patients were generally satisfied with their services, many of them reported that the frequency of these appointments did not necessarily meet their needs.

> For example:
>
> *Patient A: “Would like to see the consultant more often. Feel once in 12 months is not enough.”*
>
> *Patient B: “Resources are obviously limited, but I do feel some patients would like/need to see the consultant 3 times a year if they are actively involved in self-managing their drug regime and other care!”*
>
> *Carer A: “Service is improving and consultant is excellent, but [patient]'s condition is rapidly changing, and since appointments are every 6 months before seeing consultant, [carer] constantly phones for advice or chasing for an earlier appointment. Situation is exhausting.”*
>
> *Patient C: “We have only had 1 appointment with the consultant and 1 with the nurse in the whole year. Left feeling we are alone ....”*

In contrast to this, a few patients, who were able to see their consultant and/or Parkinson’s nurse at a frequency that better suited their needs, described their positive experiences in the following ways:

> *Patient D: “Service is greatly improved now I see the specialist nurse in between my consultant appointments. I'm seen now at least 3 times a year, which is a great improvement. This really helps.”*
>
> *Patient E: “Regular check ups with Consultant is vital to me. Parkinson's, a specialist disease needs a consultant trained and up to date with the constant variations of this condition. Nurse gives of her time unstintingly, we are never rushed, all our worries and concerns are addressed and we always leave feeling better …”*

Nevertheless, the findings have also suggested that at present not all patients with Parkinson’s are able to regularly see both a consultant and Parkinson’s nurse, with some patients reporting that they only have access to one of these services, as opposed to both. For example, one patient reported here: *“Excellent service from Parkinson's specialist nurse. Only seen neurologist twice in 6 years and then each session lasted less than 5 minutes …”* Whilst another patient put forth: *“We see the specialist regularly but I can only remember one or two visits from the Parkinson's nurse in many years …”* In relation to this, another patient added: *“Not having had a consultation for 2 years, the bulk of the work has been fulfilled by the specialist nurse.”*

Other patients, on the other hand, specifically pointed out that there was an urgent need to promote wider access to Parkinson’s nurses, particularly in areas that currently had limited access to this service. For instance, one patient explained here: *“It would be helpful to have access to a Parkinson's nurse. Years ago we had a Parkinson's nurse visit every month. Then the visits were stopped. We were told lack of staff.”* Likewise, another patient suggested: *“It would be nice if you could employ extra nurses. One [in] the whole [area] is not enough!”* In support of this, one patient described their disappointment around not having access to a Parkinson’s nurse in the following way:

> *“We are [extremely] disappointed at having no Parkinson's nurse for 1 year. We have little or no opportunity to discuss our future. We feel Parkinson's Disease doesn't get the support that seems to be there for other illnesses and the treatments never seem to change”.*

In a similar manner, another patient elaborated on issues around replacing members of staff who had left or retired:

> *“I was diagnosed fourteen years ago with Parkinson's and only had access to Parkinson's nurse for the first year, she was not replaced after she left. On occasions I have run out of pills (e.g. a long weekend) with no one to contact, up till now no one has asked me about a Parkinson's nurse.”*

Furthermore, other patients also touched upon some difficulties experienced when requesting appointments at a short notice, with some patients further pointing out that their appointments were at times overdue or even cancelled by their hospitals.

> For example:
>
> *Patient F: “Nurse and consultant good but sometimes difficult to gain prompt access to the service due to pressure on staff/resources.”*
>
> *Patient G: “Since the last Parkinson's assessment, 18 months ago (cancelled appointments), my condition has deteriorated to a point where my body is stiff in all my joints and movement is difficult and painful … Although I am taking my medication I don't feel I am getting any benefit from it …”*
>
> *Patient H: “… Hospital consultant appointments always get cancelled by hospital staff, needing to wait more than 6 months for a review. NOT GOOD.”*

Such findings imply that several people with Parkinson’s are, at times, experiencing significant delays in accessing appropriate medical help and support. Moreover, a few patients also expressed that they were concerned about the continuity of their care, as they were often unable to see the same consultant(s) twice. One particular patient pointed out here that this was *“a shame”* as they would have preferred to *“build a rapport and relationship with 'the same' person on each visit.”*

Other patients also highlighted the importance of receiving home visits here, whilst a few carers suggested that services needed to offer better one-to-one support to carers and families.

> For example:
>
> *Patient I: “I have been ill and unable to attend clinic but have the Parkinson's nurse visit at home and the consultant. They are always available.”*
>
> *Patient J: “Would like some support at home. My age of 90 … once a year consult is poor.”*

> *Carer B: "As dad is disabled it is hard to get him to hospital. We would like to have regular monitoring from a specialist/nurse, preferably at home."*
>
> *Carer C: "A facility for carer/consultant contact would be valuable"*
>
> *Carer D: "As a carer for my husband I feel that it would be good if you could have a few minutes alone without your husband being there as they do not always want to reveal all that is happening."*

Overall, these findings suggest that there may currently be a need to increase the frequency of appointments to better suit the needs of people with Parkinson's, along with an urgent need to ensure that all patients are able to regularly access both a consultant and Parkinson's nurse. Furthermore, there may also be a need to further improve patients' experiences of continuity in care through ensuring that they are able to see the same health professionals, where possible, during their visits. Some services may also need to place an additional focus on ensuring that patients who are no longer able to travel to clinics are able to still receive appropriate help and support in their homes. Moreover, it seems that carers would highly value receiving additional one-to-one support directly from consultants and/or Parkinson's nurses.

