

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

NATIONAL PARKINSON'S AUDIT REPORT 2011

May 2012

Acknowledgments

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We would like to thank all our colleagues for their contribution, help and advice in preparing this report. A special thanks to all of the healthcare services that took part in the audit.

Executive Summary

The National Parkinson's Audit has been running since 2009, with the aim of helping Parkinson's services across the UK, to measure their practices against the NICE Parkinson's Guidelines (2006). The audit focused on neurology and elderly care services. This has now changed as previous reports found that an integrated medical, nursing and therapy model of care is needed for effective management of the condition. Following this, for 2011, we have added three further audits to include occupational therapy, physiotherapy and speech and language therapy.

The 2011 audit evaluated a total of 6106 patients with Parkinson's from 325 services (equivalent to 191 trusts).

Key Findings

- 39% of newly diagnosed patients with Parkinson's are not provided with written information about Parkinson's
- A third of newly diagnosed patients are waiting longer than six weeks to see a specialist
- Patients on dopamine agonists are not being monitored for impulsive and compulsive behaviour and 40% of patients on long term ergot dopamine agonist therapy are not monitored
- Approximately a third of occupational therapists, physiotherapists and speech and language therapists working in specialised neurological services are not receiving updated training on the management of Parkinson's.
- Approximately a third of occupational therapists, physiotherapists and speech and language therapists do not use recommended standardised assessments
- 9% of occupational therapy referrals did not include a reason for referral nor details about the patient's Parkinson's history or medication
- Only 1.4% of the total audited patients represented black and ethnic minority (BME groups), this is a similar pattern to the previous audits

Key Recommendations

- Clinicians should provide written information about Parkinson's via signposting to Parkinson's UK (website or local information support worker)
- 100% of patients with newly diagnosed Parkinson's should be seen within six weeks
- All patients must be advised and monitored for the risk of impulsive and compulsive behaviour when starting on a dopamine agonist and have ongoing monitoring if on long term ergot dopamine agonist therapy

- All healthcare professionals working for services specialising in neurological conditions and the treatment of people with Parkinson's to receive appropriate updates in the management of Parkinson's
- The use of standardised assessments as recommended in guidelines should be encouraged
- Clinical professionals referring patients to therapies need to provide essential information about the patient with the referral
- There is a need for more engagement with black and ethnic minority groups with Parkinson's.

Foreword

One of Parkinson's UK's core goals is improving life for everyone affected by Parkinson's.

Comprehensive, high-quality health services are crucial to the lives of people affected, helping them live life to the full and maintain their independence.

And audit is central to driving up service quality.

That's why the National Parkinson's audit, now in its third year, is so important for us as a charity and for the people we represent.

In a health landscape where there are few levers for quality improvement and significant local variations in care, this is one of the strongest mechanisms to make sure services meet quality standards across the UK.

The findings of this latest audit show real progress in some aspects of Parkinson's services.

But there are other areas where improvement is clearly needed. Making sure people diagnosed with Parkinson's have the right information to manage and make sense of their condition is one of these.

The audit findings highlight just how far there is to go before health professionals automatically ensure everyone affected by Parkinson's gets the information they need. We're committed to working with professionals so that everyone is made aware of the all-round information and support that Parkinson's UK can provide and no one has to face Parkinson's alone.

The nurses, doctors and therapists involved in the Parkinson's Audit are at the forefront of service improvement. We greatly appreciate the leadership they show in using the audit to drive action for change.

Together we can help to make certain that people affected by Parkinson's get the first class care they deserve, wherever they live.



A handwritten signature in black ink that reads "Steve Ford". The signature is written in a cursive, flowing style.

Steve Ford, Chief Executive

Contents

Background	9
Description of the audits	11
Patient management audit	11
Occupational therapy audit	11
Physiotherapy audit	12
Speech and language therapy audit	12
Service audit	13
Methodology	14
Patient characteristics	15
Patient management audit	17
Patient findings	17
Patient's descriptive data	17
Specialist review	20
Diagnosis	21
Medication monitoring and information standards	24
End of life care	26
Domain scores	27
Service findings	31
Clinical consultants	31
Parkinson's specialist nurse provision	31
Model of service delivery	31

Therapy audits	32
Occupational therapy audit	32
Client findings	32
Referrals	32
Goals identified	35
Treatment strategies and techniques	37
Service findings	41
Service description	41
Clients with Parkinson's	43
Occupational therapy professionals	44
Clinical practice	45
Physiotherapy audit	47
Patient findings	47
Referrals	47
Initial assessments	49
Outcome measures	49
Service findings	51
Service description	51
Patients with Parkinson's	52
Physiotherapy professionals	53
Clinical practice and assessment	53

Speech and language therapy audit	55
Patient findings	55
Referrals	55
Assessments	58
Interventions	63
Service findings	64
Service description	64
Patients with Parkinson's	65
Speech and language therapy professionals	68
Clinical practice	70
Service audit	74
Parkinson's specialist clinics	74
Therapies	78
Medication formulary	81
DaTSCAN and neurosurgery	84
Recommendations	85
List of figures and tables	89
References	92
Appendices	95
Appendix A – List of all participating Trusts	96
Appendix B – List of all standards	103
Appendix C – Patient management audit	106

Background

127,000 people in the UK are living with the disabling effects of Parkinson's.¹

The diagnosis has profound implications for the individual and their family, as well as major cost implications for health and social services.

Management is particularly challenging due to the complex mix of problems relating to speech and swallowing, memory and mood, sleep, pain and continence, which compound the movement symptoms of the disorder. An integrated medical, nursing therapy model of care is essential – but far from the norm, based on data from 13,000 patients surveyed by the Parkinson's UK in 2008.²

The All Party Parliamentary Group Enquiry into Parkinson's services (2009) also highlights a concerning postcode variation in quality of care.

The NICE Guidelines for Parkinson's, published in 2006, predated the current arrangement for all new NICE



Guidelines to be accompanied by an audit tool.³ To fill this gap, a multi-professional steering group was established under the Chairmanship of Steve Ford, Chief Executive of Parkinson's UK to facilitate local audit against national standards of good practice by providing audit tools and the facility for central benchmarking.

The National Parkinson's Audit to date has been completed by neurology and elderly care consultants, and has comprised a 'service audit' (i.e. what services are available to people with Parkinson's compared with what is recommended by the guidelines), and a 'new patient audit'.

Previous reports have found that while an integrated medical, nursing and therapy model of care is needed for effective management of the condition, such a model is not used universally, and there is also geographical variation in the quality of care received.

This evaluation encouraged the development of new tools to audit physiotherapy, physiotherapy and speech and language therapy for the first time.

In 2011, the National Parkinson's Audit consisted of six separate audits:

- Patient management in neurology
- Patient management in elderly care
- Occupational therapy
- Physiotherapy
- Speech and language therapy
- Service audit

How to read this report

Standards

Standards for the audits are mainly derived from the NICE Guidelines for Parkinson's. The following guidelines were also used:

- National Service Framework for Long Term Neurological Conditions (NSF – LTNC)⁴
- Occupational therapy for people with Parkinson's: Best Practice Guidelines⁵
- Dutch Guidelines⁶
- Royal College of Speech and Language Therapy (RCSLT) Clinical Guidelines for Dysarthria⁷
- RCSLT Communicating Quality 3 standards for motor speech disorders and progressive neurological conditions⁸

Standards are highlighted throughout the report where appropriate and a list of all standards used for each audit can be found in Appendix B.

Recommendations

Recommendations are highlighted throughout the report where appropriate and a list of full recommendations is available in the 'Recommendations' section.

The following acronyms have been used to represent specific recommendations related to each audit:

- **PDR#** recommendations applicable to all participants of the audit
- **PM#** recommendations applicable to patient management in neurology and elderly care services only
- **OT#** recommendations applicable to occupational therapy only
- **PT#** recommendations applicable to physiotherapy only
- **SLT#** recommendations applicable to speech and language therapy only

Description of the audits

This chapter focuses on summarising the aims and objectives of each audit, including the characteristics of the audited patients.

Patient management in neurology and elderly care

The patient management audits for neurology and elderly care services are designed to examine if the assessment and management of patients complies with the NICE and National Service Framework for Long Term Neurological Conditions (NSF) guidelines.

The main aims of the audit are:

1. To encourage clinicians to audit compliance of their local Parkinson's service against Parkinson's guidelines by providing a simple peer-reviewed audit tool with the facility for central data analysis to allow benchmarking with other healthcare services.
2. To highlight areas of good and poor practice for local discussion and the development and implementation of action plans to improve quality of care.
3. To establish baseline audit data to allow:
 - national mapping of postcode variations in quality of care
 - local and national mapping of progress in service provision and patient care through participation in future audit cycles

Occupational therapy audit

The occupational therapy audit has been structured according to recommendations made in the

following guidelines: Occupational therapy for people with Parkinson's: Best Practice Guidelines, and the National Service Framework for Long Term Conditions. It has also been structured according to principles of occupational therapy for Parkinson's, as outlined by NICE Guidelines.

The principles of occupational therapy for Parkinson's include:

1. early intervention to establish rapport, prevent activities and roles being restricted or lost and, where needed, to develop appropriate coping strategies
2. client centred assessment and intervention
3. development of goals with the individual and carer
4. 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

Based on the recommendations taken from the above guidelines, questions have been formed in order to analyse the compliance of participating occupational therapy services to these particular guidelines and certain objectives have been established:

1. The extent to which occupational therapists are providing quality services for people with Parkinson's, taking into account recommendations made in the Occupational therapy for people with Parkinson's: Best Practice Guidelines, NICE Guidelines and NSF.

2. Which clients with Parkinson's are referred for occupational therapy. This will include information on number of referrals, stage of the condition, reasons for referral and quality of referral.
3. The most common areas of recommended occupational therapy intervention for people with Parkinson's.
4. The most common recommended treatment techniques and strategies being used by occupational therapists working with people with Parkinson's.

Physiotherapy audit

The aim of the physiotherapy audit is 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 the NICE Guidelines and the NSF.

It is key for physiotherapy services to record:

1. How long after diagnosis people with Parkinson's are referred for physiotherapy
2. Evidence that recommendation for physiotherapists from the NICE Guidelines, NSF and the Quick Reference Cards for Physiotherapy have been implemented.

With this audit we want to answer the following questions:

1. Are those physiotherapists assessing and treating people with Parkinson's aware of the Quick Reference Cards for Physiotherapy? These cards provide standardised guidance for physiotherapists working in

Parkinson's and directly support clinical practice, and were adapted from the Dutch Guidelines for Physiotherapy.

2. Is there a match between 'reason for referral' and 'areas identified for physiotherapy intervention' at the point of initial assessment?

Speech & Language Therapy audit

The aim of this audit is to evaluate if speech and language services currently provide assessment and interventions appropriate to the needs of people with Parkinson's, judged against recommendations made in the NICE Guidelines, NSF and RCSLT Clinical Guidelines for Dysarthria and RCSLT Communicating Quality 3 standards for motor speech disorders and progressive neurological conditions.

Through the audit, speech and language therapy managers will be able to identify strengths within their service provision and organisation and possible areas for change. Participants will be able to compare themselves against other responding services across the UK. Through these steps they will be able to formulate specific goals for change or maintenance of standards. If they participate in later audits, it will enable a comparison against their own previous responses and against the national trend.

The audit also makes possible a notes review against agreed guidelines. Through this participating services and individual clinicians are able to monitor the completeness and appropriateness of the information appearing in individual charts. Again, this will assist in identifying strengths and areas to address in further development.

