

2015 UK Parkinson's Audit Summary Report

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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 multi-disciplinary 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 most significant findings of the *2015 UK Parkinson's Audit. A Reference Report* of all the audit results is also available. It includes details of the audit design and methods, the participating services, the dataset and the Patient Reported Experience Measure (PREM) questionnaire.

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 PREM, obtained by directly surveying clinic patients. This summary report includes PREM results where they relate to the audit data, and also reports on key PREM findings (the complete PREM results are available in the Reference Report).

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 (a list of the guidelines is available in the Reference 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 gives a brief outline of 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 and neurology consultants who care for people with movement disorders, Parkinson's nurses, occupational therapists, physiotherapists, and speech and language therapists who also care for people with Parkinson's. The audit engages services within these professions to measure the quality of their practice, within their model of care provision.

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. Across all service areas, the audit identified a need for improvements in the following areas:

- 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 about potential adverse effects of new medication.

Shortcomings

- 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 anticipatory 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).

¹ Elderly Care refers to services provided by a geriatrician.

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.
- 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 continuing professional development.
- 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.
- Little 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 or 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.
- Just under half of patients admitted to hospital in the last year always received their medication on time.

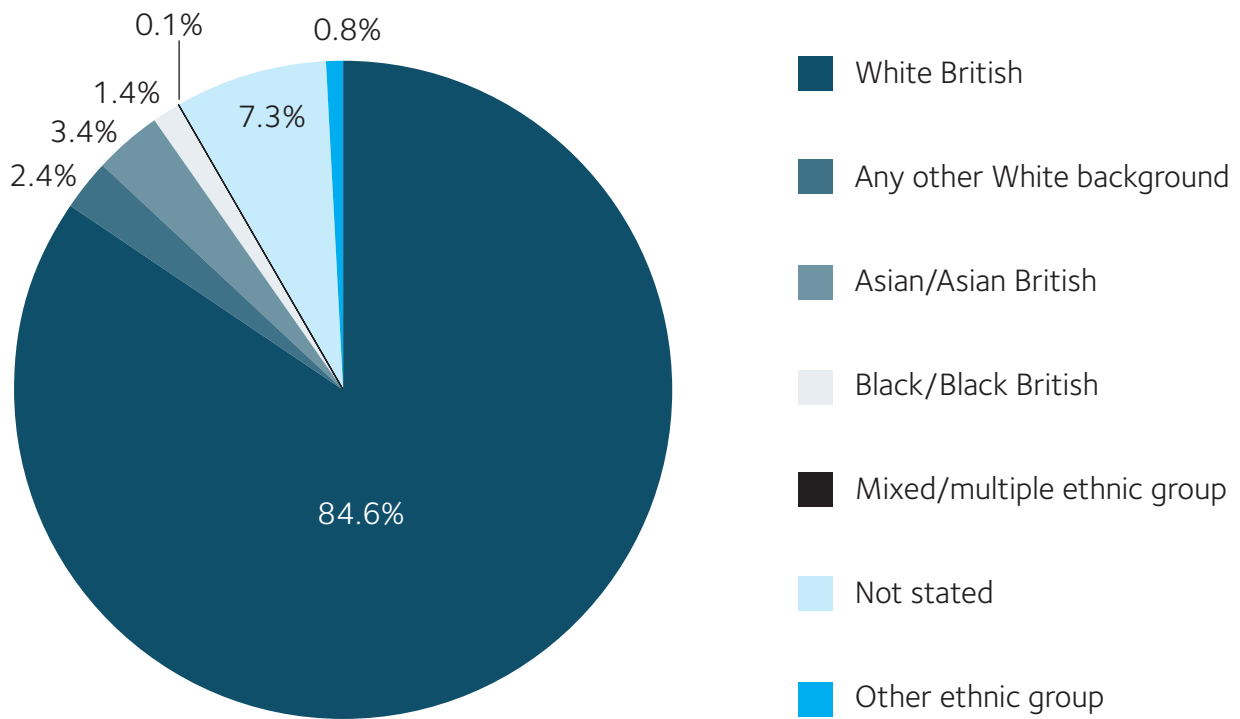
Services taking part and patients included

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

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

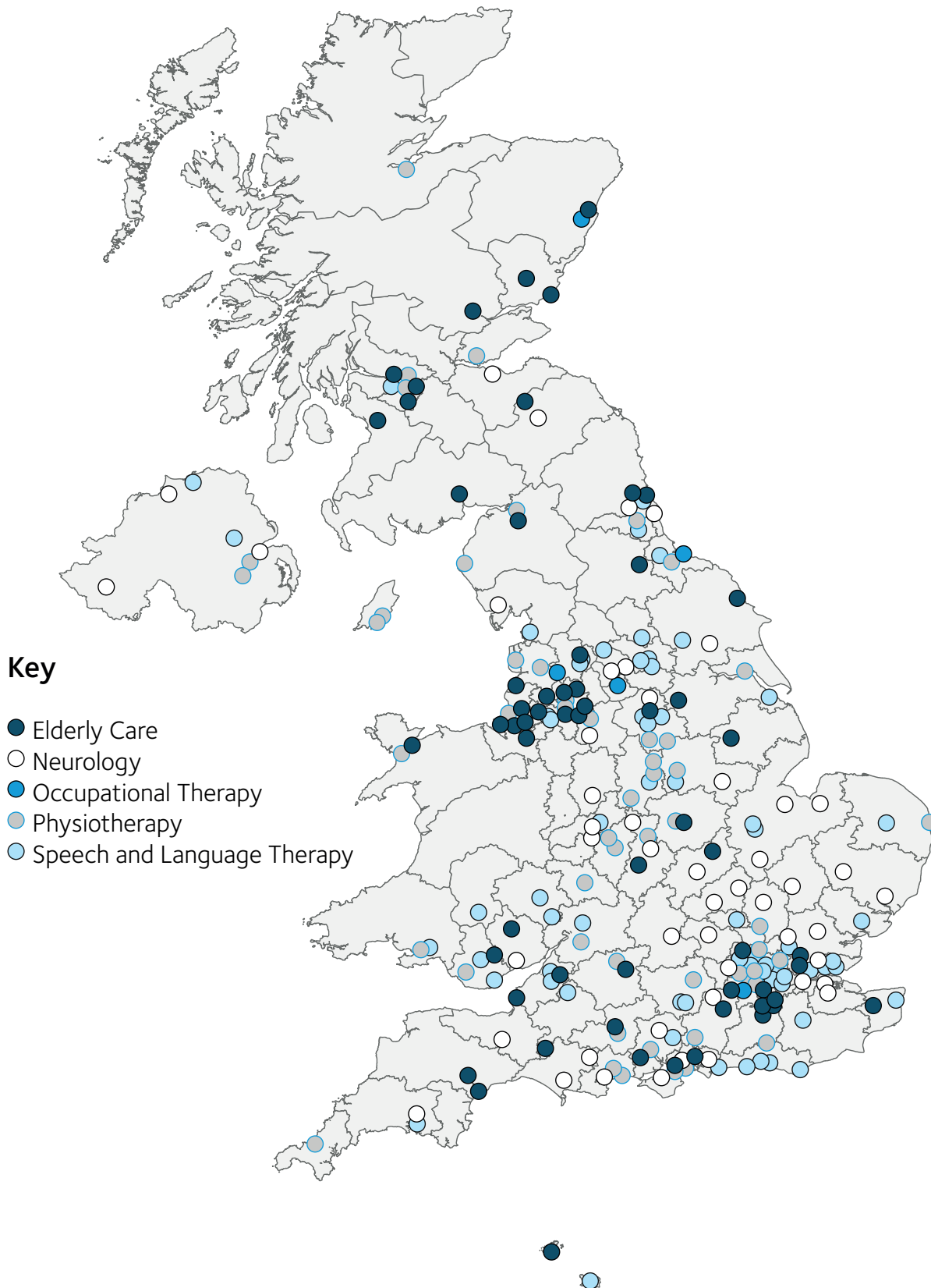


PREM

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 in the Reference Report.

Selected audit findings

Elderly care and neurology

Aims

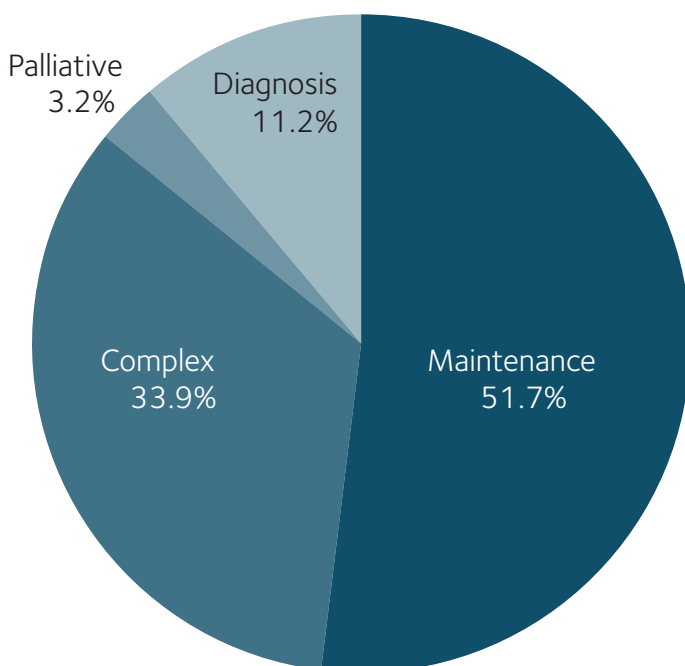
These audits are intended to measure the quality of assessment and management of people with Parkinson's attending Elderly Care and Neurology clinics, and to describe the models of service delivery used. They allow benchmarking of services against good practice standards and guidance relating to the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

Demographics

Neurology and Elderly Care 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%). 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).

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).