8. Do you feel able to contact your Parkinson's service for advice in between scheduled reviews? (ie Service co-ordinator/helpline, Parkinson's nurse, Occupational therapist, Physiotherapist, Speech and language therapist)

In total, 59 patients described their experiences of contacting their Parkinson's health services in-between scheduled reviews. Just over half of these patients were indeed very satisfied that they were able to call or email their consultants and/or Parkinson's nurses when they were in need of urgent advice.

> For example:
>
> *Patient L: "I cannot speak highly enough of the service and advice given by [Parkinson's nurse]. If new issues arise, I can leave a message on the answerphone, with calls usually returned the same day."*
>
> *Patient M: "As far as [Parkinson's Nurse] is concerned, I am always able to contact her if I have any problem or concern about my medication and she is very reliable. Where necessary she will contact the consultant and come back to me."*
>
> *Patient N: "I am very pleased with the service by Consultant and Nurse. If I ring with a query, they get back to me asap …"*

Nevertheless, this did not reflect the experience of all patients with Parkinson's. Many of the remaining patients, for example, pointed out that their services were generally *"too busy"* and *"stretched"*, meaning that a response to many of their calls and voicemails were often too slow or, at times, left unreturned. In general, most of these comments reflected patients' difficulties in seeking advice from a consultant or Parkinson's nurse outside of scheduled reviews, and very little references were made to experiences of contacting other health services (eg occupational therapy, physiotherapy and speech and language therapy).

> For example:

> *Patient O: “Parkinson's nurse service is stretched with far too many patients. This can mean she is a bit tricky to get hold of - she is very good when she is seen.”*
>
> *Patient P: “The demands on the service mean the response to any answerphone is poor. Sometimes days before a call back. Service always good but difficult to get it!”*
>
> *Patient Q: “Someone [available] to speak to when needed feels very short staffed.”*
>
> *Patient R: “One Parkinson's nurse is not sufficient, and puts a lot of pressure [on] that person. We really need to know that a nurse is always available.”*

Moreover, one particular patient further elaborated on feelings of confusion around seeking advice in the following way:

> *“Variable nature of the disease causes confusion as to when to seek advice, as by the time it is organised situation has often escalated to detriment of patient and carer. The Parkinson's nurse has too large a remit so you feel it is only fair to contact her for very serious problems.”*

Overall, such findings suggest that although most patients are generally satisfied with their Parkinson’s health services, they are at times experiencing considerable difficulties in accessing appropriate help and guidance in-between scheduled reviews. There, therefore, seems to be a need to further improve access to support at this level. Furthermore, one particular patient had also mentioned here that they were at present unaware of who to contact when they experienced any problems, further highlighting the importance of providing clearer information to patients about the services available to them.

9. How would you rank the quality of service provided by the various parts of your Parkinson’s service?

Overall, 1163 patients commented on the quality of care they received from their Parkinson’s health services. Of these, a total of 905 patients described various aspects of these services in a very positive manner, using words like “excellent”, “very good” and “very helpful”.

Examples of general comments in this area included:

> *Patient S: “I receive very good service and all the assistance required to manage my Parkinson's and give me a reasonable standard of living and quality of life …”*
>
> *Patient T: “I could not ask for a better service from Reception to the Consultant. All are excellent and very personable and make you feel like you are the only patient they have …”*
>
> *Patient U: “Have always found the Parkinson's team friendly, very helpful and not at all pushy. They give informed advice and mostly let me make my own decision.”*

Moreover, one particular patient further elaborated on their positive experiences since diagnosis in the following way:

> *“The service I have received from the clinic from Day 1 has been excellent. I have always been treated with kindness and patience from the consultant, doctors, nurses, physios, reception staff and waiting room staff. I am never made to feel I am being a*

> *[nuisance] when I have asked a question whether face to face, online, or on the phone. I am grateful to them ..."*

In addition to this, many patients specifically highlighted the importance of having access to multidisciplinary teams.

> For example:
>
> *Patient V: "The multidisciplinary team (i.e. Physio, OT, [dietician]) are very good and helpful. Keen to help in whatever way they can."*
>
> *Patient W.: "I feel I am very well supported by the Service with Consultant/Nurse and Physio. I do not feel I am facing it alone."*
>
> *Patient X.: "Experience of Physiotherapy and voice therapy has been excellent. Occupational therapy has also been very helpful."*
>
> *Patient Y.: "Weekly exercise class/tai chi/voice exercise and choir run by [rehab service name] is excellent and has rendered some immobile people ambulant again. The multidisciplinary approach is to be recommended and should be a benchmark for others to follow."*

Moreover, one patient suggested that a multidisciplinary team approach would also be helpful at scheduled reviews. On the other hand, some of the key concerns raised by patients in relation to the quality of their care included:

- **Delays in signposting to appropriate services**

One carer argued, for example: *"We were disappointed that my father has not yet received occupational therapy, speech therapy and physiotherapy as yet. All were noted to be actioned on diagnosis. It's only now that any action has been taken. Here has been some confusion as to [who] (GP or hospital) should action this."*

- **Lack of integration between services**

One patient pointed out, for example that: *"Service is not integrated and you wait long time in clinic for very little. Like many of my friends I feel that PD patients are abandoned by the medical profession as we cannot be "cured" and they have little interest in making our lives more bearable."* Similarly, another patient put forth: "*It would be useful to see more of a link-up between different NHS departments so that each medical practitioner can see the WHOLE history picture of their patients."*

In relation to this, one particular patient argued that they received insufficient psychological support as part of their care. This patient reported, for example: *"I have felt that psychological support is insufficiently covered in my treatment, especially where anxiety is concerned. I also feel depressed at the ongoing progression of the disease."*

Furthermore, another patient highlighted that different services did not always recognise the potential side effects of Parkinson's medication. This patient suggested, for example that: *"more practical help [is] needed for people that are/have been affected by medications that have caused compulsive disorders. Support services do NOT seem to understand this side effect at all."*

Such findings therefore suggest that Parkinson’s health services need to place an additional focus on integrating different services, including those that offer psychological support, as some patients might be struggling to accept or cope with the progressive of their condition.

Consultant

In total, 236 patients specifically described the quality of care they received from their consultants. A majority of these comments were extremely positive.

> For example:
>
> *Patient Z.: “My consultant always gives me a morale boosting consultation and a feeling of having all the time in [the] world for me. No sense of rush or clock-watching and is always unfailingly cheerful!!”*
>
> *Patient A.A.: “Consultant has always acted in a professional/compassionate and caring manner. Very approachable and gives time for me to voice concerns/questions without being rushed.”*
>
> *Patient A.B.: “The consultant is very good and I feel he treats me with care and dignity and almost as a friend and not a patient.”*
>
> *Carer E: “Excellent, clear and positive advice given by consultant, very informative and easy to understand … Left mum and the family much more positive and [hopeful] now we know more about her condition.”*

From such comments it is apparent that having access to a friendly and informative consultant is equally important to patients as not feeling rushed during their consultations. In support of this, one particular patient suggested here that *“consultants should give patients longer appointments” as they “feel to be rushed.”*

In general, most of the negative comments about consultations reflected patients’ desire to see their consultants more frequently, as they felt that once or twice a year was not sufficient. Moreover, a few patients also suggested here that consultants needed to further improve their communication with other health professionals. One patient pointed out, for example, that: *“Communication among service, Consultant and pharmacist regarding prescription is not 100%.”* In a similar manner, other patients explained:

> *Patient A.C.: “Typically we see a student and then the Consultant, and both ask the same questions - perhaps they need to share the information first so the patient doesn't need to repeat themselves.”*
>
> *Patient A.D.: “It takes a long time for the Neurologist to respond to the Parkinson's nurse if they wish to change my medication. It is too long to wait and take weeks.”*
>
> *Patient A.E.: “I think there should be more communication between the consultant doctors and other professionals. I don't think they act together.”*

Some patients also reported that their medication history was not recorded very well during consultations, implying that services were wasting a considerable amount of time by repeatedly asking the same questions. For example, one carer described their experiences here in the following way:

> *“We are asked about the patient's medication schedule at every visit. Perhaps this could be documented and reviewed rather than the patient having to give this same information at every appointment. It seems there is a lot of repetition of information that the patient needs to give.”*

Likewise, another carer added:

> *“consultant asked for patient's medical history since diagnosis with Parkinson's, when consultant should have known it.”*

Overall, it seems that a majority of patients are indeed satisfied with the quality of care they are receiving from their consultants. However, it seems that there may be a need for services to place some additional focus on improving the communication process between consultants and other health professionals.

Parkinson’s Nurse

A total of 259 patients described their experiences of engaging with their Parkinson’s Nurses. Over half of these responses were very positive, with many patients expressing that they were highly satisfied with the help and support received.

> For example:
>
> *Patient A.F.: “We would not have survived without the support of [Parkinson's Nurse] -- everyone needs a [Parkinson's Nurse]! Just a shame she wasn't there at the point of diagnosis but her support and knowledge have been invaluable.”*
>
> *Patient A.G.: “Our Parkinson's Nurse Specialist is a fantastic support, always ready to listen and advise in a very professional way.”*
>
> *Patient A.H.: “Having been recently diagnosed with Parkinson's, I have found the specialist nurses to be both friendly and ready to listen. I feel that if I should have any problems I could easily contact them and they would be able to help … If they offer this advice to all new and existing patients it must put them at ease.”*
>
> *Patient A.I.: “We have every faith in our specialist nurse and the care and advice she provides us.”*

Many of the negative comments in relation to this service mainly reflected patients’ concerns around Parkinson’s nurses being *“too stretched”* and *“overworked”*. For example, one patient reported here: *“We get very good service from our Parkinson's nurse, but feel she doesn't have enough hours in the day to keep up with all our needs …”* Likewise, another patient added: *“[Parkinson's Nurse] is very helpful but she has too much to deal with.”*

In support of this, two specific patients further suggested:

> *Patient A.J.: “Parkinson's nurse appears to be overstretched as she frequently rings into evening to respond to any query I have …”*
>
> *Patient A.K.: “Why 2 valuable nurses were pushed and over-stressed with all they were given to do, like extra clinics, putting pressure on them, till they could not take any more … I feel these nurses were pushed to their limits … and they left.”*

Some patients also reiterated here that, in general, *"the lack of access to a Parkinson's Nurse is a concern",* with many patients suggesting that *"it would be advantageous to have more Parkinson's nurses available."* In light of this, a number of patients also explained here that as they were unable to initiate contact with a Parkinson's nurse when they were first signposted, they had decided to *"give up"* on this service. Moreover, a few patients also pointed out that they were unable to use this service simply because there were no Parkinson's nurses employed, at present, in their area.