Service audit

The service audit aim to achieve the following:

1. To establish, by trust or equivalent organisation, if people with Parkinson's can access services and treatments recommended by NICE Guidelines and NSF including:
 - specialist medical assessment
 - Parkinson's specialist nurse support
 - therapy services (physiotherapy, occupational therapy, speech and language therapy)
 - NICE-approved medication
 - DaTSCAN imaging
 - neurosurgery
2. To explore the likely quality of Parkinson's therapy services by collecting information on access to different specialists and if delivered via an integrated multidisciplinary team.

Methodology

All healthcare services providing elderly care, neurology, occupational therapy, physiotherapy and speech and language therapy services were encouraged to participate. The registration for the audit ran until 30 June 2011.

Data collection

The audit ran over a five-month period from the 1 July to the 30 November 2011.

There were five different audit tools created for each specialty. Registered audit leads were sent specified password protected audit tools (excel spreadsheets), to capture and record the data via email.

Data security

All participants were required to remove all information relating to named patients from the spreadsheet

prior to submission. The completed audit tools were sent to pdaudit@parkinsons.org.uk, which is the main Parkinson's Audit mailbox. When the audit tools were received, they were checked by the clinical audit team at Parkinson's UK for their completeness and compliance to NHS confidentiality requirements.

If the data was complete, the audit tools were saved in encrypted password protected files for data analysis.

If the data was incomplete, the audit lead was contacted.

Access to the raw data sets was restricted to the Director of Research and Innovation and the Clinical Audit Manager.

Data Analysis

The Clinical Audit Manager was responsible for the processions and analysis of all submitted data. Data was analysed using Excel 2003 and SSPS 19 programs.

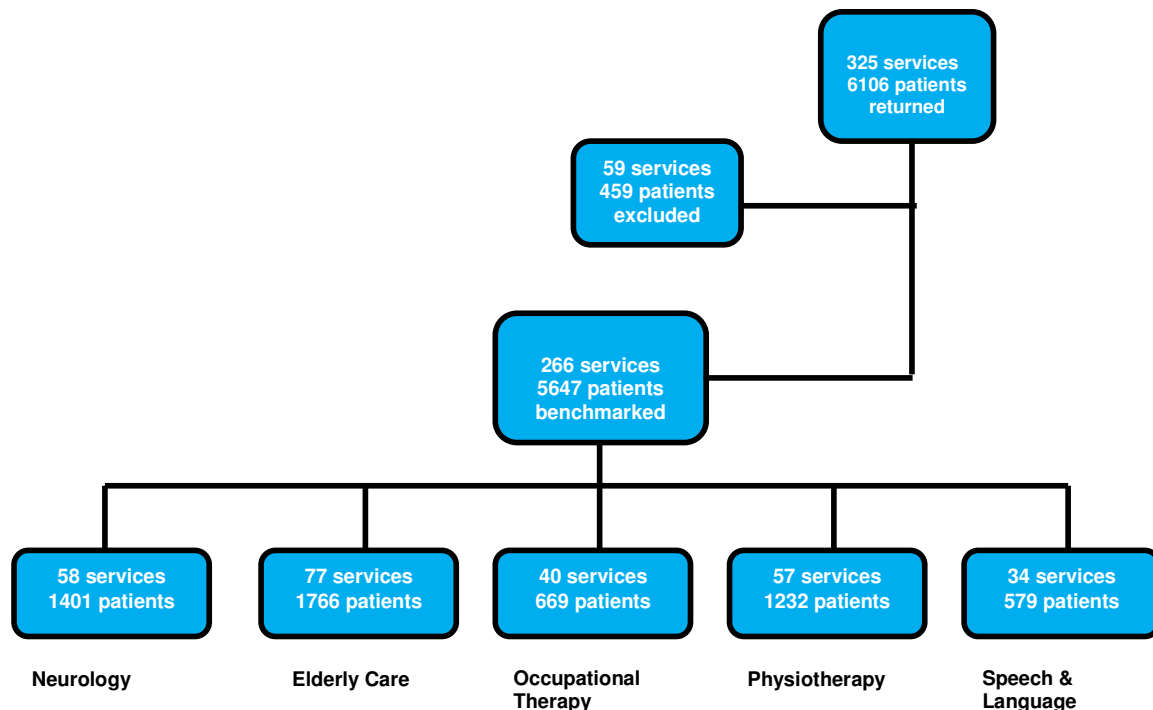


Figure 1 – Total number of services and patients analysed after benchmarking

Participation and benchmarking

A total number of 300 trusts registered to take part in the audit. A total of 191 (64%) trusts (including hospitals and primary care providers) submitted data, trusts included primary care services. Many trusts submitted data from different departments; in this case trusts were counted as one.

Initially, a minimum of 20 patients were required to complete the audit. However, after preliminary analysis it became evident that the therapy audits did not see as many patients as the patient management audits. The decision was made to include data sets of a minimum of 20 patients for patient management audits and include data sets with a minimum of 10 patients for the therapy audits.

Patient characteristics

This chapter summarises the common patient characteristics gathered from all audits (Table 1).

The patient management audits (neurology and elderly care) represented the majority of patients and services.

Average age

The average age of the patients with Parkinson's presenting to all audited specialties was 73.8 years, with elderly care patients representing the highest average 76.6 years of age.

Gender

The majority of patients were male (61%).

Ethnicity

96% of patients were of white origin. This has been consistent in previous audits.

Duration of Parkinson's

Audited patients have had Parkinson's for an average of 6.8 years.

	Neurology		Elderly care		Occupational therapy		Physiotherapy		Speech and Language Therapy		Total	
	67 services		85 services		64 services		65 services		44 services		325 services	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
	1502	25%	1890	31%	801	13%	1278	21%	635	10%	6106	100%
	Patient Characteristics											
Average age	70.3		76.6		74.8		73.7		73.5		73.8	
Gender												
Male	896	60%	1104	58%	508	63%	778	61%	429	68%	3715	61%
Female	606	40%	786	42%	293	37%	500	39%	206	32%	2391	39%
Ethnicity												
White	1330	92.7%	1775	96.2%	763	96.0%	1227	97.7%	584	96.2%	5679	95.6%
Asian	77	5.4%	42	2.3%	22	2.8%	17	1.4%	17	2.8%	175	2.9%
Black	27	1.9%	21	1.1%	6	0.8%	6	0.5%	4	0.7%	64	1.1%
Mixed	1	0.1%	7	0.4%	4	0.5%	6	0.5%	2	0.3%	20	0.3%
Duration of Parkinson's (years)	6.6		5.7		6.9		7.1		7.5		6.8	

Table 1. Patient characteristics

Patient Management Audit

This chapter of the report reviews the results presented by the patient management audits:

- Neurology
- Elderly care

This audit is analysed in two sections, patients' findings and service findings.

The patient management audits represented 67 neurology services and 85 elderly care services across the UK, auditing a total number of 3392 patients.

For the purpose of benchmarking, the analysis of this audit has been based on the data submitted by 58 neurology services and 1401 patients and 77 elderly care services and 1766 patients, where anonymised information for 20 or more clients was submitted.

Patient findings

This section analyses the patient findings of the patient management audit. It is important to highlight that both newly diagnosed patients (i.e. patients diagnosed with Parkinson's within the year) and existing patients have been analysed separately in some of the sub-subsections. For example, the diagnosis phase section only relates to newly diagnosed patients.

For neurology, 271 newly diagnosed and 1,130 existing patients were identified. For elderly care, 365 newly diagnosed and 1,401 existing patients were identified.

Patient's descriptive data

This section provides descriptive data for the patients in the audit sample, including disease stage, whether the patients' are living alone and current medication.

Parkinson's phase

Participating consultants were asked at which stage of their Parkinson's condition each audited patients were at. Four phases were identified, as described below:

- **Diagnosis:** First recognition of symptoms/sign/problem and diagnosis is not established.
- **Maintenance:** Diagnosis has been established and reconciled to diagnosis. Patient either on no drugs or single drug or two drugs or stable medication.
- **Complex:** Patient is on more than five doses or more than two drugs or frequent changes to medication.
- **Palliative:** Patient is unsuitable for surgery and has advanced co-morbidity.

Full definitions of the phases can be found in Appendix C.

Figure 2 shows that maintenance and complex stage patients accounted for a half and a third of the sample, respectively.

It is also important to highlight that the data from patients in the diagnosis and palliative stages have the caveat of being based on relatively low numbers.

A total of 87 out of 3,167 (3%) patients were identified to be in the palliative phase of Parkinson's. 33% (19/58) of neurology services and 39% (30/77) of

elderly care services recorded patients at the palliative phase (range 1-4 respectively).

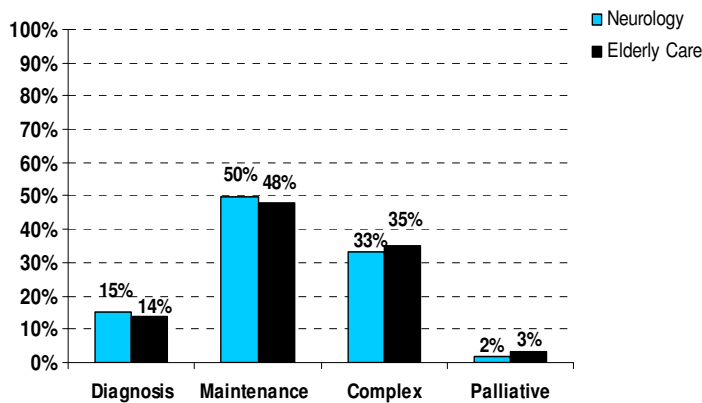


Figure 2. Parkinson's phase

Living alone

Participating consultants were asked whether the patients lived alone or not.

74% (2141 out of 2899) of patients were not living alone. Of the 26% of patients who were living alone most of them were at the diagnosis or maintenance phases.

Current Medication

Table 2 shows the pattern of prescribing for newly diagnosed (i.e. patients diagnosed within the last 12

months) and existing patients in neurology and elderly care.

The pattern of prescribing was broadly similar across neurology and elderly care but with a slightly higher dopamine agonist use in neurology, especially in early stages of the condition and a lower use of MAOB inhibitors by elderly care physicians in early stages of the condition.

Adherence to prescribing guidelines

The NICE Guidelines for Parkinson's recommends levodopa, dopamine agonists and MAOB inhibitors as first line treatment options in early stages of the condition. Amantadine and anticholinergic can be used as second line agents (anticholinergic only in young tremor-predominant patients).

New patients

Four patients in the recent diagnosis cohort were prescribed amantadine (two neurology and two elderly care) and only two were prescribed an anticholinergic (both neurology patients). A COMT inhibitor was prescribed to three neurology patients (1%) and 11 elderly care patients (2.8%) This medication is only licensed

	New Patients				Existing Patients			
	Neurology		Elderly Care		Neurology		Elderly Care	
	n	%	n	%	n	%	n	%
Levodopa/PDI	136	48.4%	225	58.3%	966	47.2%	1228	51.4%
COMT inhibitor	3	1.1%	11	2.8%	227	11.1%	318	13.3%
Dopamine agonist	68	24.2%	60	15.5%	536	26.2%	519	21.7%
MAOB inhibitor	38	13.5%	20	5.2%	198	9.7%	190	7.9%
Amantadine	2	0.7%	2	0.5%	77	3.8%	80	3.3%
Anticholinergic	2	0.7%	0	0.0%	26	1.3%	23	1.0%
Other e.g. research trial drug	2	0.7%	1	0.3%	5	0.2%	7	0.3%
Untreated	30	10.7%	67	17.4%	13	0.6%	25	1.0%
Total	281	100.0%	386	100.0%	2048	100.0%	2390	100.0%

Table 2. Current medication

for adjunct treatment in later stages of the condition.