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



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 (fewer 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 2: Patients seen within specific Parkinson's or movement disorder clinics

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

	Elderly Care	Neurology	Elderly Care and Neurology
Doctor alone	26.4%	30.9%	28.5%
Joint or 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 4: Access to a Parkinson's nurse in Elderly Care and Neurology services

	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.

Availability of written information

Written information about Parkinson's and its 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.

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.

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.

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%).

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.

Table 5: Patients given information about potential adverse side effects of new medication

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	82.1%	84.7%	83.3%
No	17.9%	15.3%	16.7%
Number	2,012	1,929	3,941

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 6: Evidence recorded that people with Parkinson’s taking dopamine agonists are monitored for compulsive behaviours (2012 and 2015 audits).

	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%	33.6%	18.5%	22.5%
Number:	–	1,238	–	1,317	2,555

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

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	60.6%	52.1%	56.5%
No	39.4%	47.9%	43.5%
Number	808	758	1,566

Advance care planning

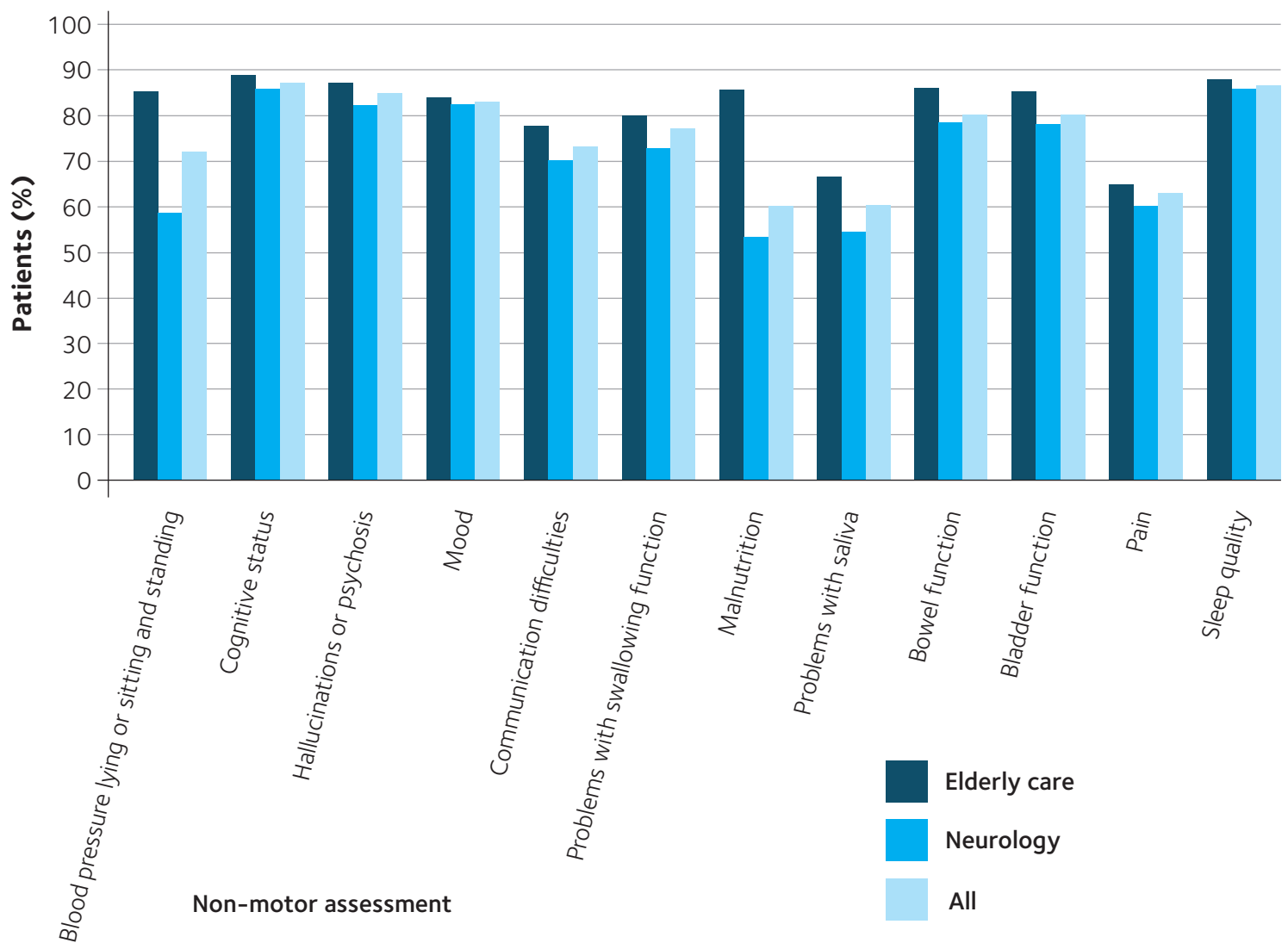
Of those people with Parkinson's who had markers of advanced disease (23.5%), discussions regarding end of life care issues and advice about lasting Power of Attorney were recorded in only 25.6% and 25.5 % respectively for Elderly Care and 31.2% and 27.4% for Neurology.

Domain scores

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

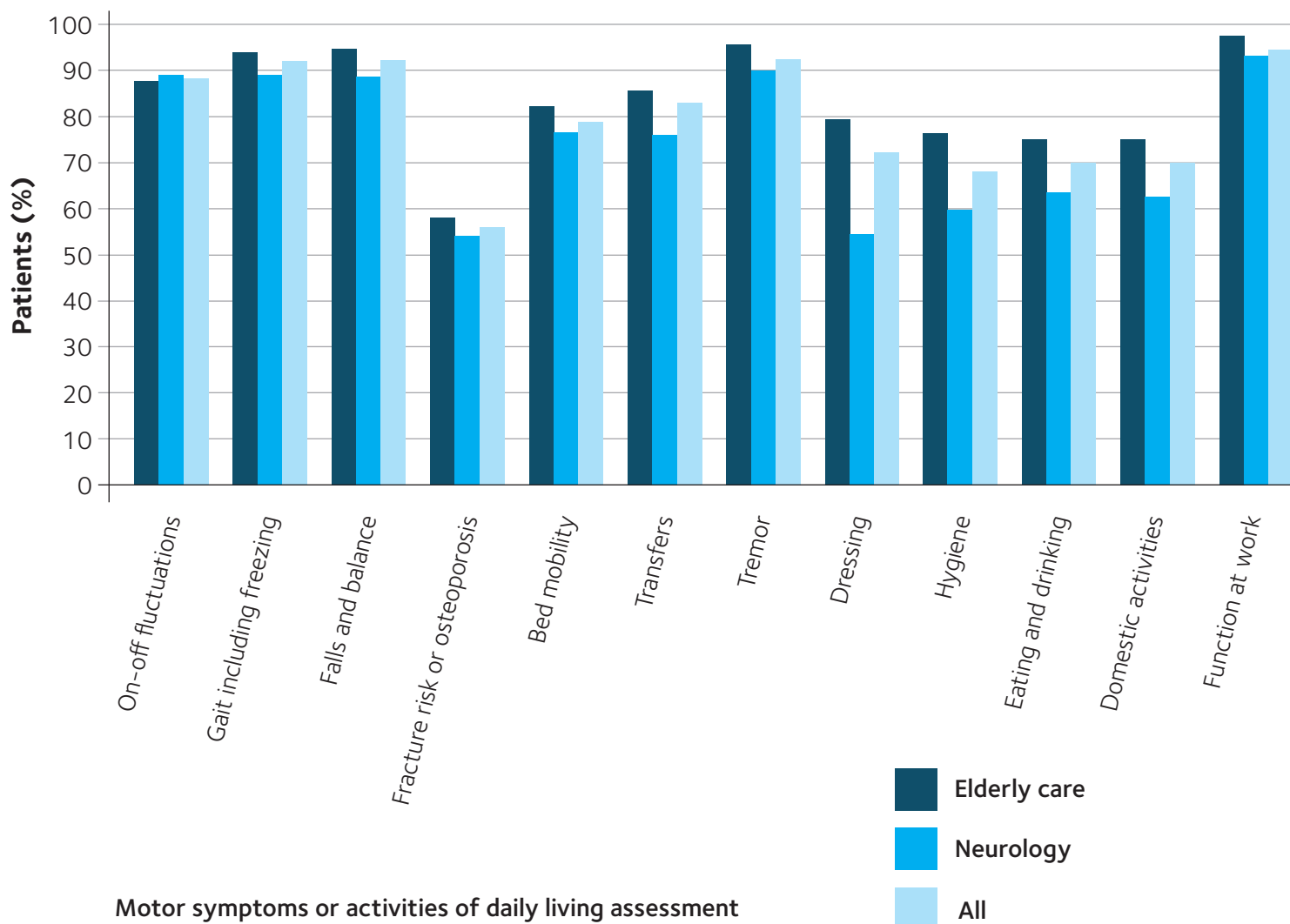
For each element within a domain, total scores were calculated by summing passes (scoring 1) and fails (scoring 0) for each patient. A pass was achieved if the assessment was done. However, a pass was also achieved if an assessment was not done but was considered and not felt to be indicated or appropriate.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

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



Neurology clinics scored poorly compared with Elderly Care clinics in documenting blood pressure assessments (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 within both services.