Physiotherapy

Overall, 75 patients commented on their use of physiotherapy services. Over half of these patients were very happy with this service, implying that physiotherapy is highly valued by people with Parkinson's.

> For example:
>
> *Patient A.L.: "I have only recently been diagnosed and main contact has been with physio who has been very helpful."*
>
> *Patient A.M.: "An excellent service and cannot fault anything and feel very lucky to be in the area. Not only do we exercise, the new physio gives us information and advice on our illness."*
>
> *Patient A.N: "Was very pleased to be referred to a physio and to find they were more than happy to discuss Parkinson's symptoms. Excellent service."*
>
> *Patient A.O: "… the range of exercises have greatly helped my mobility."*

Moreover, many patients argued here that, in general, there needs to be better access to this service. For instance, one patient put forth: "*Access to physiotherapy is limited (but of good quality when available)."* Likewise, another patient reported: *"Would like more physiotherapy if possible. What I do receive is very good."* Incidentally, many of the negative comments made by other patients in relation to this service were due to limitations in accessing it in their own local area. For example:

> *Patient A.P.: "Getting any form of physio in our area is very difficult."*
>
> *Patient A.Q.: "Lack of physio support in the community is unhelpful."*
>
> *Patient A.R.: "Long waiting list for physiotherapy…"*
>
> *Patient A.S.: "…There is very little support in the area. It would be beneficial to have some physio."*

Occupational Therapy

Only a few patients commented on their use of occupational therapy here. These comments were fairly positive. For example:

> *Patient A.T.: "The occupational therapists have been very useful and helpful!"*

> *Patient A.U: "I am very grateful for the care and attention I have received from all concerned since I have been in the care home, especially with visits from my Consultant and the Occupational Therapists."*

Speech and Language Therapy

Overall, 25 patients commented on their experiences of using speech and language therapy. A majority of these comments were very positive. For example:

> *Patient A.V.: "I think the service is very good generally ... The speech and language therapist is particularly good and encouraging."*
>
> *Patient A.W.: "Recently been seen by a speech and language therapist and this has been most helpful."*
>
> *Patient A.X.: "Our speech therapists are excellent."*

In general, the very few negative comments in relation to this service reflected patients' desire to have better access to it. For example, one patient reported here: *"Very disappointed about lack of speech therapy service. Hope something will happen soon."* Similarly, another patient added: *"Would like speech therapy on a weekly basis."*

Other patients pointed out that, overall, there needed to be better access to all of the above services:

> *Patient A.Y.: "Would like more access to services of physiotherapist, speech & language therapist and occupational therapist"*
>
> *Patient A.Z.: "Services such as physiotherapy and speech therapy could be more frequent (understand the cost issue)."*

GP Services

Though patients were not asked to evaluate their satisfaction with their local GP surgeries, a few patients shared their thoughts on the quality of care they had been receiving in relation to managing their Parkinson's. Most of these patients reported that were very happy with the care they were receiving. However, some patients mentioned that their GP's were not very knowledgeable about Parkinson's. Moreover, a few patients also highlighted some issues around poor communication between GPs and pharmacists in relation to obtaining medication:

> *Patient B.A.: "Very satisfied but difficulty getting medication from GP and there is then difficulty in getting prescription from pharmacy - it is always a challenge."*
>
> *Patient B.B.: "Communication between GP and Pharmacy is not consistent and results in incorrect medication at times."*
>
> *Patient B.C.: "One problem I have had sometimes is getting medication on time - not always good coordination between GP's surgery and pharmacy, but situation is better now."*

10a. Do you feel you were given enough information about Parkinson’s when you were diagnosed?

A total of 59 patients commented on the degree to which they felt they were informed about Parkinson’s during their initial diagnosis. Though one particular patient reported here that they had just been diagnosed *and “was impressed with the amount of time spent making sure [they were] well informed before leaving”*, many of the other patients felt that they had not received enough information.

For example, one patient reported:

> *“Hospital initial diagnosis was terrible. No information, just "you have PD". No leaflets, nothing.”*

Similarly, other patients explained:

> *Patient B.D.: “When I was seen by GP and [later] by Consultant who diagnosed Parkinson's, I was given no info (e.g. leaflets or where to send for them) about the disease. I obtained a great deal of info from Parkinson's UK”*
>
> *Patient B.E.: “When I was told I had PD by the specialist I was given no information about the condition or any advice. I had to find out all about it by myself.”*

One particular patient, who was recently diagnosed, pointed out that they still had many questions that were unanswered and, at this point, did not know what Parkinson’s is and how it affects them. In relation to this, some patients suggested that it was crucial to see a Parkinson’s nurse as soon as possible after diagnosis, in order to overcome such issues.