Existing patients

The medications listed in Table 2 can all be prescribed in later stages of the condition. Only 1.3% of Neurology and 1% of Elderly care patients were taking an anticholinergic, reflecting increased awareness of the neuropsychiatric problems in Parkinson's.

New medication in the last year

Two thirds of recently diagnosed patients (68% neurology (n=165) and 67% elderly care (n=224) respectively) and a quarter of existing patients (26% neurology (n=281) and 27% elderly care (n=329)) started a new medication in the previous year.

Table 3 shows the breakdown of medication prescribed within the last year.

There are clear differences in prescribing patterns of newly diagnosed and existing patients. Dopamine agonists are prescribed more regularly in existing patients (23% of newly diagnosed patients and 27% in existing patients), with neurologists prescribing more in newly diagnosed patients and elderly care consultants

prescribing more in existing patients. Amantadine is also prescribed more in existing patients.

Participants were also asked if the new medication prescriptions complied with NICE Guidelines. Prescription of new medication complied with the NICE Guidelines for 99% (431/494) newly diagnosed patients and 98% (923/939) of existing patients.

Overall, the medication data suggests good compliance with prescribing guidelines.

	New Patients				Existing Patients			
	Neurology		Elderly Care		Neurology		Elderly Care	
	n	%	n	%	n	%	n	%
Levodopa/PDI	104	54.9%	171	68.7%	126	38.2%	126	30.8%
COMT inhibitor	5	2.9%	8	3.2%	48	14.5%	85	20.8%
Dopamine agonist	53	28.6%	44	17.7%	82	24.8%	117	28.6%
MAOB inhibitor	25	12.6%	24	9.6%	48	14.5%	45	11.0%
Amantadine	0	0.0%	1	0.4%	16	4.8%	27	6.6%
Anticholinergic	1	0.6%	1	0.4%	5	1.5%	4	1.0%
Other e.g. research trial drug	1	0.6%	0	0.0%	5	1.5%	5	1.2%
Total	189	100.0%	249	100.0%	330	100.0%	409	100.0%

Table 3. New medication prescribed within the last year

Specialist review

This subsection discusses the time periods which patients with Parkinson's are seen for specialist review, including medical review and Parkinson's nurse specialist reviews.

Standard 1: Patients with Parkinson's must be reviewed at 6-12 monthly intervals (NICE: R12, R77; NSF LTC: QR2).

Time since most recent medical review

The design of the audit, with separate questions regarding medical and nurse specialist review, obscures what proportion of the remaining 11% of neurology patients and 6% of elderly care patients had truly failed the standard, or had been seen by a Parkinson's specialist nurse specialist. It does appear that most centres are achieving the standard for ongoing review in the majority of patients.

The medical review data indicates that 89% of neurology patients and 94% of elderly care patients met the standard for at least yearly review (Figure 3).

Time since most recent Parkinson's specialist nurse assessment

The PD NICE Guidelines recommend as a key priority for implementation that

people with Parkinson's should have regular access to specialist nursing care (which may be provided by a Parkinson's specialist nurse) for

- clinical monitoring and medication adjustment
- a continuing point of contact for support, including home visits, when appropriate
- a reliable source of information about clinical and social matters of concern to people with Parkinson's and their carers

79% of neurology patients and 68% elderly care patients had seen a Parkinson's specialist nurse within the last year (see Figure 4). 22% of elderly care patients were receiving no nurse specialist support due to either a lack of service (12%), or failure to refer (10%). 9% were known to a nurse specialist but without contact for more than a year. The situation was better for neurology patients but there were still 16% who either had no access to this service (9%) or who hadn't been referred (7%) and 5% with no recent review.

For further analysis, data from both the time since medical review and time since Parkinson's specialist nurse review questions were cross matched for each patient to see whether patients who had not received a medical review

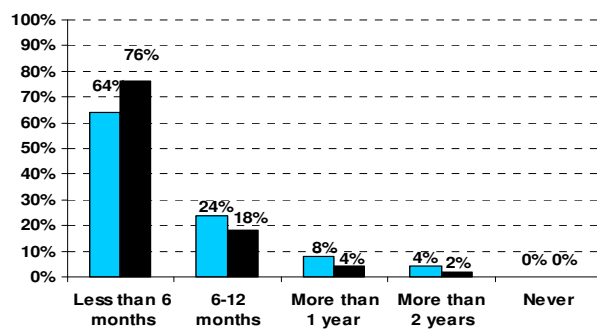


Figure 3. Time since most recent medical review

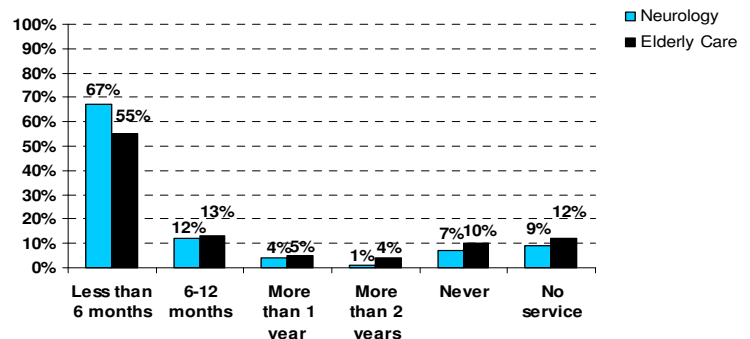


Figure 4. Time since most recent Parkinson's nurse review

for more than one year had seen a specialist nurse. This cross matching revealed that 66% of patients without a medical review for more than a year had seen a Parkinson's specialist nurse within the last six months (73% neurology patients and 58% elderly care patients respectively) and 82% without medical review for over two years (87% neurology patients and 77% elderly care patients respectively) had also had a Parkinson's specialist nurse review within the last six months.

The role of the Parkinson's specialist nurse is shown to be pivotal in the provision of ongoing review.

PM1: 100% of patients with Parkinson's attending services must be reviewed at 6-12 monthly intervals.

Diagnosis

Participating services were asked to complete a separate section, 'Diagnosis phase', for patients diagnosed within the last year. The following data relates to 271 newly diagnosed patients in neurology services and 365 newly diagnosed patients in elderly care services. It is important to highlight that many participants also provided diagnosis data for existing patients, which were omitted in the analysis.

Standard 2: People with Parkinson's should be referred quickly and untreated to a specialist with expertise in the differential diagnosis of the condition (NICE: R11).

Figure 5 shows that an average 93% of patients were referred untreated (95% in neurology and 89% in elderly care. This is an improvement from 2010

results where 86% of patients were referred untreated.

Of the 16% referred on medication, 37 were treated with levopoda, and six with a dopamine agonist. However, it is fair to highlight that more patients are referred to elderly care consultants on treatment.

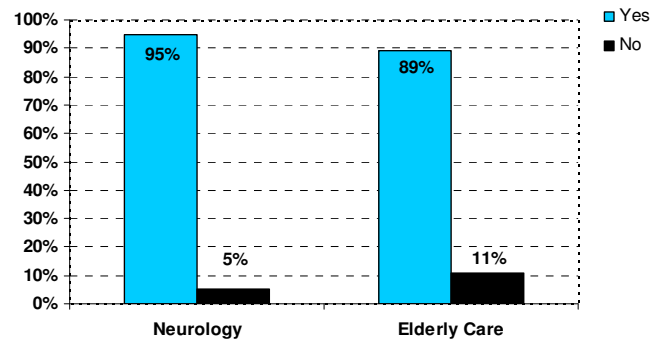
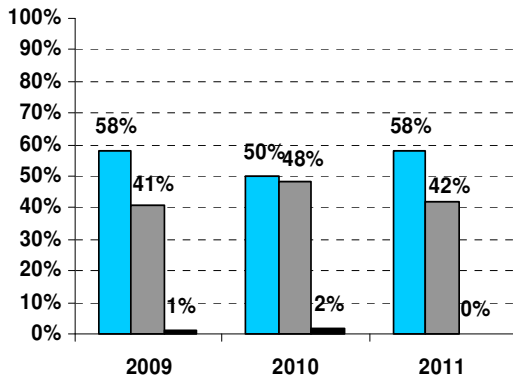


Figure 5. Newly diagnosed patients referred untreated

Standard 3: People with newly diagnosed Parkinson's should be seen within 6 weeks (NICE: R11; NSF LTN QR2.1).

69% of patients were seen within the target time of six weeks from the initial appointment. This is no change in the proportion of patients seen within six weeks, (63% in 2009 and 66% in 2010). Elderly care services have not shown any significant changes (78% in 2011 and 77% in 2010), however neurology services have improved from 50% in 2010 to 58% in 2011.

Neurology



Elderly Care

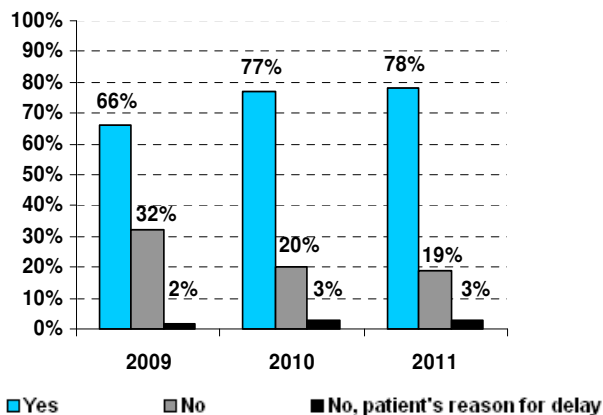


Figure 6. Newly diagnosed patients seen within six weeks

Of the 130 benchmarked healthcare services, 68 (52%) achieved 100% compliance with the six-week target for all patients. Elderly care services comply with this target slightly more than neurology (58% compared to 46% respectively).

PM2: 100% of patients with newly diagnosed Parkinson's should be seen within six weeks.

Standard 4: Patients with a new diagnosis of likely Parkinson's should be given written information regarding Parkinson's (NICE: R3; NSF LTN QR1.4).

61% of audited patients were provided with written information about Parkinson's. There is no significant change (60% in 2010, 57% in 2009). Figure 7 shows that elderly care consultants are more likely to provide written information compared to neurology consultants. A similar trend was found in the 2010 audit, where 63% of elderly care consultants provided this information and 57% for neurologists.

It is fair to highlight here that Parkinson's UK provide free, high-quality written information about the condition. Therefore, it would be beneficial for consultants to signpost newly diagnosed patients to Parkinson's UK for this information.⁹

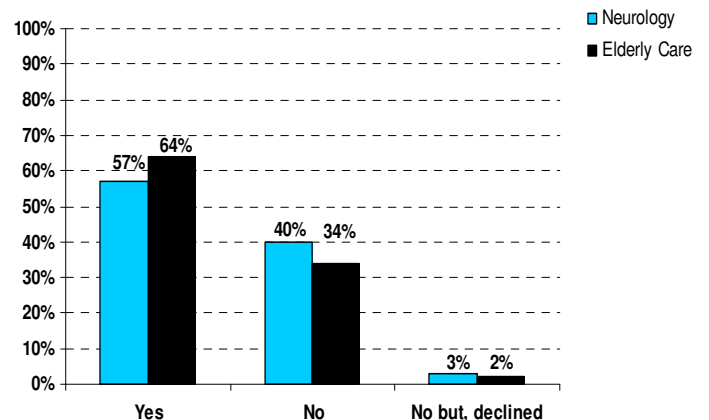


Figure 7. Newly diagnosed patients who are given written information about Parkinson's

PM3: All consultants should provide written information about Parkinson's via signposting to Parkinson's UK (website or local information and support worker).