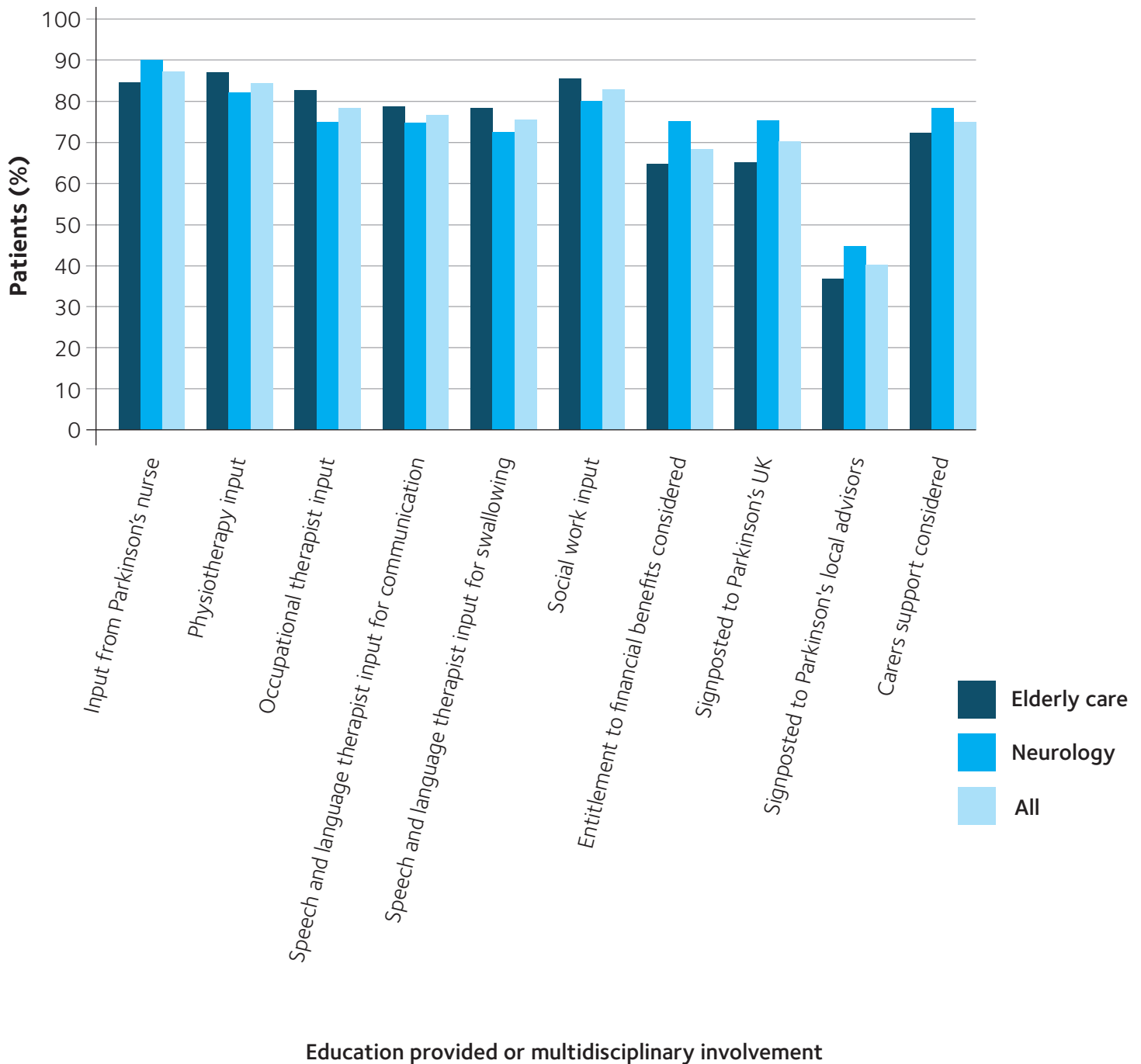
Figure 4: Domain 2 – Assessment of motor symptoms and Activities of Daily Living (ADL) during the previous year



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

Please note: the percentages above in the bar chart reflect the total percentage of patients in whom evidence of fracture risk or osteoporosis was considered. The chart includes people whose notes document no falls and no concerns about balance, so 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.

Demographics

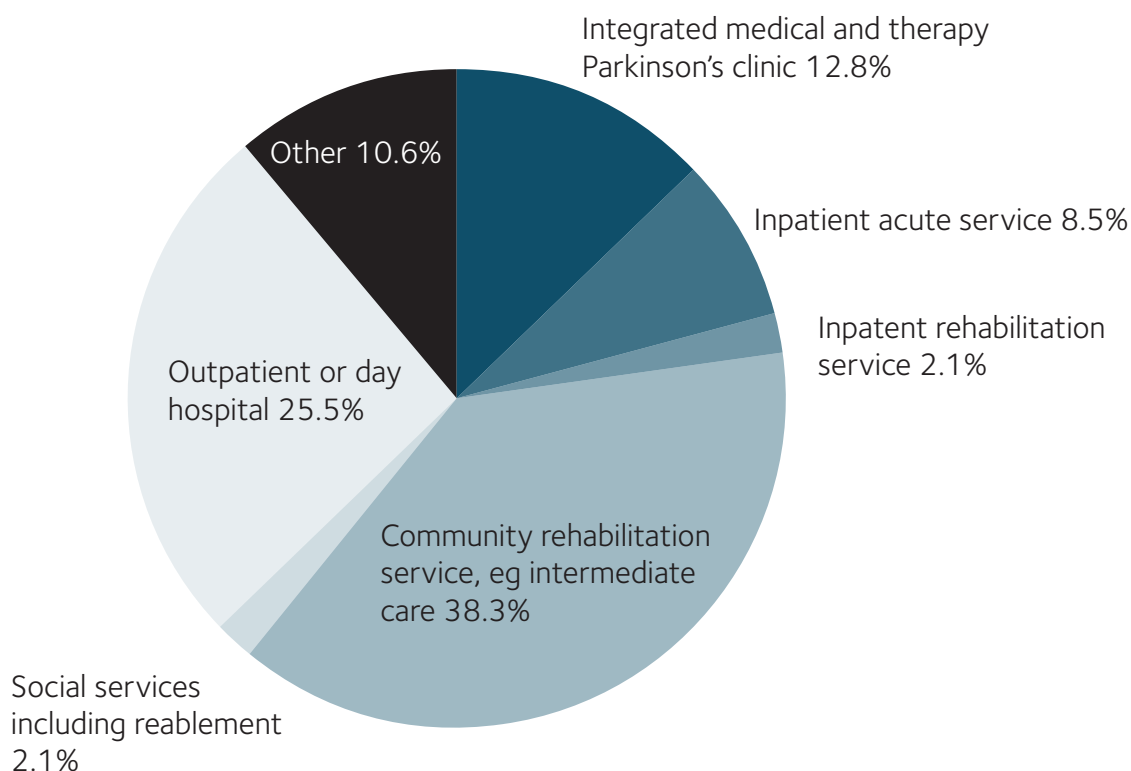
OT services saw 561 people with Parkinson's who were included in the audit. The majority were over 70 years of age (mean age: 75.4 years; SD 8.6 years), male (59.9%) and White British (87.5%). The mean length of time between diagnosis and referral for OT was 6.1 (SD 5.5 years). Typically, people seen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

Service audit

Models of service provision

The 47 OT services that supplied data for the audit offer care 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 where 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. The majority of services (55.3%) employed one or two full time equivalent occupational therapists.

The percentage of patients with a Parkinson’s diagnosis ranged from none to 19% in 20 OT services. OT services received an average of between 100 and 200 referrals of people with Parkinson’s each year.

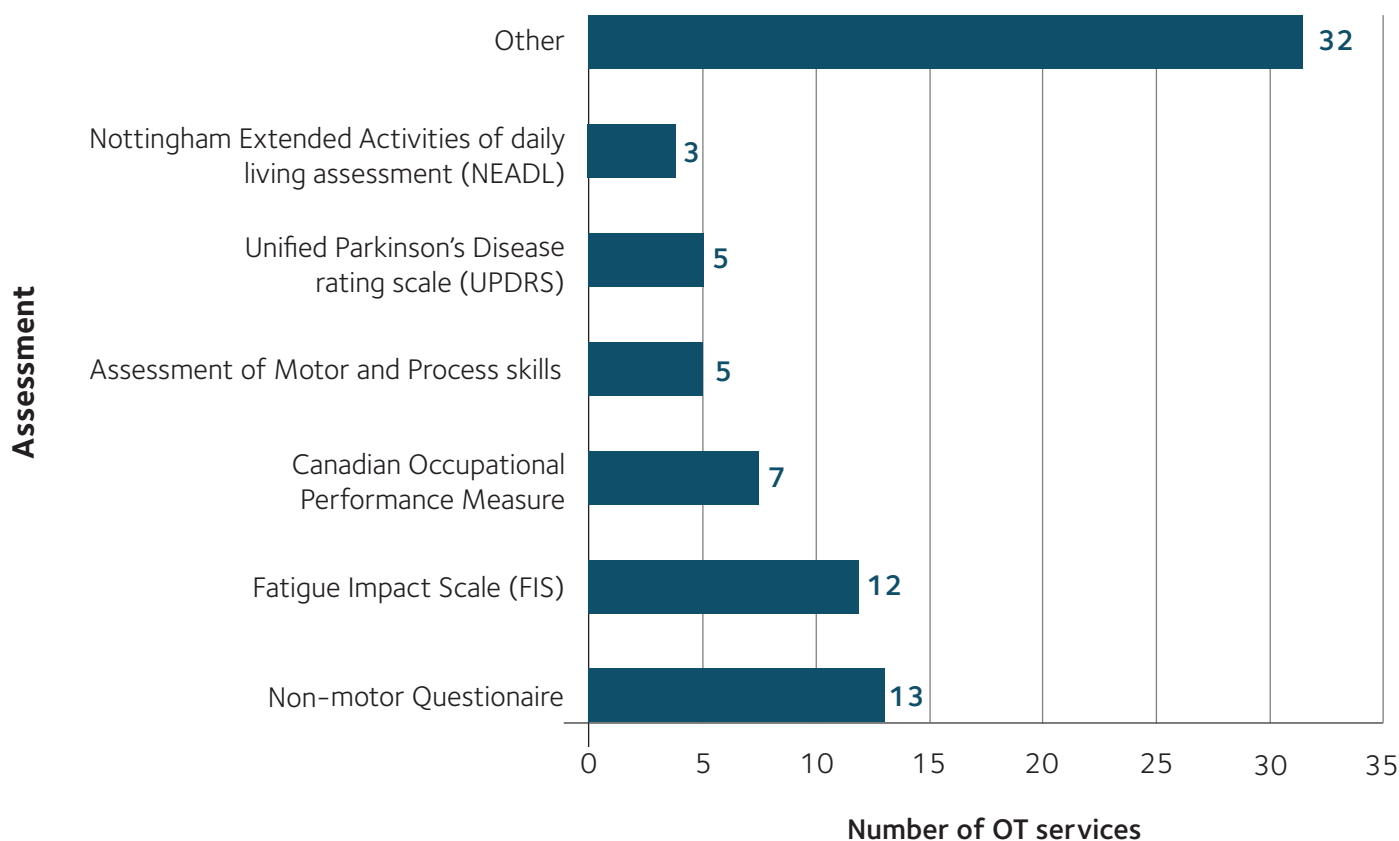
Accessing Parkinson’s-related Continuing Professional Development (CPD)

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

Use of standardised assessment and outcome measures

Figure 7: Number of Occupational therapy services using standardised assessments



Just over half (55.3%) of the OT services 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.