For example, one patient reported:

> *“Long wait to see Parkinson's Nurse - 11 weeks. As I do not use a computer, I could not access information about my condition and had no understanding of how the disease can progress. I would like to see information sheets offered on diagnosis.”*

In addition to this, another patient highlighted the importance of offering peer support services:

> *“I do feel that the Parkinson's Nurse should contact the patient as soon as they are diagnosed and offer them the opportunity to speak to a patient with the same problem who can offer advice on how to deal with depression and daily problems.”*

Furthermore, other patients reflected on the way in which their consultant had delivered their diagnosis, suggesting that these experiences were not handled as sensitively as the patients had expected them to be. For example, one patient mentioned:

> *“Poor and insensitive consultation at [initial] diagnosis appointment caused me distress and led to change of consultant.”*

Likewise, other patients added:

> *Patient B.F.: “When I was diagnosed, the diagnosis was given very abruptly and came as a bombshell.”*

> *Patient B.G.: "I would like my consultant to have more empathy when diagnosing people with Parkinson's … The emotional support at diagnosis was missing."*

Overall, these findings suggest that people with Parkinson's are not necessarily offered enough information and support when they are first diagnosed with the condition. Thus, it seems that health professionals may need some additional training in this area. Moreover, it seems that services need to place an additional focus on ensuring that newly diagnosed patients are signposted to a Parkinson's nurse as soon as possible following their diagnosis. This will allow them to further discuss any concerns that were left unaddressed during their initial consultation.

Furthermore, in relation to this, two particular patients suggested here that arranging "information days/evenings" can indeed be a useful and effective way to inform patients about Parkinson's following their diagnosis. For example, one patient pointed out:

> *"Our hospital service is excellent with 6 Education evenings a year for our [Parkinson's UK] branch meetings where its staff give us their time to come and talk to us on various issues involving the disease."*

In a similar manner, another patient mentioned:

> *"The consultant who gave me the diagnosis gave no information at all (he is no longer here), but I attended a day for newly diagnosed PD people and a carer and everything was covered."*

10b. Do you feel that you are given enough information about any new medication, including potential side effects?

In total, 41 patients commented on the amount of information they were given about new medication and potential side effects. Nevertheless, only a few of these patients pointed out that this information was sufficient enough to meet their needs. For instance, one patient reported: *"I've asked about surgery treatments. The consultant explained the scenario very clearly and comprehensively."* In a similar manner, a carer elaborated: *"We get good advice on medication and as a carer I find this very helpful. We are trying different medication to help us through the night."* However, a majority of the remaining comments have suggested that this is not always the case for all patients with Parkinson's.

For example:

> *Patient B.H.: "When I see my consultant I feel not enough information is given about drugs …"*
>
> *Patient B.I.: "We find that the service is very good. Just like to have more info on new drugs and how to test them"*
>
> *Patient B.J.: "would like specialist to prescribe better meds as we have heard there is effective meds but Dr will only give us the same."*

In addition to the above, two patients further suggested that there was a lack in information about alternative forms of treatment and therapy, which they felt was also necessary:

> *Patient B.K.: "Need more advice on alternative medicine treatments since there in no cure. Only alternative treatments like [acupuncture] and massage has improved my condition. The downside of my medicines have not been explained enough …"*
>
> *Patient B.L.: "Natural therapies (e.g. diet, exercise, relaxation, meditation, stretching, hydration, etc) I believe, can be of value … but these therapies not normally suggested. I have found them very helpful in alleviating some of the Parkinson's symptoms."*

Overall, it seems that most patients feel that they are not given enough information about new medication and potential side effects. Moreover, it seems that some patients also feel that they do not know enough about their existing medication. In relation to this, one particular patient suggested that it might be beneficial for consultants to write a letter after each consultation, detailing what was discussed and/or reasons for changing medication, as *"it is difficult to retain all information given within the half hour or so of seeing the consultant."* Moreover, another patient suggested that organising Q&A sessions regarding medical changes, breakthroughs and education about different medication might also be useful for people with Parkinson's.

11. Does your Parkinson's service give you information about:

how to access the range of support and information available from Parkinson's UK?
the role of social work for people with Parkinson's and their carers?
support for carers?

A total of 94 patients commented on the level of information they were given by their health services in relation to accessing further support following their diagnosis. Overall, a majority of these patients expressed that they were not informed very well about the different services available to them, with some reporting that they had found out about certain services on their own.