Standard 5: Patients with a new diagnosis should be offered Parkinson's specialist nurse contact information (NICE: R6; NSF LTN QR1.2, QR2.4).

62% of newly diagnosed patients were offered Parkinson's specialist nurse contact information. There is a significant decline of 13% since 2010 (75%), across both elderly care and

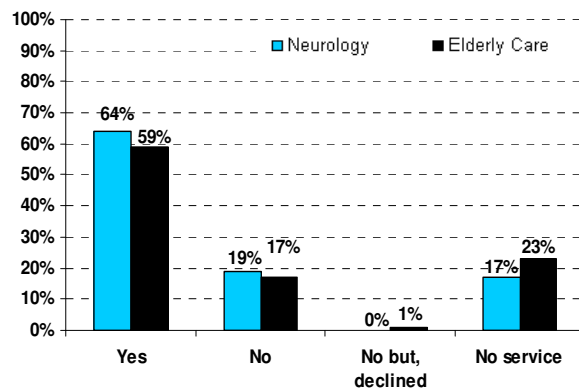


Figure 8. Newly diagnosed patients offered Parkinson's nurse contact information

neurology services.

Five services (two neurology services and three elderly care services) did not provide contact details for a Parkinson's specialist nurse to any of their patients even though they did have a Parkinson's specialist nurse service.

Only 19% of services (21% neurology services; 17% elderly care services) provided all of their patients with contact details of a Parkinson's specialist nurse.

PM4: All Parkinson's services should provide Parkinson's specialist nurse contact information to newly diagnosed patients, where there is one.

Standard 6: Driving status should be determined and patients who drive advised of need to inform DVLA and their insurance (NICE: R7).

Driving status is still poorly documented. It was recorded in only 70% of patients and only 54% of patients had DVLA/car insurance discussed. These statistics are similar to the ones reported in the 2010 audit (70% and 61% respectively), although there is a decrease in the discussion of DVLA/car insurance.

Elderly care consultants enquire about driving status slightly more than neurology services (71% to 69%) and are also now more likely to discuss DVLA/car insurance (57 % of elderly care patients were advised, improved from 34% in 2010). There is also slight improvement in neurology services discussing DVLA/car insurance from 50% in 2010 to 52% this year.

70% participating neurology services reported to have not documented the driving status and discussed DVLA/car insurance in at least one of their patients. The same applied 47% of participating elderly care services.

Although there are improvements in the reporting of this standard, there is still remaining concern in the fact that not all patients are advised on this matter.

PM5: All patients who drive should have their driving status determined and be advised about DVLA/car insurance.

Medication monitoring and information standards

This year's audit evaluated the compliance of services with the monitoring and information provision of patients on certain Parkinson's medication.

Standard 7: Clinicians should be aware of dopamine dysregulation syndrome (NICE: R74).

Participants were asked whether there was any documented evidence that patients taking dopamine agonists are monitored for impulsive and compulsive behaviour.

Impulsive and compulsive behaviour can have significant detrimental effects on a patient's life and as such it is vital that patients are monitored for the development of these and advice is provided to patients and carers on how to deal with such behaviour.

New patients

16% of new patients on dopamine agonists are not being monitored for impulsive and compulsive behaviour. Neurology services are better at documenting the monitoring of patients taking dopamine agonists for impulsive and compulsive behaviour (91%) compared to elderly care services (77%).

Existing patients

28% of existing patients on dopamine agonists are not being monitored for impulsive and compulsive behaviour.

Neurological services appear to monitor new patients taking dopamine agonists (91%) for impulsive and compulsive behaviour better than in existing patients (74%).

PM6: All patients must be advised about the risk of impulsive and compulsive behaviour when starting on a dopamine agonist and have

	New Patients				Existing Patients			
	Neurology		Elderly Care		Neurology		Elderly Care	
	n	%	n	%	n	%	n	%
Yes	107	91%	75	77%	445	74%	435	71%
No	11	9%	23	23%	155	26%	179	29%
Total	118	100%	98	100%	600	100%	614	100%

on-going monitoring.

Table 4. Monitoring for impulsive and compulsive behaviour of patients on dopamine agonists

Standard 8: People with Parkinson's who have sudden onset of sleep should be advised not to drive and to consider any occupational hazards (NICE: R72).

Participants were asked whether there was any documented evidence that patients with daytime sleepiness are advised about driving.

80% of patients with daytime sleepiness were advised about the impact (81% neurology patients and 78% elderly care patients); however there are still 20% of patients with daytime sleepiness with no documentation that driving safety has been considered (19% neurology patients and 22% elderly care patients).

New patients attending neurology services are more likely to be advised on this subject than new patients in elderly care services (85% and 73% respectively).

Standard 9: If an ergot-derived dopamine agonist is used, the patient should have a minimum of renal function tests, erythrocyte sedimentation rate (ESR) and chest radiograph performed before starting treatment, and annually thereafter (NICE: R30, R40).

102 patients were prescribed an ergot dopamine agonist, mainly as long-term therapy with only nine patients starting an ergot preparation during the year of audit. This reflects the national prescribing trend to use non-ergot dopamine agonists now they are available.

Only 60% of patients on long-term ergot dopamine agonist therapy were being monitored as per the Guidelines and the recommended baseline tests had not been done in any of the 9 patients starting treatment in the previous year. Neurologists were more likely to arrange appropriate monitoring than elderly care consultants (44% and 16% respectively).

PM7: Services using ergot-derived dopamine agonist should ensure their compliance with baseline investigation and early monitoring standards.

End of life care

This subsection analyses the end of life care standards for patients with Parkinson's.

Standard 10: End of life care requirement should be considered throughout all phases of the condition and both patient and carers should be given the opportunity to discuss end of life issues (NICE: R82, 83)

Although the NICE Guidelines for Parkinson's recommend considering end of life issues at all stages of the illness, participants were only required to enter data on patients in the palliative stage or with markers of advanced stages of the condition, such as poor swallow or dementia. Discussions in early stages of the condition are often informally and poorly documented.

81 patients (30 neurology patients and 51 elderly care patients) were described as being in the palliative stage, but the audit questions would also have been relevant for a proportion of complex phase patients.

To audit this particular standard, participants were asked the following questions:

- Is there any documented discussion regarding end of life care?
- Is there evidence the patient/carers has been offered information about, or has set up a Lasting Power of Attorney?
- Is there evidence the patient/carers has been offered information about, or has established an End of Life Care Plan?

Documentation of end of life care discussion

53% (42/79) of patients were documented to have had a discussion about end of life care. Neurology services were better at documenting this than elderly care services (64% and 47% respectively).

Information about Lasting Power of Attorney

40% (31/77) of patients were provided information about Lasting Power of Attorney. Neurology services were better at providing information about this than elderly care services (54% and 33% respectively).

Information about End of life care plan

39% (31/79) of patients were provided information about an end of life care plan. Neurology services were better at providing information about this than elderly care services (43% and 37% respectively).

Figure 9 summarises the findings reported above.

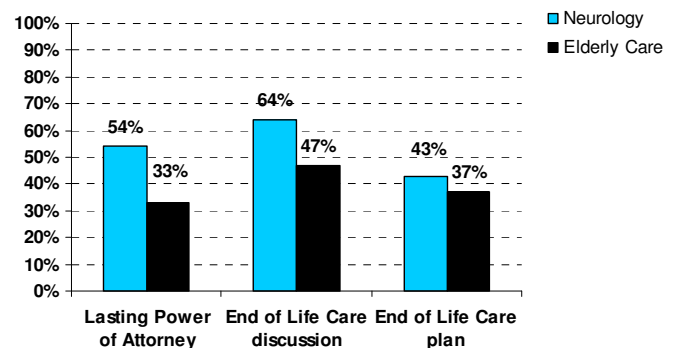


Figure 9. End of life care requirements

PM8: End of life care requirements should be encouraged throughout the stages of Parkinson's.

Domain Scores

The assessments included in the domain scores were chosen as they form the basis for achieving compliance with NICE guidelines 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

The following four domains were audited.

- Domain 1: Non-motor assessment during the previous year (12)
- Domain 2: Motor and ADL assessment during the previous year (12)
- Domain 3: Multidisciplinary involvement during the previous year (8)
- Domain 4: Communication and education during the previous year (4)

The () numbers represents the number of questions and also the highest score that can be achieved within each domain. (see Appendix C for list of questions contained within the domains)

Services were instructed to base answers on whether the problem/issue had been addressed at least once over the previous year - including the current visit "No, but.... answers" were allowed if there was a pre-determined accepted reason for non compliance

with the standard. These exceptions reflect the variable complexity of patients in differing stages of the condition.

Figures 10 to 13 represent the range of group domain scores for the individual participating services.

PM9: Participating services recording domain scores should examine their assessment (and documentation) process if they have a low amalgamated domain score and derive an appropriate action plan.

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

Figure 10 represents the average domain 1 score attained by different healthcare services.

The average domain 1 score for neurology was **8.3** and elderly care **9.5** (represented as black lines on the scatter graphs).

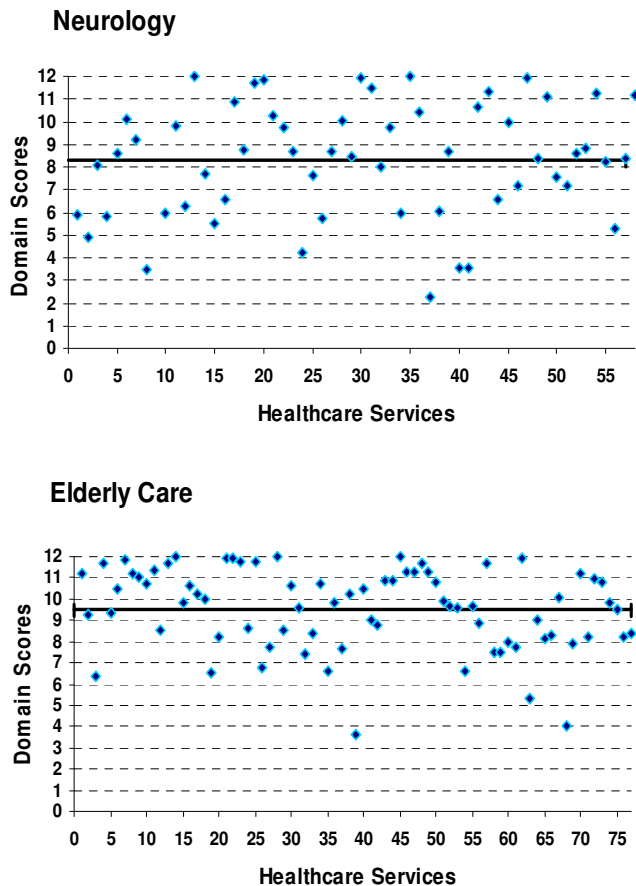


Figure 10. Scatter diagrams of domain 1 average scores

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

Figure 11 represents the average domain 2 score attained by different healthcare services.

The average domain 2 score for neurology was **8.8** and elderly care **9.7** (represented as black lines on the scatter graphs).