Table 8: Evidence used in Occupational therapy to inform clinical practice and guide choice of intervention for patients

Type of evidence	% of services
Clinical experience	94.7
Advice from colleague or supervisor	76.3
Occupational Therapy for People with Parkinson's: Best Practice Guidelines (Parkinson's UK, 2010)	78.8
Information from Parkinson's UK website	72.4
National Service Framework for Long Term Conditions (2005)	64.7
NICE Guidelines (2006)	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 Occupational therapy

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 9: Time between diagnosis and OT referral

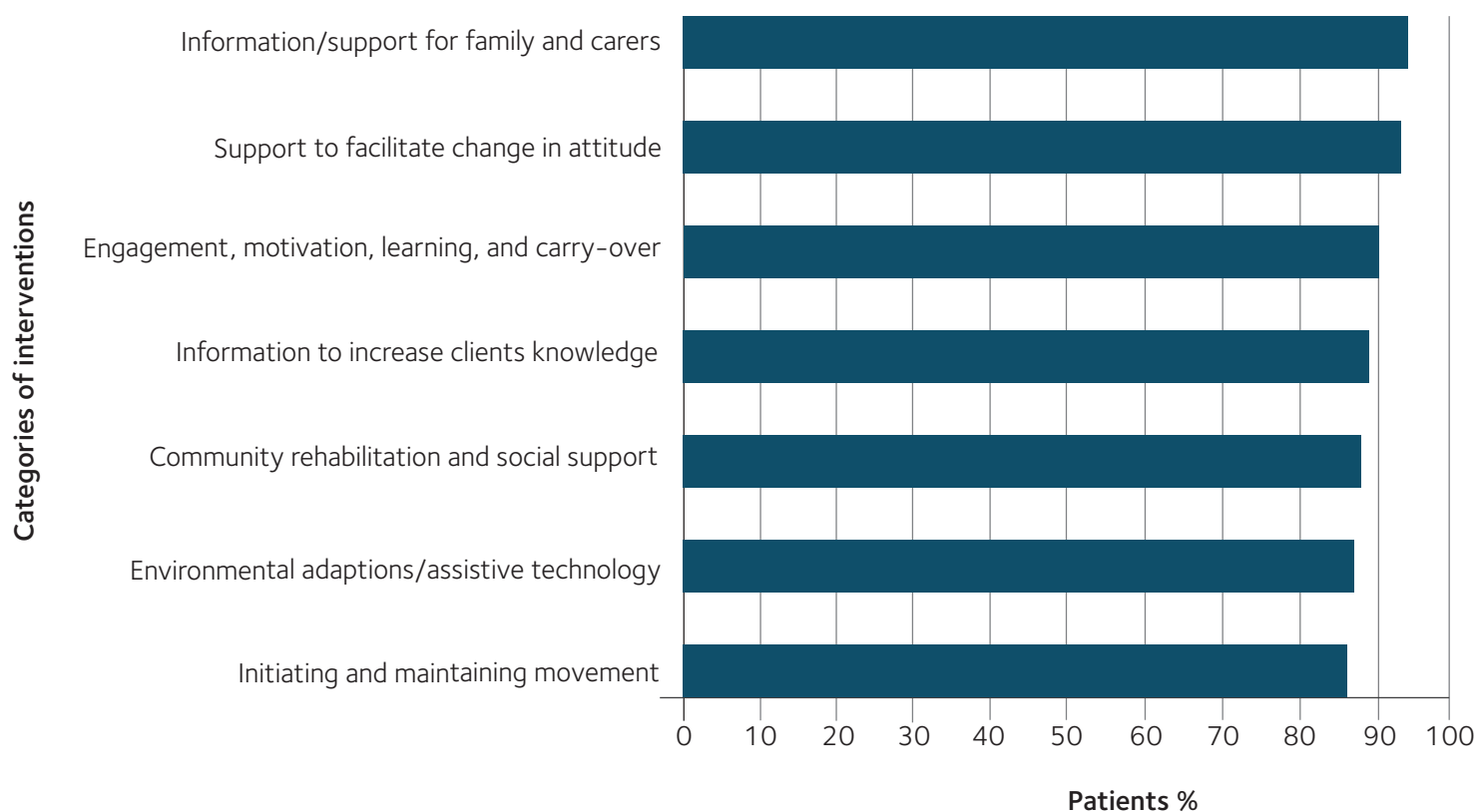
Duration of disease	Patients
Less than 1 year	13.9%
1–2 years	17.2%
3–5 years	25.2%
6–10 years	25.2%
11–15 years	12.0%
16–20 years	4.8%
More than 20 years	1.7%
Number:	540

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.

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



Physiotherapy

Aims

The Physiotherapy audit intended to establish whether Physiotherapy services are currently providing quality services for people with Parkinson's, taking into account recommendations from evidence-based guidelines and using standardised assessments. It allows local and national mapping of service provision, patient management and access to continuing professional education.

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.

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. 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.

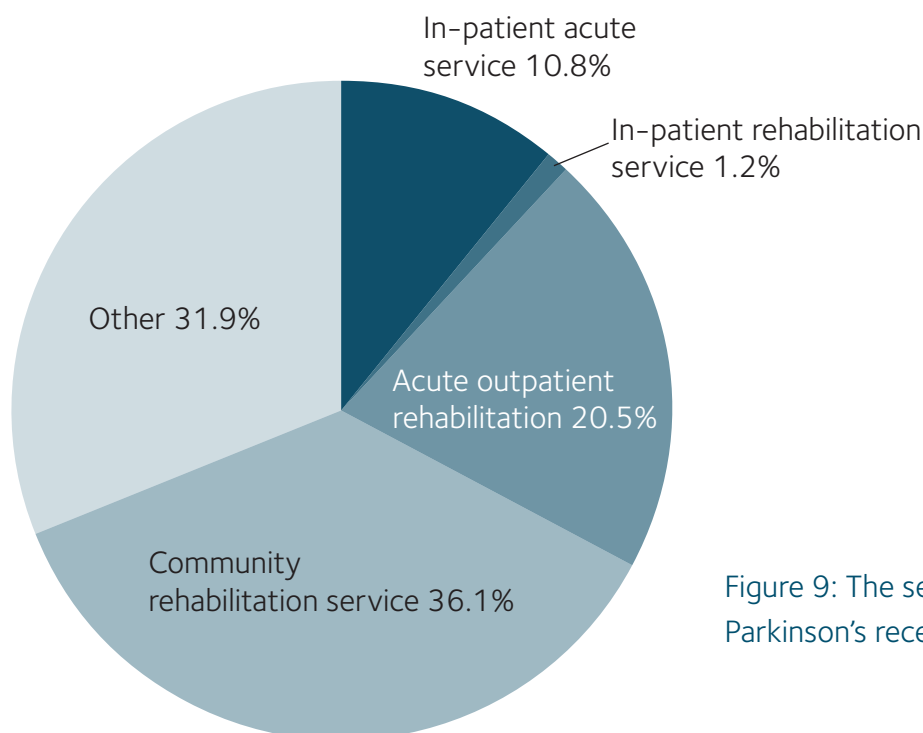


Figure 9: The settings in which people with Parkinson's receive Physiotherapy

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

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

Accessing Parkinson's-related Continuing Professional Development (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.

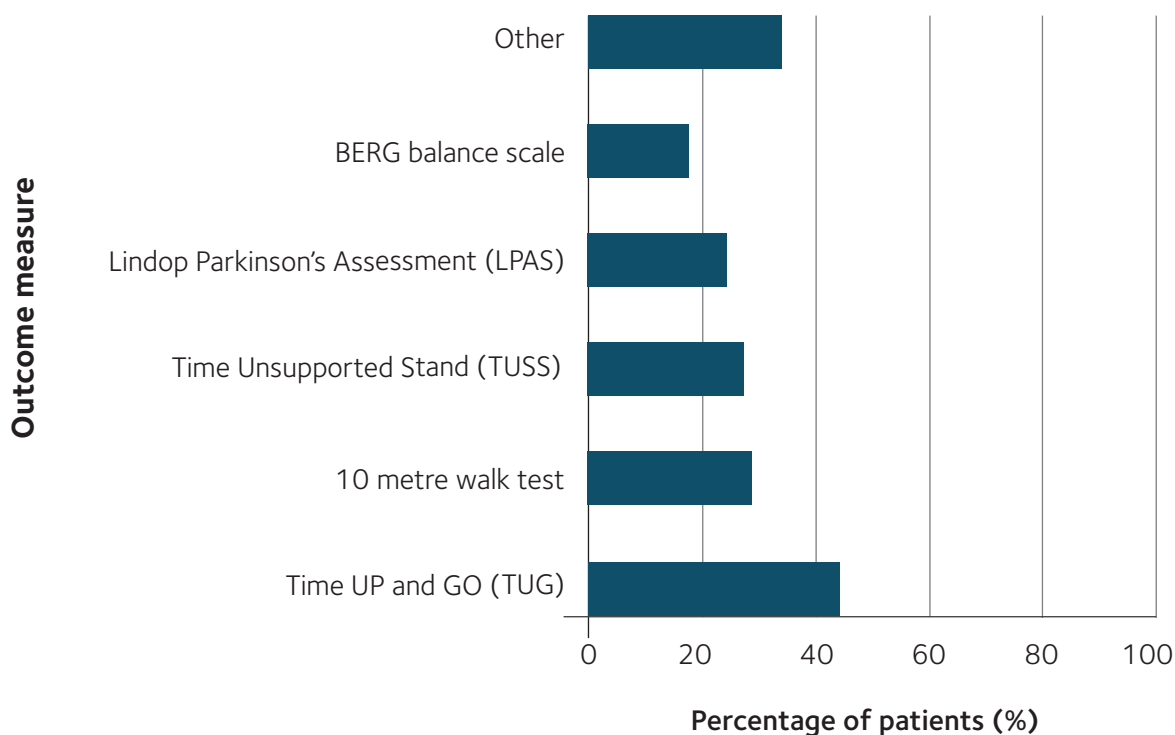
Table 11: Support available to individual physiotherapists