For instance, one particular carer reported: *"When the doctor diagnosed for my husband we felt abandoned. It took me a few weeks to realise anything that was needed had to be sourced by myself through social services, who have been wonderful."* Similarly, another patient mentioned: *"I had to find out all about it by myself. The local Parkinson's Group which I discovered in town on an information stall helped me find out about the Parkinson's Nurse, who has been a great help."*

On the other hand, many patients, who were still unsure about the services available them, expressed their confusion in the following ways:

> *Patient B.M.: "Occupational Therapy? Didn't know about this service. Unsure about how to access it."*
>
> *Patient B.N.: "Since diagnosis I have not been introduced to the Parkinson's service so have been unable to access it and I have not seen a consultant or been referred that I am aware of."*
>
> *Patient B.O.: "newly diagnosed and unaware of what Parkinson's Service provides, let alone how to access it."*

> *Patient B.P.: “I'm not really sure what the Parkinson's Service is. Most of the referrals are self-motivated or done by the GP, rather than any central body called the "Parkinson's Service"”*

In relation to this, one particular patient pointed out that *“unless you are inclined to ask all the right questions that may affect your Parkinson's you are not made aware of any advice or help that may be available to you.”* Moreover, another patient argued that *“sometimes the service doesn’t feel joined up. There is no automatic referral to other services, it feels as if you have to find out for yourself and ask to be referred.”* Such comments imply that services need to provide clearer information to patients about the different services available to people with Parkinson’s (e.g. physiotherapy, occupational therapy, etc.), including those offered by Parkinson’s UK. Moreover, it seems that a clearer signposting process needs to be established so that patients are automatically referred to all of the necessary services at the point of diagnosis.

In addition to this, it seems that patients also need some clearer information from their services with regards to applying for financial support and other benefits. For instance, one patient mentioned: “[*No-one] informed us about Attendance Allowance, we only knew about it when friends told us about it 2 [years] ago. Would be nice if patients were informed of this at the onset of other benefits.”* A few patients also expressed concerns about travelling to and from the hospital and were unsure of any services that might be able to help them with arranging transportation.

On a final note, many carers also expressed here that they were unaware of any support services directed specifically to carers. One carer argued, for instance, that *“services should provide more information about caring for the patient and facilities on offer for help in the home and to hire a carer.”* Likewise, another carer added that: *“little attention goes into the partners if they are not wanting to be active carers. The alternatives are not discussed.”* In general, these findings highlight that both carers and patients with Parkinson’s are currently in need of clearer information from their services with regards to accessing different support services available to them.

14a. Do you feel your Parkinson’s service involves you in decisions about your care?

Only 3 people commented on the extent to which they felt they were involved in decisions about their care. Of these, 2 people expressed that they were treated very well by their services and were involved in all decision making processes. For instance, one patient pointed out that the services were not *“pushy at all”*, whilst a carer mentioned: “*My mother is treated as an individual and the service involves everyone concerned in the decision making process.”*

The remaining patient, on the other hand, put forth that, as health services do not always inform them about the full extent of the decisions that need to be taken, it was difficult for them to know whether they were being fully included or not. Therefore, due to this lack of information, the patient reported that they felt that they were not involved in every decision.

14b. Do you feel listened to?

Overall, 22 patients commented on the degree to which they felt they were listened to by their Parkinson’s health services. Just over half of these patients reported that they were *“always listened to”* and treated *“as an individual”* by their services.

For example, one patient reported here: *“The whole team treat me as an intelligent human being and listen to what I am saying and then act upon it.”* Similarly, another patient added: *“I am always viewed as a person, not just a body with Parkinson's. The medical staff are always courteous and have time to listen to me.”*

In relation to this, two people highlighted how listening to carers was equally important as listening to the patient during consultations. For instance, one carer described their positive experiences of this in the following way:

> *“As the carer I [always] feel that my worries are listened to and never feel rushed during my appointments. As this is a progressive we know there are no quick fixes but whatever can be done is done.”*

In a similar light, another patient suggested: *“Please listen to my wife more as she is my main carer. She knows me best as we have been married for over 26 years.”*

Nevertheless, the above experiences did not reflect the experiences of all patients with Parkinson’s. A few patients pointed out here, for example, that they were *“not listened to enough”* by their health professionals and that most of their problems were blamed on their Parkinson’s. For instance, one patient reported: *“I feel that having Parkinson's gives health professionals an excuse to blame that when there may be something else wrong.”* Similarly, other patients added:

> *Patient B.Q.: “Everyone of my problems appears to take an eternity to be taken seriously and resolved.”*
>
> *Patient B.R.: “I find it difficult to communicate with the consultant. I feel he does not listen enough to understand the problems in detail.”*
>
> *Patient B.S.: “everything gets blamed on Parkinson's*.”

Moreover, one particular patient mentioned here that being asked to take part in this survey had in fact made them feel that they were being listened to more than usual. Such findings suggest that, at present, not all patients with Parkinson’s feel that their services are listening to them. Therefore, it seems that further improvement may be necessary in this area.

Q15b. While in hospital, how often did you receive your Parkinson's medication on time?

Overall, 30 patients commented on the frequency at which they received their Parkinson’s medication on time during their stay in hospital. A majority of these patients reported that ward staff did not understand their needs, with many patients experiencing significant delays in receiving their medication.

For example, one patient described this lack of understanding from staff in the following way:

> *“My experience in hospital was awful. There was seemingly no understanding of Parkinson's and I was seen as a [nuisance] patient asking for my pills on time. No*

> *access to PD nurse on the ward. Huge need for educations as staff didn't know anything about Parkinson's."*

Similarly, other patients highlighted how people with Parkinson's are often expected to wait until scheduled delivery times, with no specific attention being paid to their needs to take their medication outside of these hours.