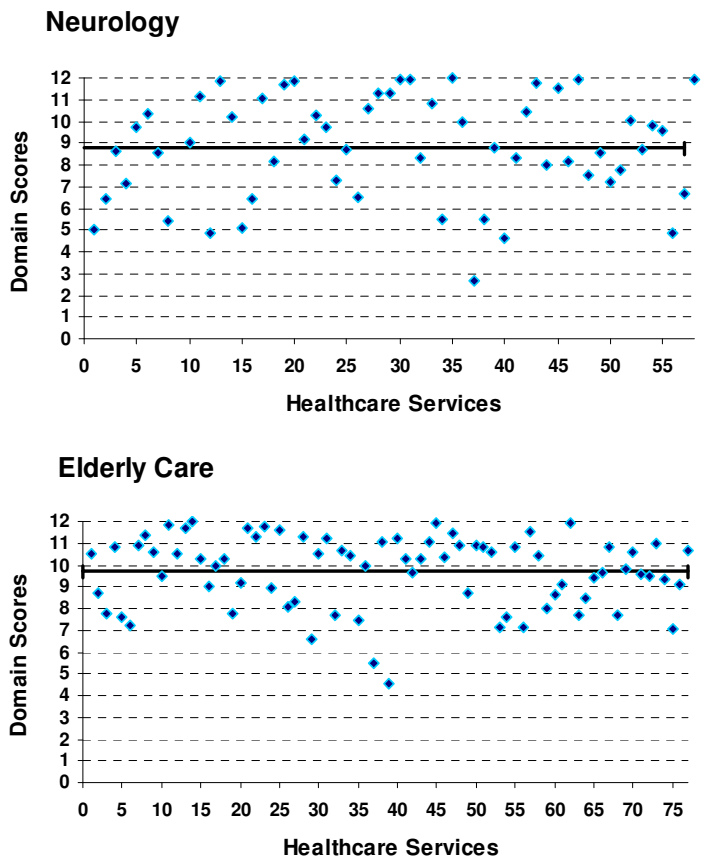
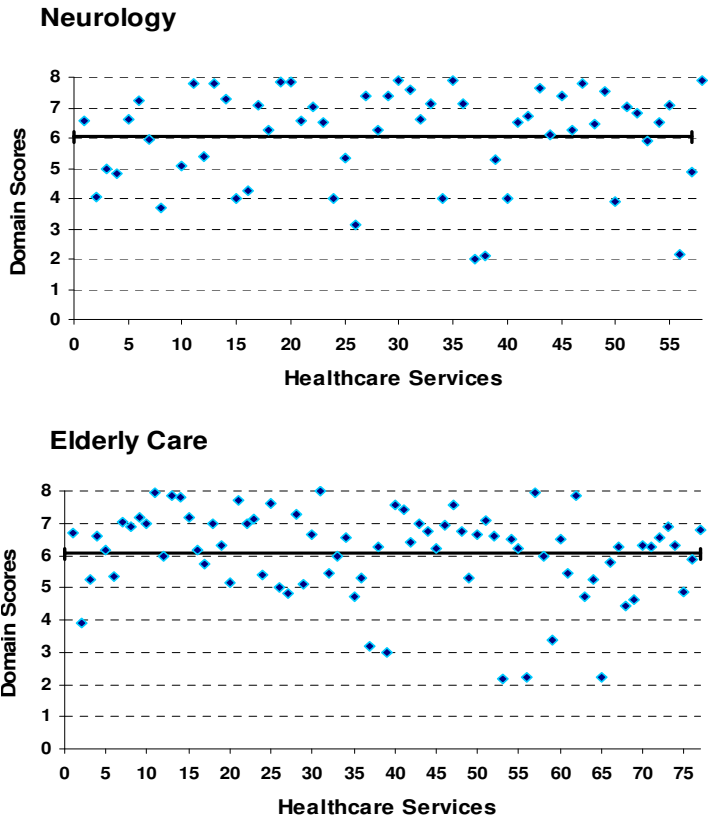


Figure 11. Scatter diagrams of domain 2 average scores

**Domain 3: Motor and ADL
assessment during the previous
year (8)**

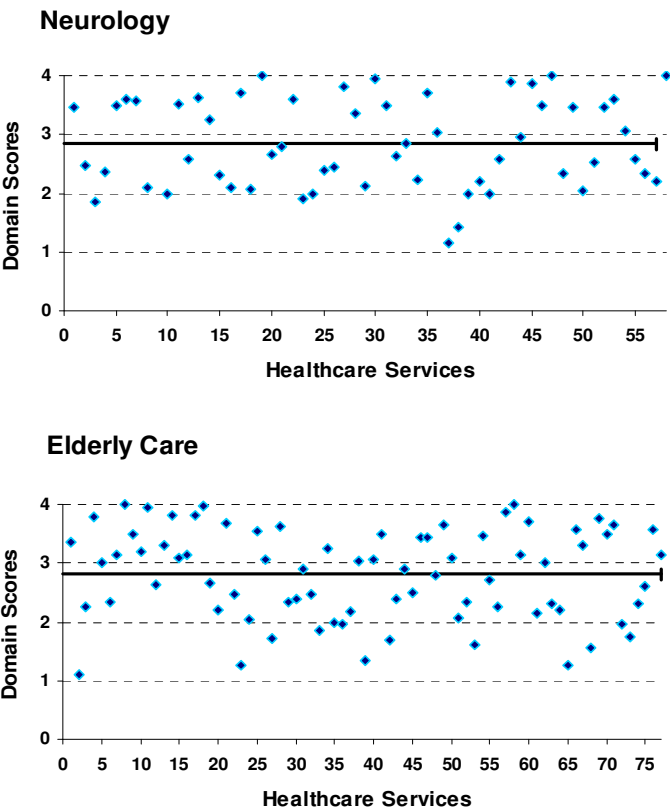
Figure 12 represents the average domain 3 score attained by different healthcare services. The average domain 3 score for neurology was **6.0** and elderly care **6.1** (represented as black lines on the scatter graphs).



**Figure 12. Scatter diagrams of
domain 3 average scores**

**Domain 4: Communication and
education during the previous year
(4)**

Figure 13 represents the average domain 4 score attained by different healthcare services. The average domain 4 score for both specialties was **2.8** (represented as black lines on the scatter graphs).



**Figure 13. Scatter diagrams of
domain 4 average scores**

Overall, for each of the four domains, neurology services presented a wider spread of scores and elderly care services presented more clustered scores. Although both specialty presented similar percentages in the number of services above and below the average domain score.

The domain scores were analysed further to see whether there was an association between model of service delivery and achieving compliance with domain standards.

Table 5 shows that services seeing more than 90% of their patients within a purely medical setting (i.e. doctor alone) (a model of service delivery more common in neurology services, see Figure 14), achieve lower scores across all domains in comparison to the overall average domain scores.

	Average scores for all services with medical alone setting	Average scores for all participating services
Domain 1	8.3	8.9
Domain 2	8.7	9.3
Domain 3	5.4	6.0
Domain 4	2.5	2.8

Table 5. Average domain scores of services with medical alone setting

Service Findings

This section of the patient management audit consists of general questions about the Parkinson's service of the participating healthcare services. It was found on the audit tool under the name 'Service description'.

Clinical consultants

Participating neurology and elderly care services were asked whether the audited patients related to a single consultant and if not how many consultants the patients related to.

34% of neurology services and 59% of elderly care services reported the audited patients to relate to a single consultant.

The average numbers of consultants that the audited patients were related to were 3.2 neurology consultants and 2.5 elderly care consultants.

Parkinson's specialist nurse provision

Participating neurology and elderly care services were asked whether there was a Parkinson's specialist nurse provision.

Two neurology services and eight elderly care services reported not have Parkinson's specialist nurse provision.

Model of service delivery

Participating services were asked in which clinic setting the majority of Parkinson's patient reviews took place in their services. The options were:

- Doctor alone
- Combined doctor/specialist nurse
- Integrated doctor/specialist nurse/therapy
- Nurse specialist alone
- Combined nurse specialist/therapy

Figure 14 represents the percentage of services seeing >90% of patients reviews in the different categories of settings.

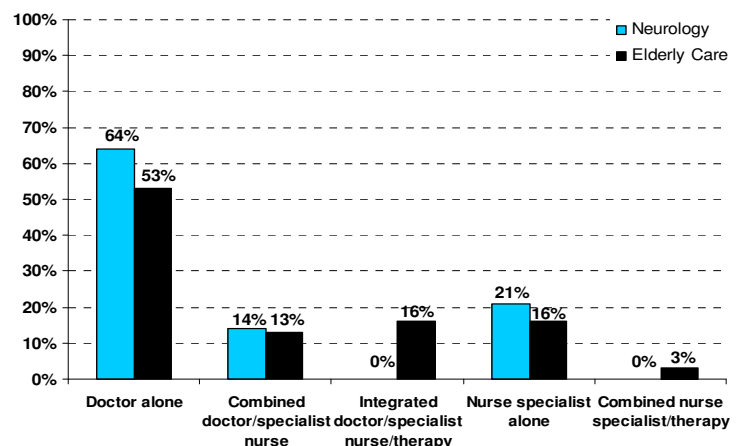


Figure 14. Model of service delivery

Neurology services are more likely to have patient reviews in a doctor alone, combined doctor/specialist nurse and nurse specialist alone settings and elderly care services are more integrated with therapy.

PM10: Integrated doctor, specialist nurse and therapy reviews should be encouraged among neurology services.

Therapy Audits

This chapter of the report reviews the results presented by the therapy audits:

- Occupational Therapy
- Physiotherapy
- Speech & Language Therapy

Each therapy audits have been analysed in two sections:

- Client/Patient findings
- Service findings
 1. Service description
 2. Clients/Patients with Parkinson's
 3. Therapy professionals
 4. Clinical practice

Occupational therapy audit

The occupational therapy audit represented 64 services across the UK, auditing a total number of 801 clients.

For the purpose of benchmarking, the analysis of this audit is based on the data submitted by 40 services and 669 participants, where anonymised information for 10 or more clients was submitted.

Client findings

This section focuses on the client (patient) findings of the occupational therapy audit.

Referrals

This section focuses on analysing the different aspects of referrals made to occupational therapy for people with Parkinson's.

Referred by

26.7% of the audited clients were referred to occupational therapy services by a Parkinson's specialist nurse and 20.5% by a geriatrician.

Of the 24.7% that answered 'Other', the majority of referrals were made by other occupational therapists and/or due to multidisciplinary team review.

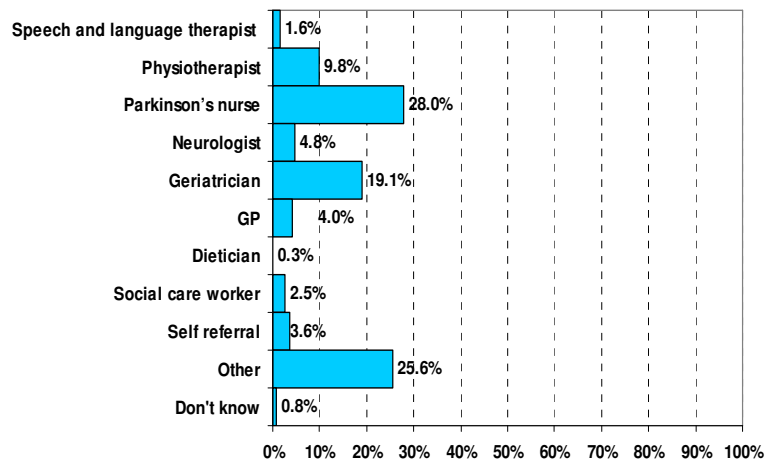


Figure 15. Referred to occupational therapy by Average time from occupational therapy referral to intervention

The average number of calendar days representing the time from referral to intervention was **25**.