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%
Don't work directly in specialist Parkinson's clinics but access to Parkinson's specialist MDT/ Parkinson's nurse	34.9%
Don't work directly in a specialist clinic but 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. Outcome measures were reported as being used in 84.9% of patients (85.1% in 2012).

Figure 10: Most frequently used Physiotherapy outcome measures



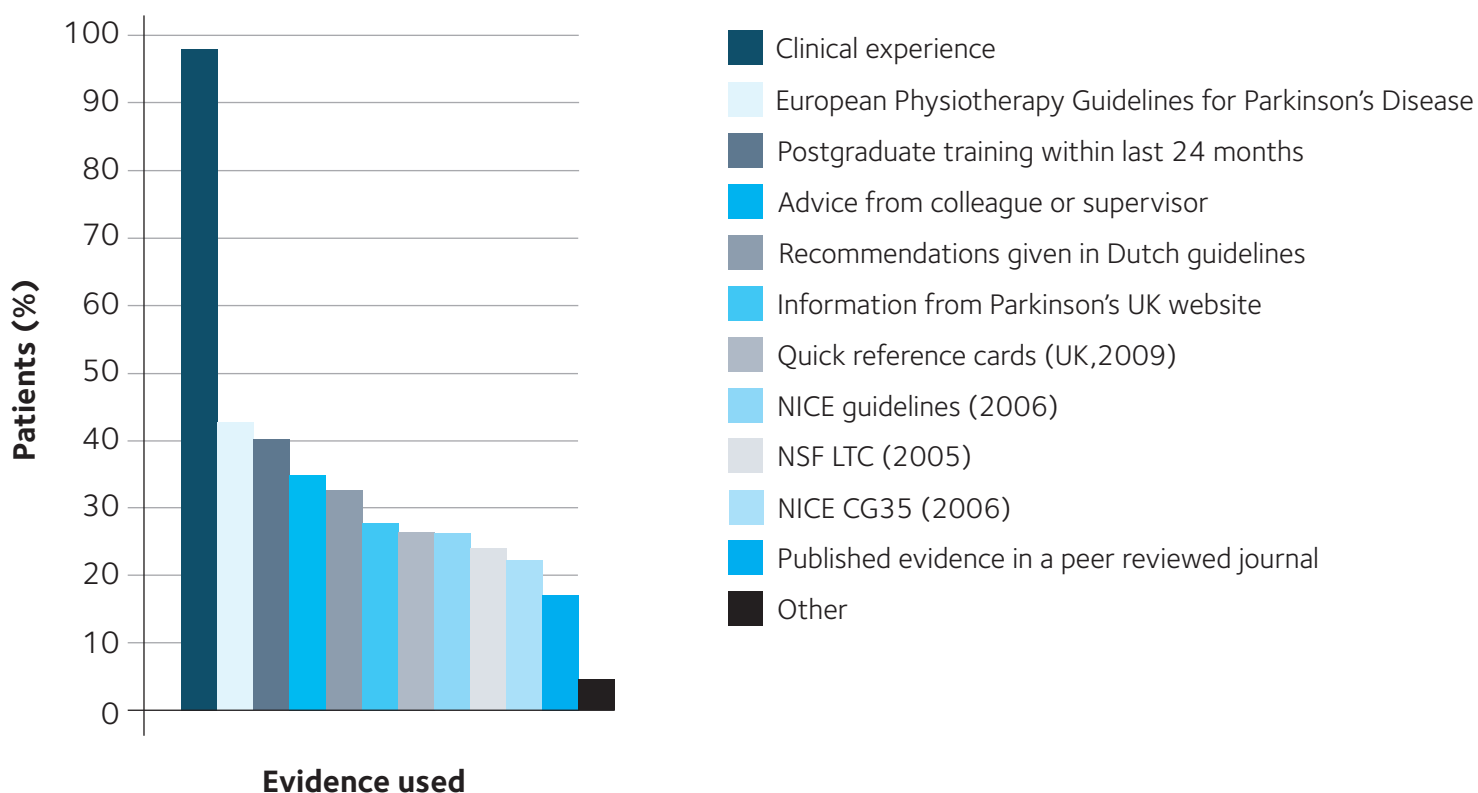
For many patients, multiple outcome measures were used and in 32.3% of cases, use of “other” outcome measures that did not appear on the audit suggested list was reported. Some of these were not specific to Physiotherapy (a list is included in the Reference Report). For 15.4% of people with Parkinson’s,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

Evidence based practice and training

The European Physiotherapy Guideline for Parkinson’s Disease 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 (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). 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.

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.

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 12: 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.

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.

Demographics

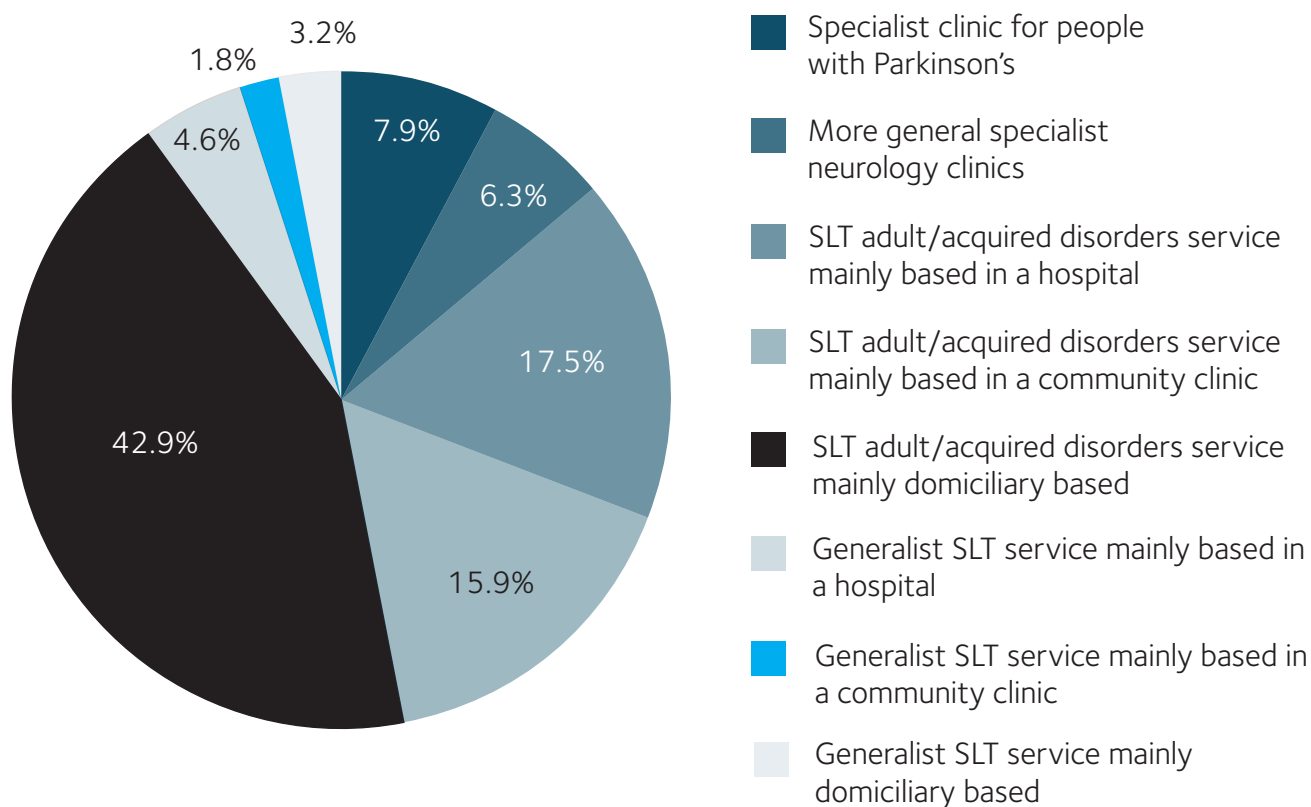
Speech and language therapists in 63 services registered for the audit reported on 820 people with Parkinson's. Patients were aged between 28 and 97 years (mean: 73.7 years; SD 9.7 years) and the majority were male (71.1%) and living in their own home (88.3%). Audited patients had a mean disease duration 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.

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: The settings in which people with Parkinson's received SLT



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 fewer 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.

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

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

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%).

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.

Review policy

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

Table 13: Review policies in SLT services

Review policy	Services
All patients in SLT service routinely reviewed at between 6–12 month intervals	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

Patient audit

Referrals

In people with Parkinson's referred for SLT, most (79.0%) were referred for assessment of specific aspects of their communication/swallowing. On first referral, 92.8% of patients received a full 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%.