For example:

> *Patient B.T.: "It depends on the nature of the person who is giving your tablets out. My body knew when I needed my medication, but even the staff was told we got the tablets when they reached each individual with the remark that we all are waiting and no preferential treatment was given."*
>
> *Patient B.U.: "When in hospital, the meds were given when every patient got their meds, not at regular intervals. It made it difficult trying to regulate with meal times."*
>
> *Patient B.V.: "… the hospital muddled through, one size fits all, not communicating with main carer or Parkinson's nurse and consultant. This results in delayed rehab and poorer outcomes."*

In relation to this, one particular carer added: *"As a family we are very concerned about the lack of attention in hospitals (when the patient is not allowed to bring in his Parkinson's medication) for the patient to receive medication on time. We would be pleased to see more staff trained to give out the relative medication on time."* Likewise, another patient explained that due to the poor management of their medication whilst they were in hospital, they had felt the need to make contact with Parkinson's UK so that a representative was sent to "educate" the ward staff. It was also suggested here that ward staff should be made aware of the complicated medications for Parkinson's and *"should allow dosimeter boxes pre-prepared by carers/pharmacy"* as *"too many mistakes"* are made otherwise.

Such findings suggest that, at present, many ward staff are in need of additional training on Parkinson's and the importance of receiving medication on time. Furthermore, there seems to be a need to improve processes in all wards so that patients are able to receive their medication at intervals that suit their individual needs as opposed to adhering to a "one size fits all" approach.

Q15e. Was it possible for you to manage and take your own medication while in hospital?

A total of 19 patients described their experiences of managing their own medication whilst in hospital. A few patients mentioned here that they were allowed to do so on their last visit and that this had made a positive difference in contrast to previous visits.

For example:

> *Patient B.W.: "The last admission to hospital was positive as I was able to self-medicate. Previous admissions have been very different, often receiving medication late or not at all. This is an issue."*
>
> *Patient B.Y.: "Three weeks in Hospital last. Denied soft medication, with disastrous results. This year, self medication accepted, so no ill effects."*

Nonetheless, other patients highlighted that it was not always easy for them to manage their own medication and that they had experienced some barriers when they had requested to do so.

For example:

> *Patient B.Z.: "Had to ask if I could self-medicate and this had to be agreed with a doctor."*
>
> *Patient C.A.: "My Parkinson's medicine was taken away from me causing great distress, only being returned to me after my wife complained to staff!!"*
>
> *Patient C.B.: "I asked to manage it [medication] myself but refused!"*
>
> *Carer F: "Only after repeated requests to nursing staff - they really didn't like [patient] self administering."*

Moreover, one particular patient pointed out that staying in hospital can be *"very problematic"* as *"staff are unaware of symptoms of Parkinson's and patient is not allowed to use own medication despite clear labelling."* Such findings further highlight the importance of providing additional training to all ward staff about Parkinson's medication. Furthermore, it seems that hospitals need to place an additional focus on improving their processes so that people with Parkinson's are able to manage their own medication should they wish to do so. In addition to this, it seems that patients need to be better informed by their services about their right to manage their own medication, as a few patients had reported here that they were unaware they could do this.

16. When you are seen by your Parkinson's service, are you treated as a whole person (including other conditions you may have) rather than only as a Parkinson's patient?

A total of 30 patients described the extent to which they felt they were treated as a whole person by their Parkinson's health services. Though one patient mentioned here that their consultant was very helpful and had looked after them as a whole person, investigating other issues where necessary, a few other patients felt that this was not the case for them.

For example, one patient reported:

> *"Being treated as a whole person is a big issue for me. I can understand how individual issues need specialists, but it is frustrating for the patient not to be seen as a whole, and leaves issues which do not get addressed."*

In relation to this, another patient added:

> *"Where there have been significant problems not directly influenced by or influencing Parkinson's it has been difficult to treat my problems holistically."*

Furthermore, one particular patient explained here that having multiple illnesses was a problem in itself, as "*it's virtually impossible to coordinate all of your consultants at the same time."* Nonetheless, it seems that some services are more flexible than others in managing multiple appointments at the same hospital, as one patient described their positive experiences of this in the following way:

> *“I had a phone call from "appointments" to make an appointment [with] the Parkinson's Consultant. I was amazed that they were aware that I had already an appointment with the orthopedic surgeon. And so, they arranged an appointment on the same day with an hour's difference. Impressive that they had co-ordinated the system and saved me the effort and time of coming to the hospital on two different days …”*

Other issues that were raised here included:

- **Lack of home visits**

Some patients mentioned here that they would like more home visits, as this would allow professionals to “*see how patient is in own environment.”*

- **Translated material/interpreter services**

Two patients highlighted that they would like more written material in their own languages, with one of these patients further mentioning that this would help them better understand everything as they feel that they are unable to disclose everything when their children were around, due to feeling that they might become *“worried”* or *“feel sad.”*

- **Service hours not ideal for patients who are working**

One particular patient, who was still working, put forth that they were unable to attend clinics and drop-in sessions, as they were generally *“aimed at people out of work-force.”* Moreover, another patient explained that they sometimes struggled in making contact with their Parkinson’s nurse, as they *“worked shifts”* and often missed each other’s calls and messages.