The standard Referral to Treatment (RTT) time of 18 weeks (126 calendar days) requires clients to be seen within this time frame. The collection of data on RTT has been made mandatory since 1 April 2011.¹⁰

93% (37) participating occupational therapy services meet this criterion.

Two of the participating occupational therapy services were excluded from the analysis as they exceeded the

average and would have caused discrepancies in the data.

Referral made at an appropriate time

87.9% of occupational therapists thought that the client was referred at an appropriate time.

This is an interesting finding as people with Parkinson's had, on average, been diagnosed with the condition for six years before being referred to occupational therapy. This result appears to contradict Principle 1 of the NICE guidelines for occupational therapy, which states that there is a need for early intervention to establish rapport, prevent activities and roles being restricted or lost and, where needed, develop appropriate coping strategies.

This perhaps indicates a need for education among all healthcare professionals reviewing clients with Parkinson's, including occupational therapists, about the need for early occupational therapy intervention.

Standard 1: Occupational therapy should be available and considered at diagnosis and during each regular reviews for people with Parkinson's. (NICE: R12, R80)

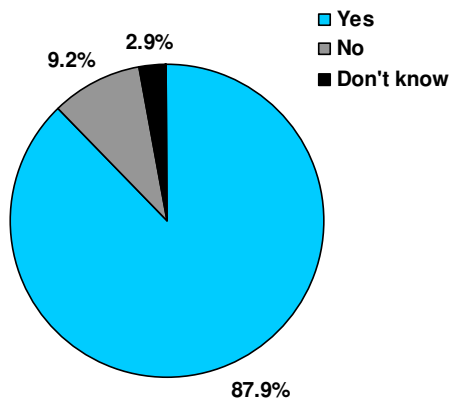


Figure 16. Referral to occupational therapy at an appropriate time

Regular reviews are often recommended for monitoring of medication and to determine whether other health professionals such as occupational therapists are needed.

61% of referrals were triggered as a result of medical review. It is encouraging that many referrals to occupational therapy are resulting from a medical review. This highlights collaboration between multidisciplinary teams. Approximately one third of referrals are being received at times other than during medical review. This result does not seem too surprising, as a person with Parkinson's may experience problems with occupational performance at any time and these times may not correlate with reviews.

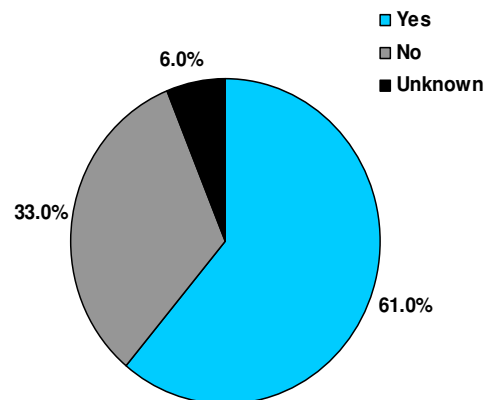


Figure 17. Referral to occupational therapy triggered by medical review

Standard 2: Occupational therapists reviewing people with Parkinson's should give particular consideration to (NICE R80):

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

Over a quarter (26.5%) of clients was referred for the improvement and maintenance of transfers and mobility. The next most frequent reasons for referral were (in order) improvement of personal self care activities (17.9%) and environmental issues to improve safety and motor function (14.9%).

There were very few referrals for maintenance of work roles (0.9%), despite this being a key part of the occupational therapy role. This could be due to the average age at which a person is referred to occupational therapy (74.8 years). There were also relatively few referrals for maintenance of family roles (3.0%) leisure activities (3.9%) and mental wellbeing (7.2%).

While it may be the case that fewer people with Parkinson's experienced problems in these areas, it may nevertheless be useful to promote these aspects of the occupational therapy role among health and social care professionals.

OT1: Promote less well-known aspects of the occupational therapy

role amongst health professionals working with people with Parkinson's, in particular, mental wellbeing, and management of fatigue and continued participation in leisure activities, maintenance of family roles and maintenance of work.

Standard 3: There is timely integrated assessment involving all relevant health agencies leading to individual care plans, which ensure that staffs have access to all relevant records and background information about the person's condition, test results and previous consultations. (NSF QR1)

71.9% of participating occupational therapists stated that most of the information was available and 19.1% of participating occupational therapists stated that some of the information was available. 9.1% of referrals for which the occupational therapists answered "No" to the question, also stated which information was missing.

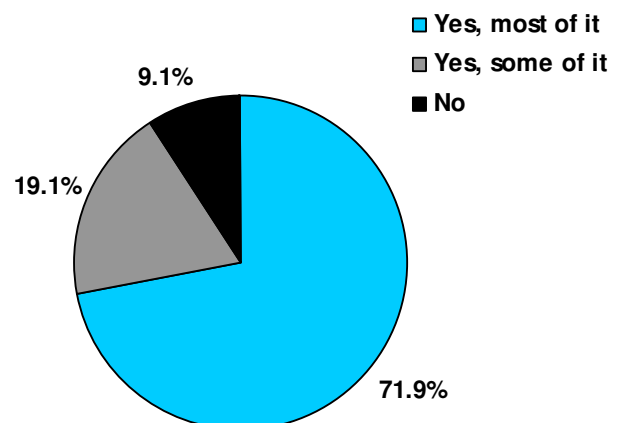


Figure 18. Essential information available for occupational therapy

The majority of the information that the occupational therapists identified to be missing was:

- details of the client's history of Parkinson's
- previous medical history
- reason for referral

Most referrals contained the necessary information required by occupational therapists. But it would be useful to highlight the importance of the above details to referrers, as a reason for referral is a key aspect of the treatment strategies and interventions to be used for the client.

PDR1: All information about the person with Parkinson's should be available at any referral. This includes details of Parkinson's history, previous medical history and reason for referral.

Goals identified

This subsection analyses the identification of areas of interventions required for the client, collaboratively by the occupational therapist, client and carer(s).

Standard 4: People with Parkinson's should have a comprehensive care plan agreed between the individual, their family and/or carers and specialist and secondary healthcare providers (NICE R5)

Principle 3: Development of goals in collaboration with the individual and carer with regular review

Participants were asked which goals amenable to occupational therapy intervention were identified and by whom. The goals have been split into three categories:

- optimising activities
- supporting participation
- end of life care

The figures (19-21) are based on percentages, rather than total numbers of goals identified within each of the three categories. For example, far more goals were identified for 'optimising activities' than for 'end of life care'. This is because 'optimising activities' includes thirteen possible categories, while end of life care contains just three, so the percentages for 'optimising activities' are lower overall. An analysis into the goals identified within each section will be discussed.

Optimising Activities

Within 'optimising activities', the most common goals identified were transfers, mobility, falls prevention, bed mobility and self care routines. These are core areas of intervention for

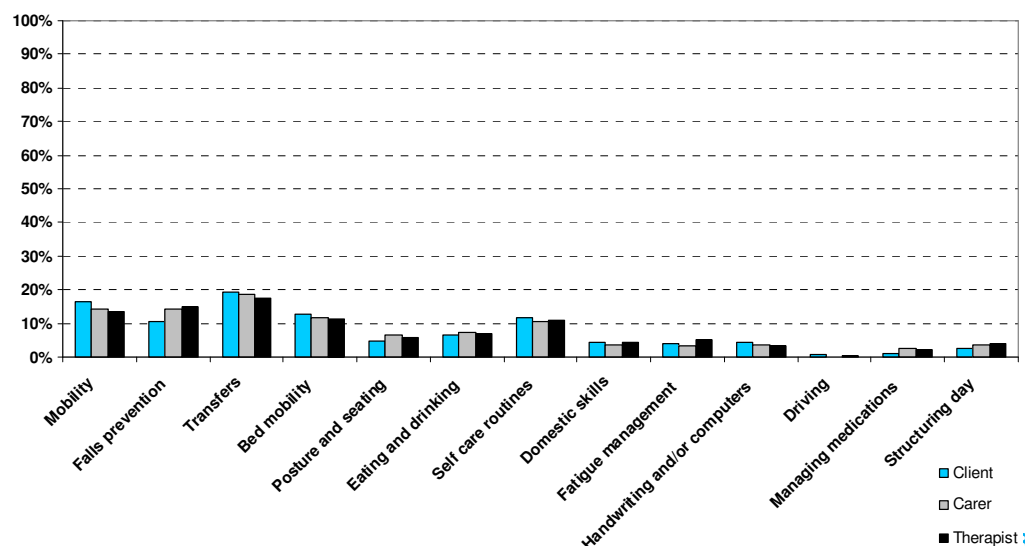


Figure 19. Goals identified for optimising activities by client, carer and therapist

occupational therapists. The fact that they were identified by clients and carers, as well as therapists, indicates the importance of these functional activities for people with Parkinson's.

These results generally indicate collaborative working between the person with Parkinson's, his/her carer and the occupational therapist. For example, all goals identified by the client were also generally identified as being of importance by the carer and the occupational therapist. Although there was some variation in who identified which goals, this variance was never greater than 4%. For example, 'falls prevention' was identified as being important by 11% of clients, 14% of carers and 15% of occupational therapists. This represented the greatest variance in results and may indicate the different perceptions of the relative importance of these problems between the patient and the carer/therapist.

Supporting participation

Maintaining a sense of control was the most important aspect of enabling participation, with importance also attached to social, recreational and leisure activities and community living skills and outdoor mobility. Occupational therapists are able to offer skills in these areas, as well as in more functional activities, and it is good to see that these skills are being offered and utilised. Again, there was some variation in who identified which goals (i.e. client, carer and/or therapist); in this instance the variance was between 1% and 6%.

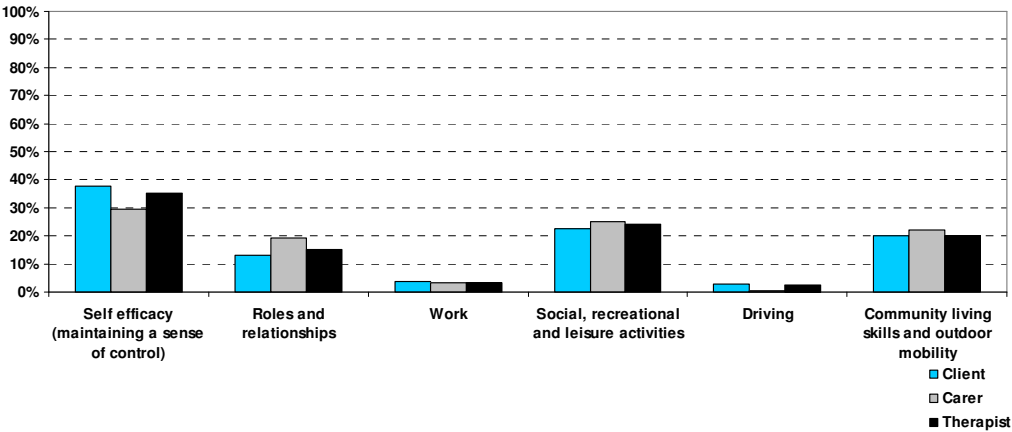


Figure 20. Goals identified for supporting participation activities by client, carer and therapist

End of life care

For clients where end of life care was appropriate, the three goals of optimising posture, positioning and pressure care, safe manual handling and alternative living arrangements were roughly of equal importance. Within this pattern, there was one area of variance. 'Manual handling and minimising risk' was identified by 52% of therapists, compared with 34% of clients and carers, a variation of 18%.