Assessments carried out

The key aspects of speech and loudness are routinely evaluated, whilst 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. Whilst swallowing is attended to in over 90% of cases, the absence of consistent, systematic more objective charting of change with recognised methods is an area for improvement. Further, although the majority of assessments examine communication in one to one situations, a little less than a third look at multispeaker situations, where communication is likely to be more difficult.

Table 14: Tasks/contents covered by assessment (in individuals not seen for swallowing only):

Tasks	Patients
Speaking	97.9%
Reading	36.9%
Writing	12.0%
One-to-one	83.4%
Group	31.5%
Number:	601

Table 15: Voice-respiration and prosody parameters assessed (in individuals 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 16: Intelligibility assessed

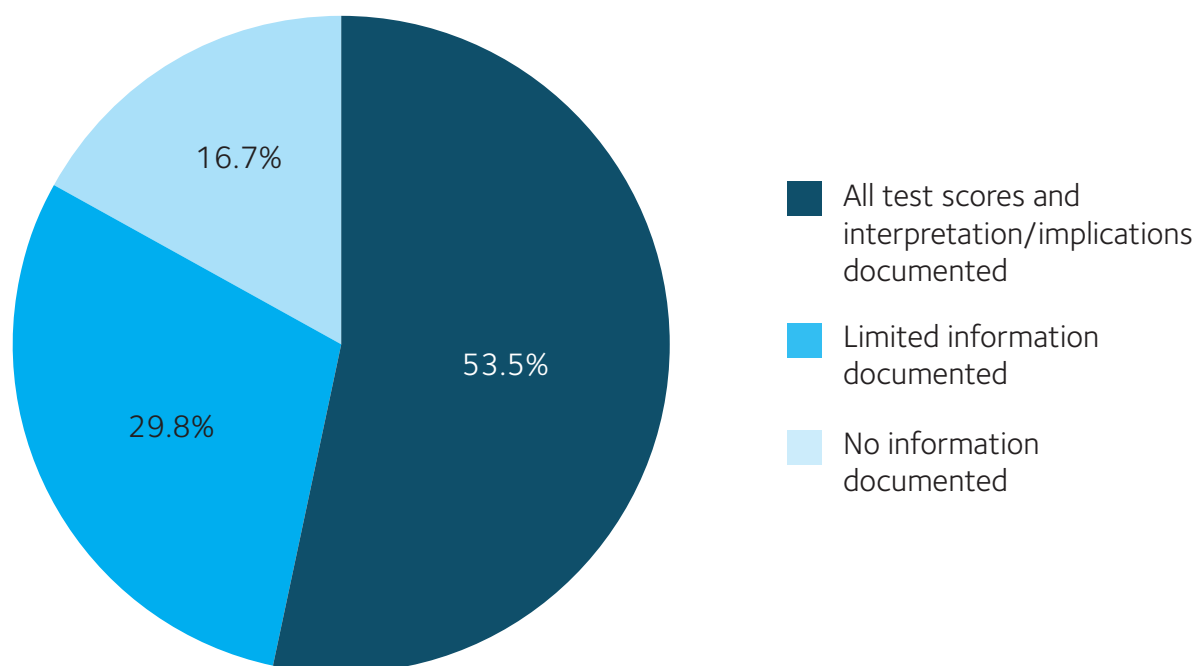
Evaluation of intelligibility	Patients
Standardised diagnostic intelligibility test completed and score given	10.5%
Informal assessment, non-standardised tool/subsection of other test completed and score given	20.5%
Informal assessment (e.g. rating scale) completed	33.2%
No assessment/results documented 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.

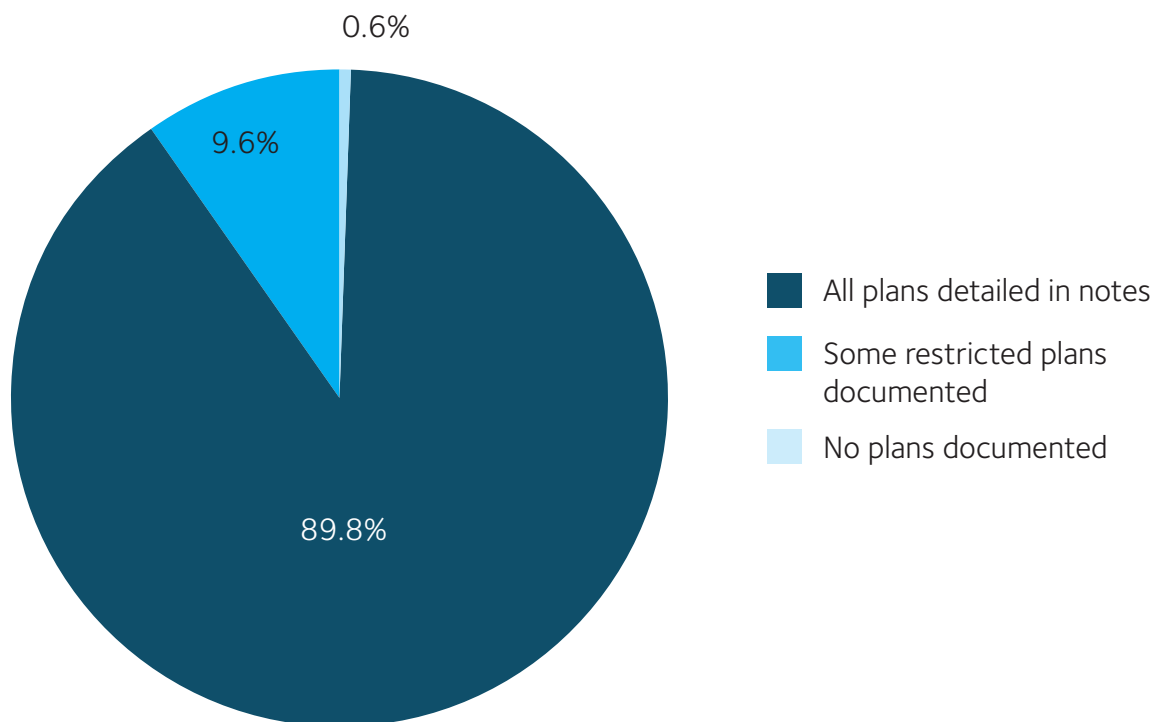
Figure 13: Percentage of SLT patients for whom communication strengths and needs were documented



Management plans based on assessment outcomes

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

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



Patient Reported Experience Measure (PREM)

“

We would like, at this stage, to say how excellent the care is that our Parkinson's nurse gives us. She has always been there for us – we can call her any time, and she has been very supportive to both me and my wife. ”

“

The Parkinson's service has always been first rate. The consultant and his staff have always responded promptly to my needs, and consequently my condition has remained as stable as possible. I am forever grateful for the quality of their service. ”

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.

Demographics

The majority of PREM questionnaires (72.4%) were completed by a person with Parkinson's rather than a carer on their behalf. The majority of people with Parkinson's represented were male (57.7%) and White British (92.0%). Fewer than 4% lived in a care home and 19.6% lived alone. The duration of Parkinson's ranged from less than a year to over 20 years. The demographics of the people with Parkinson's represented in the PREM questionnaire were comparable to those seen in the audit data.

Findings

Frequency of review by consultant or Parkinson's nurse

The majority of respondents (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%).