- **Other health professionals’ knowledge of Parkinson’s medication**

A carer described their experiences of being prescribed medication that was not suitable to be taken with Parkinson’s medication in the following way.

> *“Care needs to be taken when other health professionals prescribe medications incompatible with Parkinson's medication (e.g. Sinemet). This led to my husband being admitted to the Hospital for 10 weeks with severe hallucinations!”*

In general, these findings suggest that people with Parkinson’s are not always treated as a whole person by their health services. Thus, there may be a need to further improve communication at this level to ensure that all factors contributing to a patient’s health and quality of life are taken into consideration during consultations.

17. Do you feel that your Parkinson’s service is improving/staying the same/getting worse:

Some of the areas patients touched upon in relation to this question were as follows:

- **Difficulty accessing services due to geographic location**

Several patients expressed here that it would be more useful for them if they had a clinic at a hospital nearer to their home town, as they had to travel a considerable distance to attend their appointments. One patient pointed out, for example, that they had to travel 30 miles from their home to visit their consultant. Whilst a carer, on the other hand, pointed out that they currently had no access to a support group in their local area and that this was *"a very lonely experience"* for the primary caregiver.

Moreover, one patient further elaborated on their experience of trying to use Parkinson's health services whilst living on the border of two counties in the following way:

> *"Living on the county border there is great disparity between services. Contact with nurse and consultant is often poor as they work for different trusts. There is always a delay in getting a response which is frustrating ..."*

This particular patient then went on to explain that they were currently unable to access their local support group, which was 30 miles away from them, and suggested that *"mobile support groups/satellite groups"* might be helpful for those who live in rural areas. In a similar manner, another patient pointed out that they had experienced some difficulties in accessing health services that were not located in the same post code as their GP surgery. One particular patient also mentioned here that the drugs they had wanted were not available in their own local area, but that they could *"get them without a problem"* if they *"lived down the road in Hampshire"*, which they felt was *"unfair."*

In addition to this, some patients also explained that they had experienced some difficulties in arranging transportation to attend clinics. For example, one patient explained that they were *"refused transportation to meetings due to residence in countryside."* Likewise, another patient reported: *"the only problem we have is the difficulty getting to appointments as they are not local and travel arrangements can be difficult."* In relation to this, another patient added: *"So difficult to check that I have transport for the clinic. I spent 20 [minutes] on phone confirming transport …"*

These findings imply that many people with Parkinson's may be experiencing considerable difficulties in accessing certain services due to their geographic location. Thus, there seems to be an urgent need to improve access to these services at a local level. Moreover, it seems that patients may need some further support from their health services in arranging transportation to attend clinics. In addition to this, several patients also expressed here that the current parking facilities in their hospitals/clinics are rather were *"poor"* and *"very difficult for people with mobility problems."*

- **Concerns about funding**

A few patients expressed some of their concerns about the future of their services here. For example, one patient reported: *"I am very lucky with the quality of Parkinson's service, but it feels very vulnerable to cuts."* Similarly, a further patient mentioned that they were *"worried that there may be cuts to service because of budget reductions."*

On the other hand, a few patients also mentioned that a lack of funding in their hospital had meant that they were unable to receive a definite diagnosis of Parkinson's. For example, one patient argued here: *"It is a disgrace that the DAT scan is not available due to lack of funding, as it is urgently needed o diagnose my condition."* Likewise, another patient added: *"Very concerned on initial diagnosis I was not told that there is a scan available that is 100%*

certain of diagnosis. Apparently cost was the factor? Quite often money is not always a [patient's] problem?"

- **Services that are tailored for people with Parkinson's**

A few patients suggested here that it might be helpful to set up more *"Parkinson's only clinics" or "Day Centres"*, as this will help patients meet other people with Parkinson's. For example, one patient suggested*: "I would prefer to attend a Parkinson's only clinic. This is quite an isolating disease and it would be helpful to meet others in similar situation*." In a similar manner, another patient elaborated: *"It would be a good idea to set up a Parkinson's Day Centre promoting patients' confidence, independence and to feel that they are not alone with the disease."*

Moreover, one particular patient suggested that it might be useful for services to set up annual discussion groups for patients to share their ideas and contribute to the improvement of their services.

- **General concerns about staffing levels**

Several patients also mentioned here that they felt their services were getting worse due to limitations in staffing. For example, one patient argued: *"The service has been getting worse as we do not have enough Parkinson's nurses to look after everyone in this area, so referrals to phyios and other therapists are also affected."*

Likewise, other patients reported:

> Patient C.C.: *"… having only been diagnosed last year, I am concerned that the level of nursing cover has reduced. The service that I have received so far has been satisfactory, but unless the nursing cover is reinstated, that service will deteriorate as my condition worsens."*
>
> *Patients C.D.: "Service is getting worse because 2 years ago we had 2 full time Parkinson's nurses. Couldn't recruit when one left. Now because of pressure of work and lack of support 2nd one left. Fortunately one returned. However… is now based in [another location] and only has clinics in [hospital] 2 days a week!!"*

Such findings suggest that current staffing levels in Parkinson's health services are causing a considerable amount of concern to patients with Parkinson's with regards to the future of their care. Thus, it seems that this area may need some additional focus from services at present.

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Appendix I

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