Occupational therapists are trained to identify and manage risks, so potential risks would possibly be easier for them to identify than for each individual person with Parkinson's and his/her carer. This may account for the variation within this category.

Treatment strategies and techniques

Based on the OT, NSF - LTNC and NICE guidelines, seven areas of treatment strategies and techniques were found. This sub section discusses each of the seven areas and the techniques used for the audited clients. The percentage in brackets () represents the percentage of audited occupational therapy services who used the particular treatment techniques/strategies.

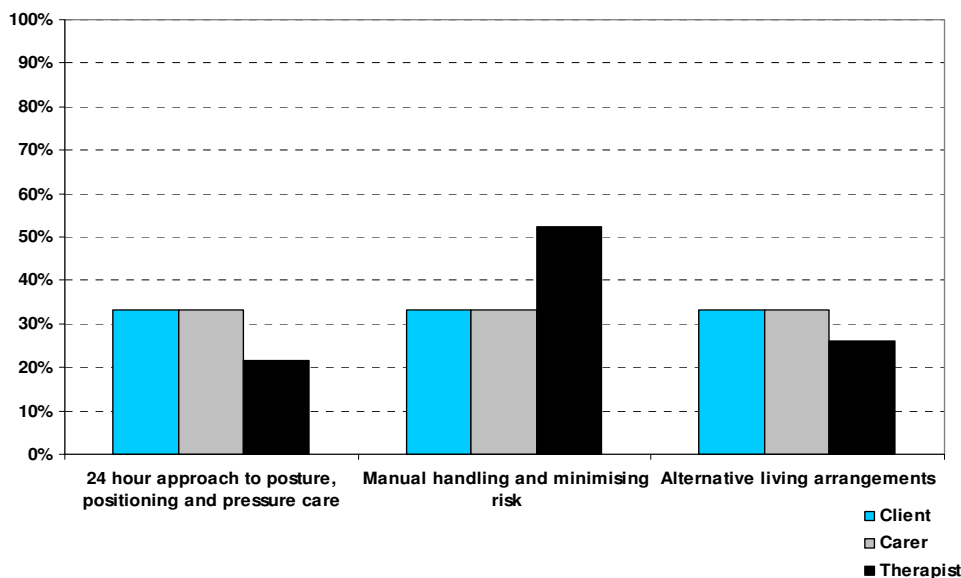


Figure 21. Goals identified for end of life care by client, carer and therapist

Initiating and maintaining movement (95%)

Figure 22 represents the treatment strategies and techniques used for initiating and maintaining movement.

Within 'initiating and maintaining movement', the most common strategy used was coordinating activities with the timing of medication (30.8%), and the least common was use of extrinsic cueing techniques such as stepping over a line on the floor or using a metronome (16.1%). It is not clear from the results whether this was because extrinsic cueing techniques were not appropriate for the client, or whether occupational therapists are less aware of this technique. This question will be addressed in future audits.

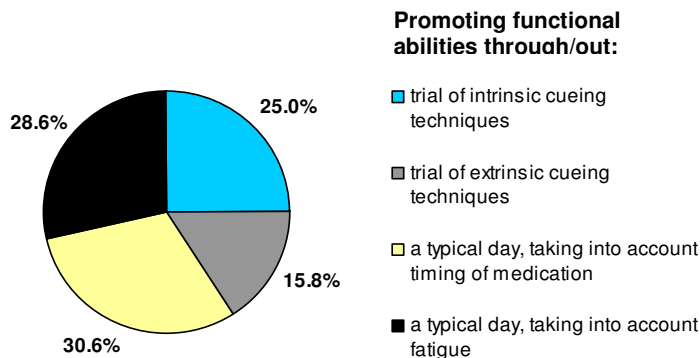


Figure 22. Treatment strategies and techniques for initiating and maintaining movement

Engagement, motivation, learning and carryover (98%)

There is roughly a 60:40 split between promoting mental well being and promoting new learning. It is difficult to comment further as the proportion of clients for whom such techniques were appropriate is not known.

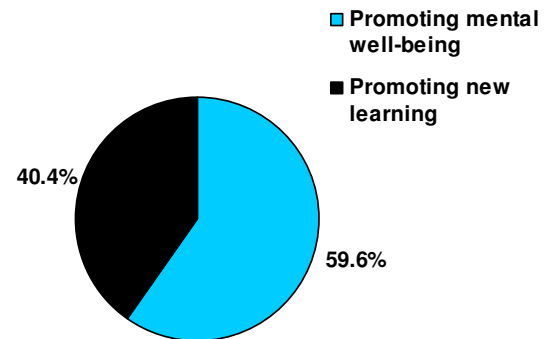


Figure 23. Treatment strategies and techniques for engagement, motivation, learning and carryover

Environmental adaptations/assistive technology (100%)

Figure 24 indicates the importance of small aids and adaptations which can be invaluable in promoting independence, as well as more complex assistive technology. A significant proportion of clients required major adaptations to their houses. The true extent of this need is likely to be greater, given that this sample did not include occupational therapists working in social service departments. This group of occupational therapists carry out many of the assessments and recommendations for major adaptations.

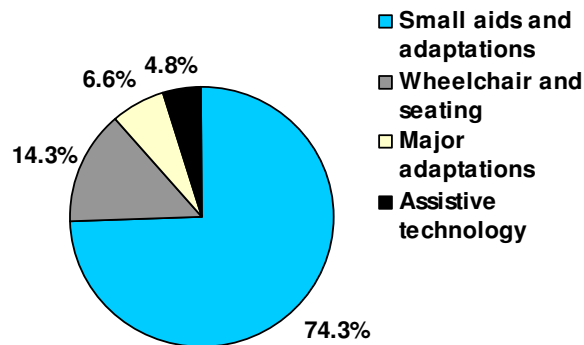


Figure 24. Treatment strategies and techniques for environmental adaptations/assistive technologies

Ensuring community rehabilitation and social support (97%)

The greatest percentage of referrals were made to other allied health professionals and the least were to access to work, perhaps reflecting the average age of clients with Parkinson's in this audit.

A significant proportion of referrals were made to voluntary services (12%), reflecting current trends in service provision. In future audits, it will be useful to see which voluntary services are being used, and also, what 'other' services are being accessed.

Figure 25 indicates that 37.1% of referrals are made to social services/workers, this further drives the need to promote the audit among occupational therapists working in social services (reflecting on recommendation OT1).

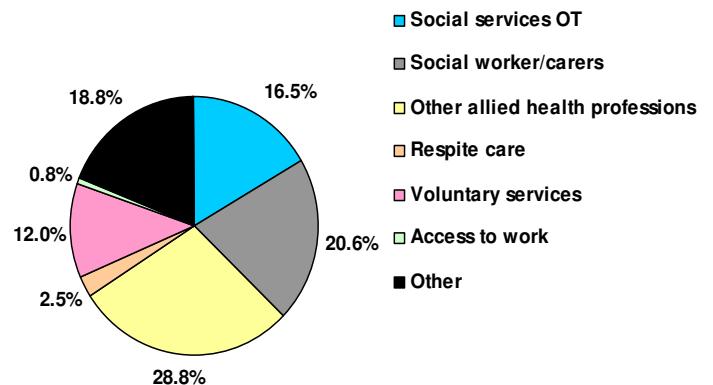


Figure 25. Treatment strategies and techniques for ensuring community rehabilitation and social

Providing information to increase client's knowledge (97%)

Most information was provided on specific techniques for activities of daily living (44.4%), while least was provided on work advice and resources (3.0%). This could well reflect the average age of clients in this audit. A significant percentage of clients received information on fatigue management (25.1%), suggesting that this is an important issue for many people with Parkinson's and a useful part of the occupational therapist's role.

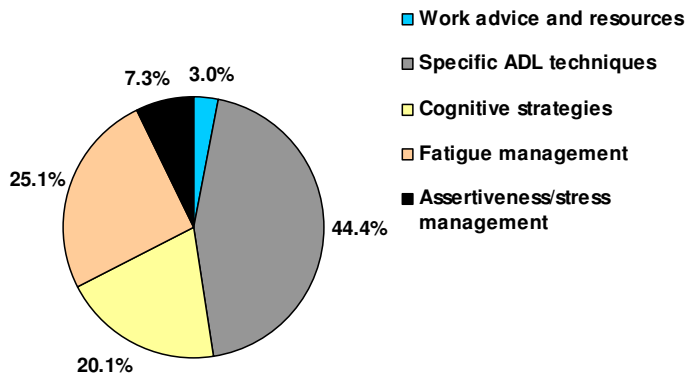


Figure 26. Treatment strategies and techniques for providing information to increase client's knowledge

Providing information and support for family and carers (97%)

Within this category, most strategies were related to optimising function (36.7%) and the least were related to managing changes in mood, cognition or behaviour (11.0%). This could well reflect the incidence of need among clients and carers. Not every person with Parkinson's will have difficulties with mood, cognition and/or behaviour, but many will need to address functional problems.

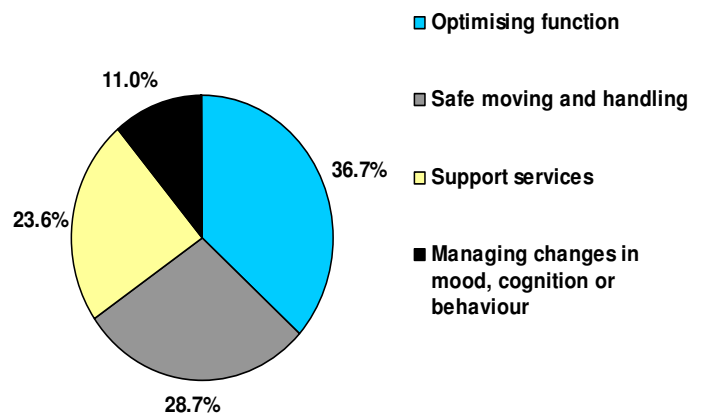


Figure 27. Treatment strategies and techniques for providing information and support for family and carers

Providing support to facilitate change in attitude (100%)

Most techniques used by occupational therapists to facilitate change in attitude were either to increase confidence (35.3%) or to develop self awareness or adjustment to limitations (34.4%). This result is to be expected. Much of an occupational therapists role is to adapt activities so that they are manageable for the person. Part of this will involve identifying any limitations, and part will involve increasing familiarity and confidence with the best methods of carrying out those activities.

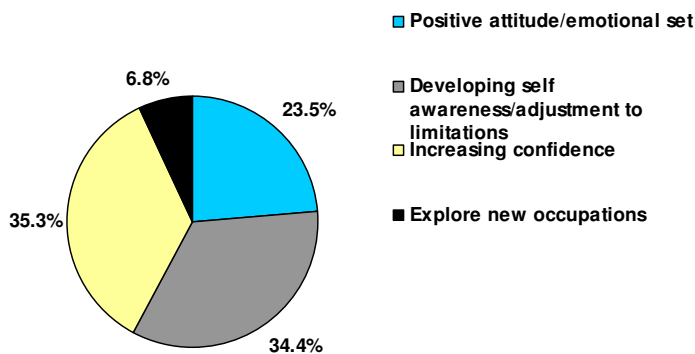


Figure 28. Treatment strategies and techniques for providing support to facilitate change in attitude

Service findings

This section of the occupational therapy audit consists of general questions about the Parkinson's service of the participating healthcare services.

Service description

Participants were asked to describe the setting in which they work in. Figure 29 represents the options given for the work settings.