Quality of services provided within a Parkinson's service

Figure 15: Quality of service offered by consultant or doctor

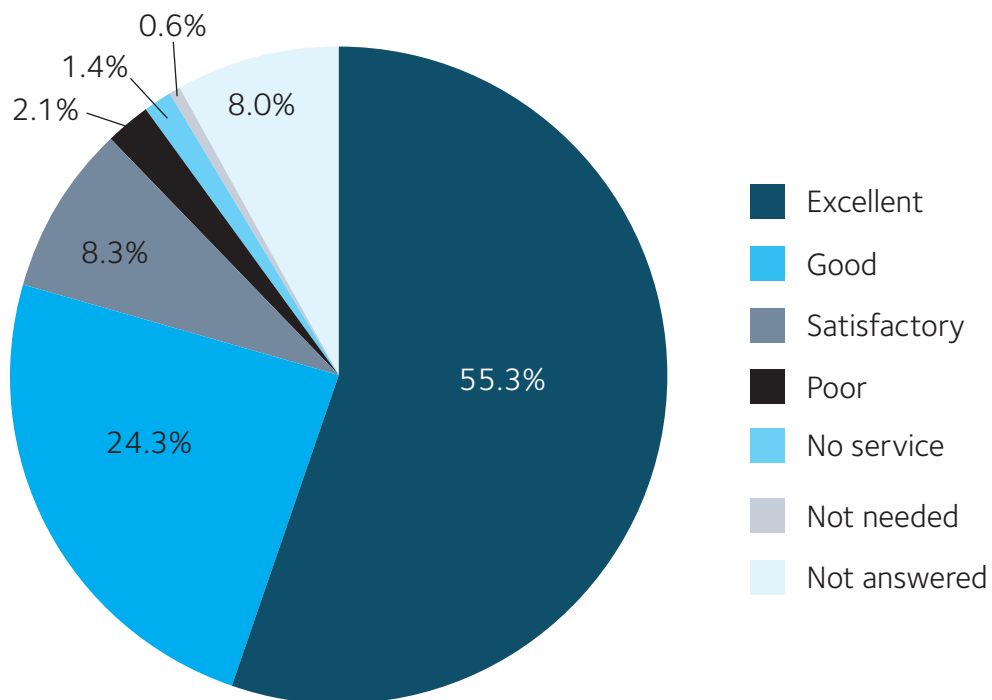


Figure 16: Quality of service offered by Parkinson's nurse

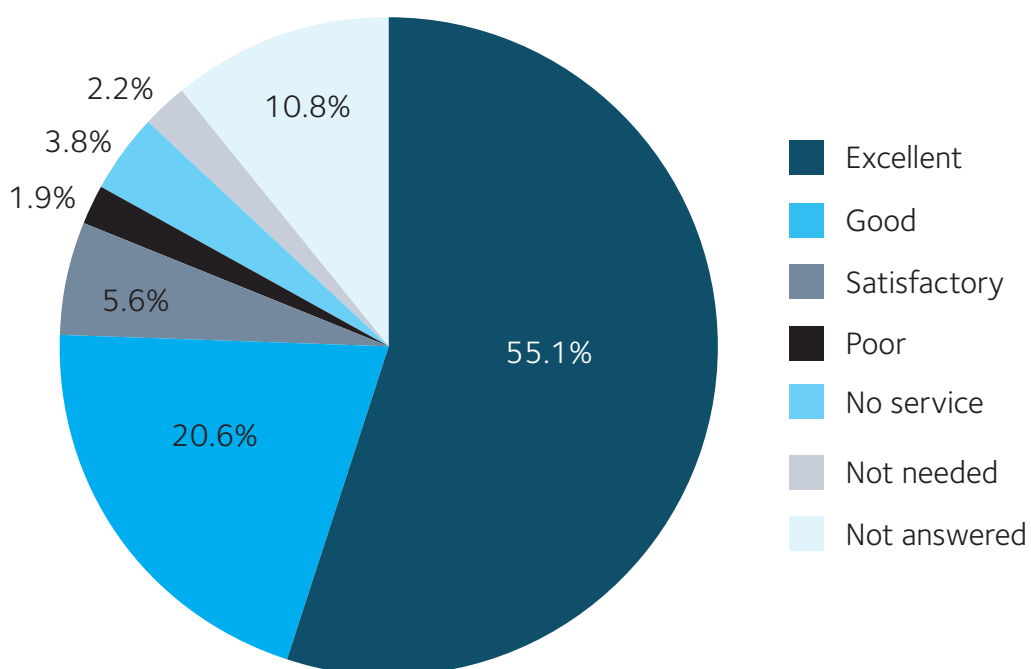


Figure 17: Quality of service offered by occupational therapists

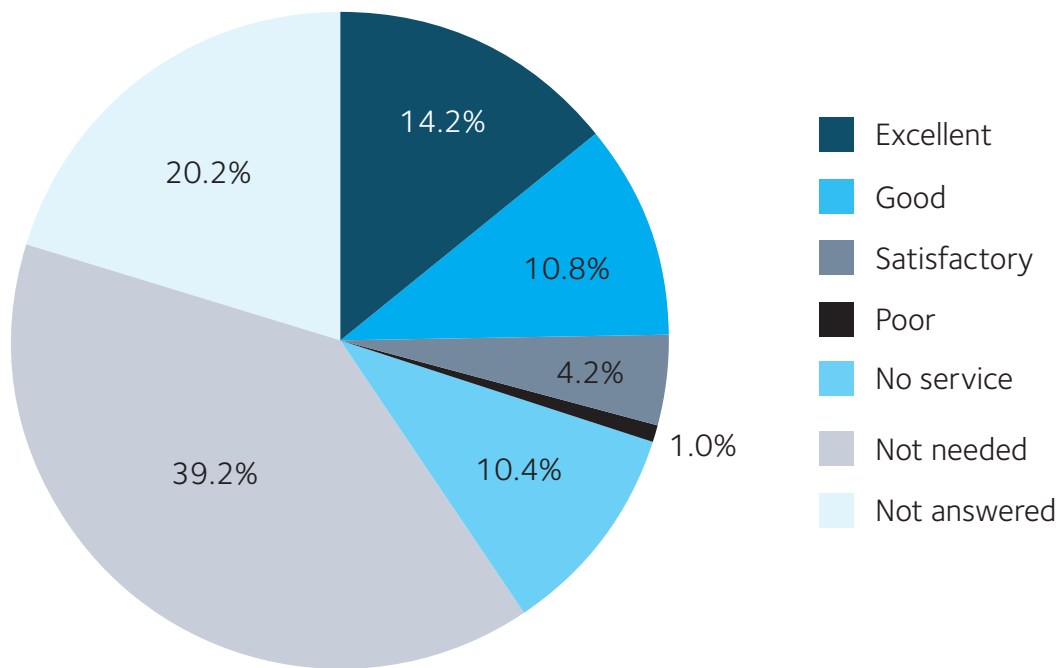


Figure 18: Quality of service offered by physiotherapists

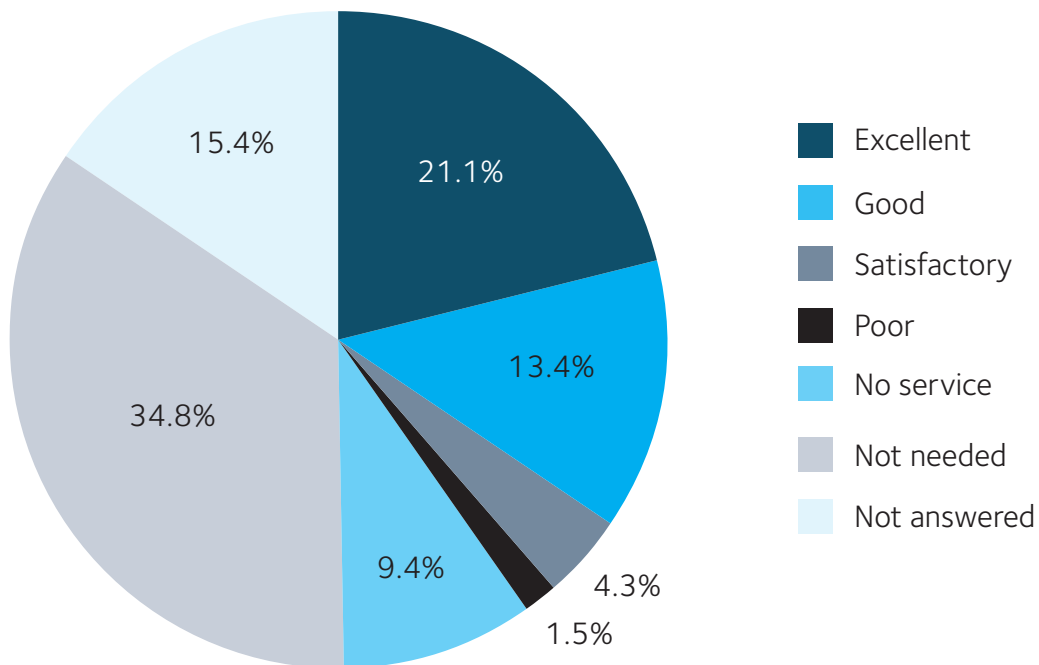
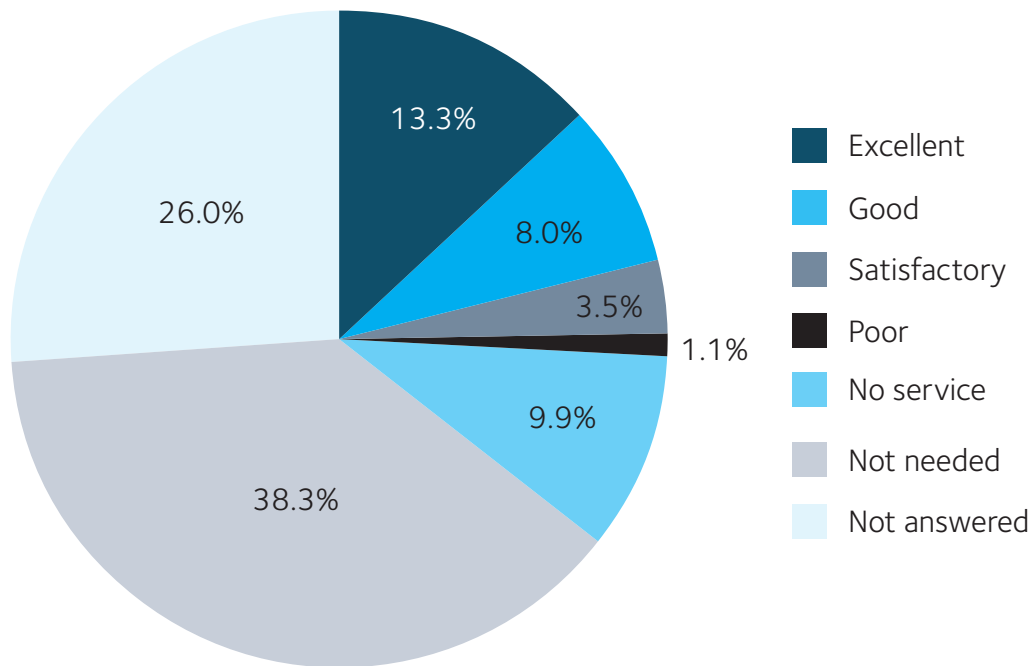


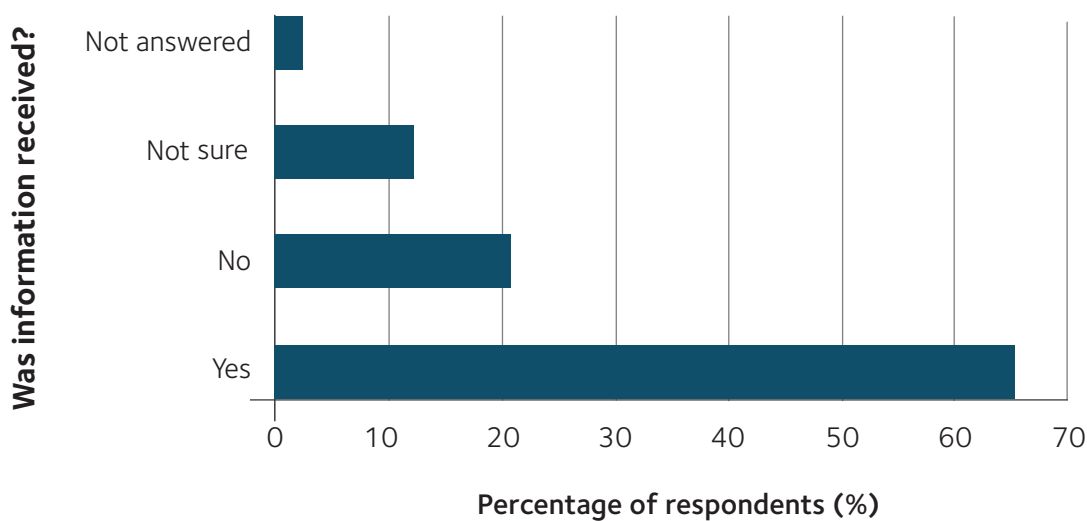
Figure 19: Quality of service offered by speech and language therapists



Information about Parkinson's provided at diagnosis

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 (%)



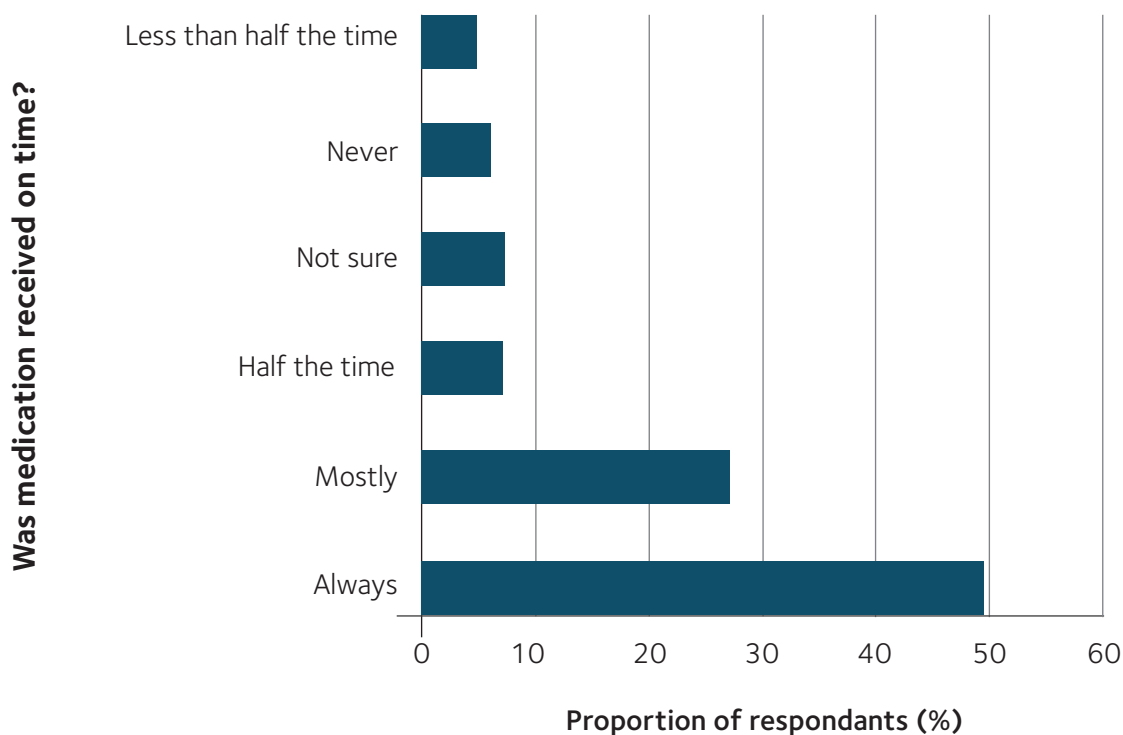
Advice given to drivers about contacting the DVLA (or DVA) and car insurance company

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.

Medicines management in hospital

In the last year, 22.7% of people with Parkinson's represented had been in hospital. 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 (ref²)). Parkinson's UK created the Get It On Time campaign in 2007 to promote better practice in hospital care of people with Parkinson's.

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



Of those who did not always receive their medication on time, 38.3% said this had a negative or significantly negative effect, 37.2% were unsure if it had an effect, 18.5% said it had no effect and 5.9% said it had a positive effect.

In some cases, hospitals will allow a patient to self-medicate, which ensures they take their medication on time – every time. 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% were not sure if they were able to.

Ref²: Low V, Ben-Shlomo Y, Coward E, Fletcher S, Walker R, Clarke CE. Measuring the burden and mortality of hospitalisation in Parkinson's disease: A cross-sectional analysis of the English Hospital Episodes Statistics database 2009-2013. *Parkinson's and Related Disorders* 21 (2015) 449-454.

Overall service quality

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

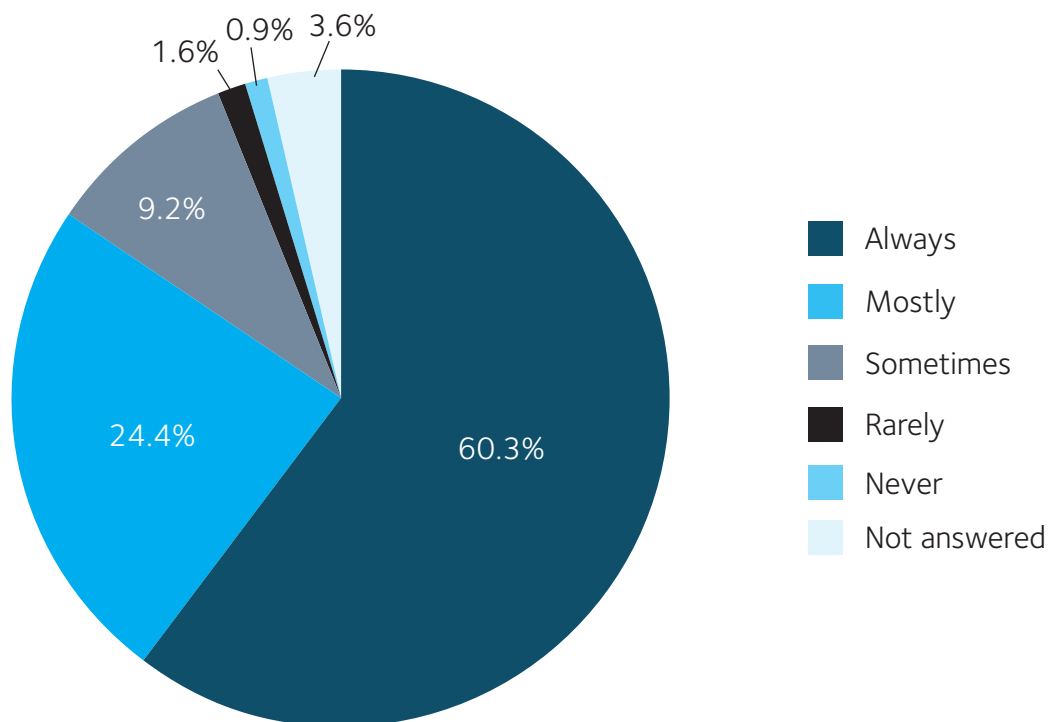
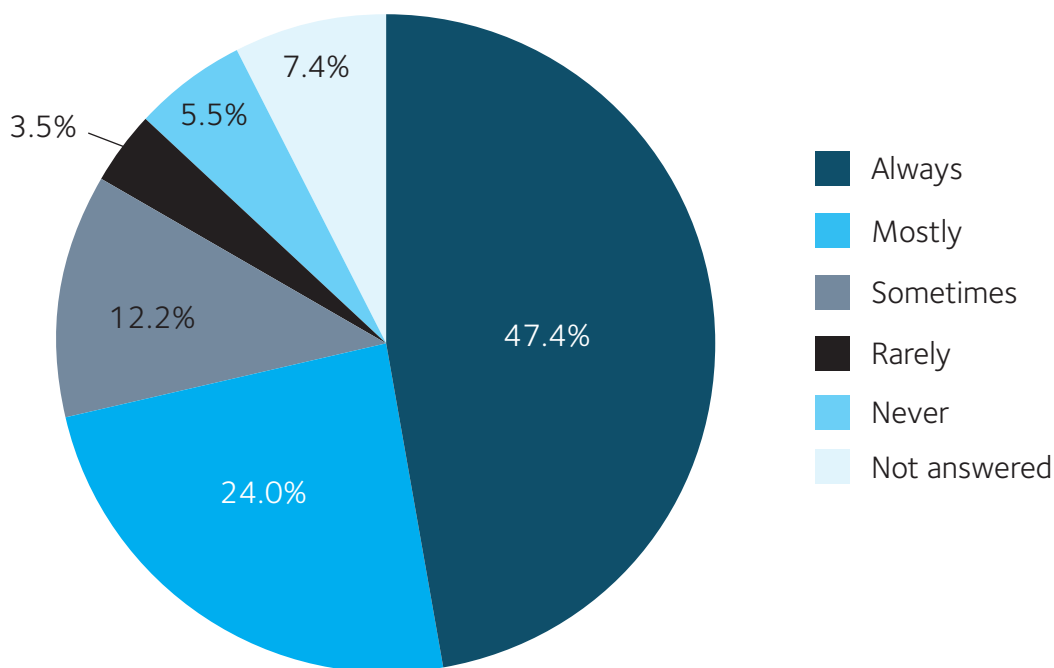


Figure 23: Percentage of people with Parkinson's who feel involved by their Parkinson's service in decisions about their care



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 report on these responses is available as an appendix to the Reference Report.

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 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.

Medicolegal 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 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 after first diagnosis. However, 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 measure 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 UK 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.

Please see the Reference Report available at parkinsons.org.uk/audit for details of the audit background, design and methods, a list of participating services, the audit questions and PREM questionnaire.

Every hour, someone in the UK is told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

Parkinson's UK
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London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm,
Saturday 10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303**
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