Most occupational therapists who completed the audit (57.5%) were based in the community, with an equal number (12.5%) being based either within an in-patient acute service or an outpatient clinic. Of the 17.5% of the services who answered 'Other', were specialised outpatient services in acute trusts. No occupational therapists working for social services departments were represented in the 2011 audit.

OT2: There is a need to promote the audit among occupational therapists working in social service services.

Participating services were also asked whether they specialised in the treatment of neurological conditions and also whether they specialised in the treatment of clients with Parkinson's.

56% (22 services) of participating healthcare services specialised in the treatment of clients with neurological conditions and 54% (21 services) specialised in the treatment of clients with Parkinson's.

Out of the 22 services that specialised in the treatment of clients with neurological conditions, six of these services did not specialise in the treatment of Parkinson's.

Parkinson's is one of the most prevalent neurological conditions in the UK, affecting 127000 people in the UK.^{1,11} Therefore specialist neurological services should be able to provide specialised interventions.

PDR2: All healthcare professionals working for services specialising in neurological conditions should be educated/attend appropriate training in the management of Parkinson's

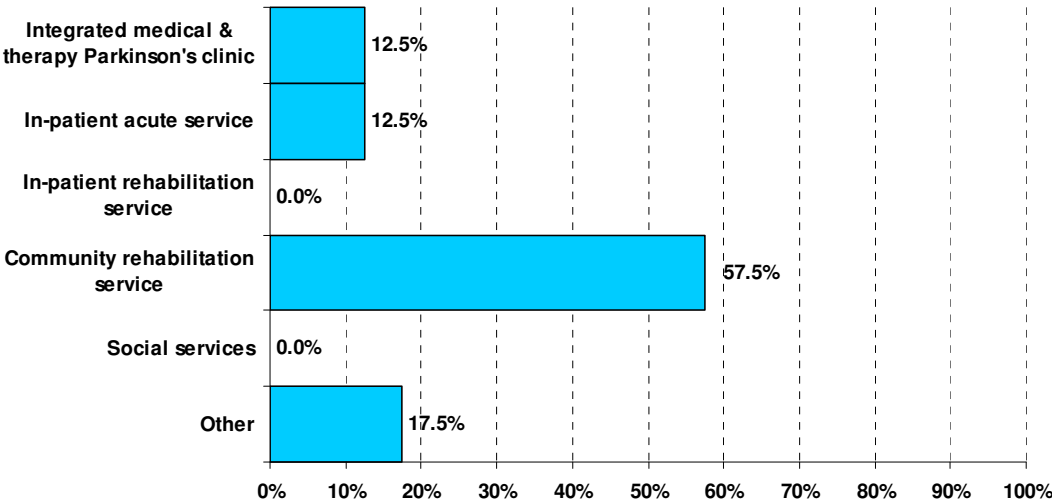


Figure 29. Work settings of occupational therapists

Clients with Parkinson's

This subsection discusses questions related to clients with Parkinson's in participating occupational therapy services.

Percentage of clients with Parkinson's reviewed by occupational therapists

Participating healthcare services were asked 'approximately what percentages of clients that you see have a diagnosis of Parkinson's'. Figure 30 represents the findings of this question. Only 15% (6 services) of the participating 40 healthcare services see around 80-100% of clients with Parkinson's.

40% (16 services) of the healthcare services see between 0 and 19% of clients with Parkinson's.

Figure 30 shows that the proportion of clients with Parkinson's seen by occupational therapy services is low, as a proportion of all the clients they see.

This is also evidenced in the comparison of the specialisation of the participating services (neurological conditions or treatment of clients with Parkinson's), in the previous subsection, and the percentage of Parkinson's clients, these services review.

Of the 22 services which specialised in neurological conditions, 35% saw between 20-39% of clients with Parkinson's, similarly of the 21 services that specialised in the treatment of Parkinson's, 42% saw between 20-39% of clients with Parkinson's.

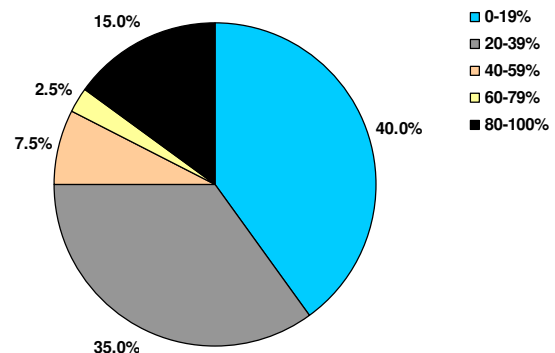


Figure 30. Percentage of clients with Parkinson's reviewed by occupational therapists

Method of review of clients with Parkinson's

Participating occupational therapy services were asked how they usually see people with Parkinson's (Figure 31).

While the majority of clients were seen individually, significant proportions (32.5%) were seen both individually and in a group. Occupational therapists are trained to use group work skills. Some clients may find participation in groups beneficial and this can also be a cost effective/efficient way of addressing clients' needs. It would be useful in future audits to identify the types of problems being addressed in group situations.

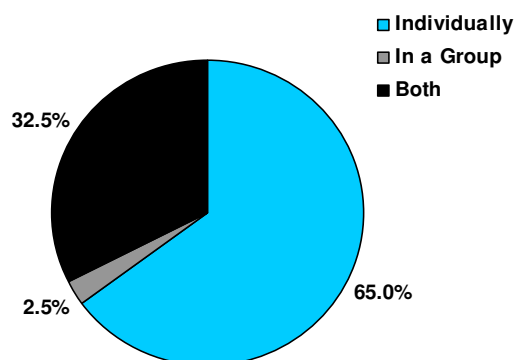


Figure 31. Method of review of clients with Parkinson's in occupational therapy

OT3: Explore the use of group work with clients with Parkinson's.

Assessment of clients with Parkinson's

Figure 32 represents the type of assessments individually carried out in participating occupational therapy services for the assessment of a client with Parkinson's.

It is evident that multidisciplinary team assessments are popular, with 88% of participating occupational therapy services providing these assessments approaches. The participating services that answered 'Other' (3%) specified the assessments to be in education groups and functional assessments.

Further analysis showed that 55% of services provide all three (single occupational therapy, multidisciplinary team and interview with patient and carer) types of assessments when consulting with a patient with Parkinson's. 10% of services used the combined approach of multidisciplinary assessment and interview with patient and carer.

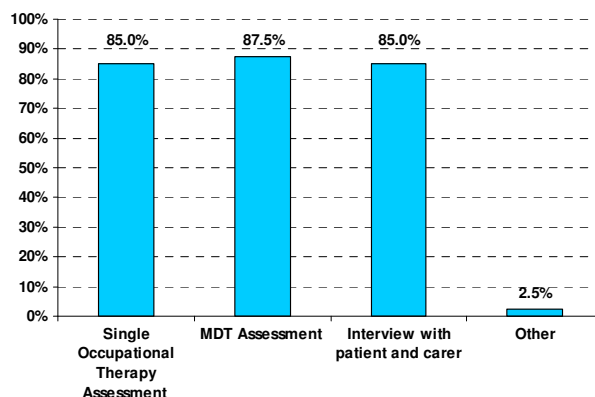


Figure 32. Type of assessment for clients with Parkinson's in occupational therapy

This result is to be expected, as most occupational therapists would need to conduct their own assessment as well as contribute to the multidisciplinary assessment.

Occupational therapy Professionals

This subsection discusses the expertise and continuing development of occupational therapists within the participating services.

NHS pay band and continuing professional development (CPD)

The NHS pay band of the occupational therapists that took part in this audit ranged between Grade 5 and 8a (Table 6). This shows that the occupational therapists seeing clients with

NHS pay Band	No. of healthcare services	
	n	%
5	1	2.5%
6	14	35.0%
7	23	57.5%
8a	2	5.0%
Total	40	100.0%

Table 6. NHS pay band of occupational therapists

Parkinson's are often specialist or advanced occupational therapists.¹²

Participating occupational therapy professionals were also asked whether they have access to Parkinson's related continuing professional development, at least yearly. 72.5% (29 services) of participants had access to continuing professional development related to Parkinson's and 27.5% (11 services) did not.

Out of the 10 services that did not have access to continuing professional development, six of these services specialised in the treatment of clients with Parkinson's.

Due to the changing and complex nature of the condition, there is a need for professionals specialising in the treatment of Parkinson's to be provided with continuing professional education about Parkinson's.

This links closely with PDR2 (see Recommendations section).

Clinical practice

This subsection discusses the guidelines and assessments used in occupational therapy to influence clinical practice and intervention.

Standardised assessments

Participants were asked which standardised assessment tools they used, based on recommendations made in the Occupational Therapy Best Practice Guidelines. These are summarised in Figure 33, although some use was made of recommended assessments, 68% of the services use 'Other' assessments. Those frequently specified were:

- Unified Parkinson's Disease Rating Scale (UPDRS)
- Model Of Human Occupation Screening Tool (MOHOST)
- Non-motor Questionnaire

28% did not use any formalised standardised assessments at all.

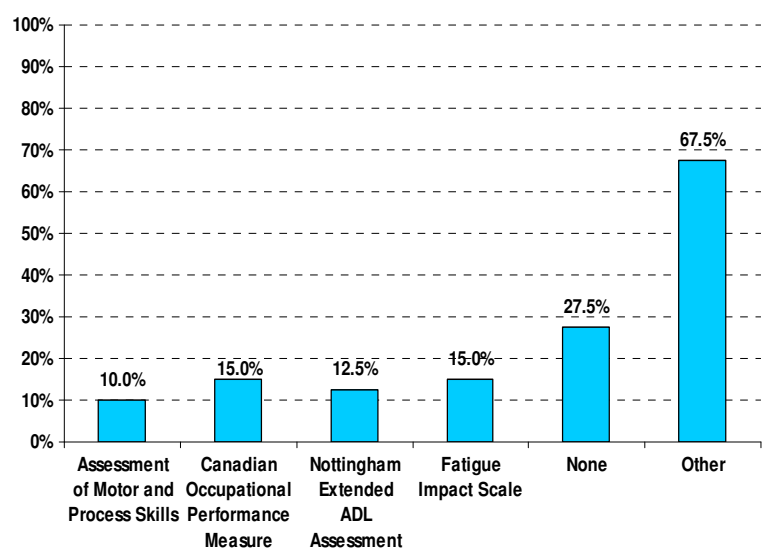


Figure 33. Standardised assessments used in occupational therapy

The findings indicate that use of assessments recommended in the guidelines is low, and it would be useful to explore the reasons for this. One factor could be that the assessment used is not considered to be appropriate for the clients needs. For example, the Fatigue Impact Scale would only be appropriate to use for a person experiencing fatigue. The use of 'Other' standardised assessments is relatively high (68%). It would be useful to determine whether these assessments should be recommended for people with Parkinson's more formally, for example, in future practice guidelines.

OT4: Encourage the use of standardised assessments, as recommended in the Occupational Therapy Best Practice guidelines and explore other standardised assessments which could also be recommended.

Guidance on clinical practice

Participating services were asked what was used to inform clinical practice and guide intervention and this is represented in Figure 34.

Most participants based their interventions on a combination of clinical experience (100%), advice and published guidelines. It is good to find that 95% of participants were using the Occupational Therapy Best Practice Guidelines, which are themselves based on the NICE Guidelines for Parkinson's and the National Service Framework for Long Term Neurological Conditions. This is particularly encouraging, given that a high proportion of services did not specialise in the treatment of clients with Parkinson's.

When analysing combined choices of interventions for participating services, 45% of services used all seven options.

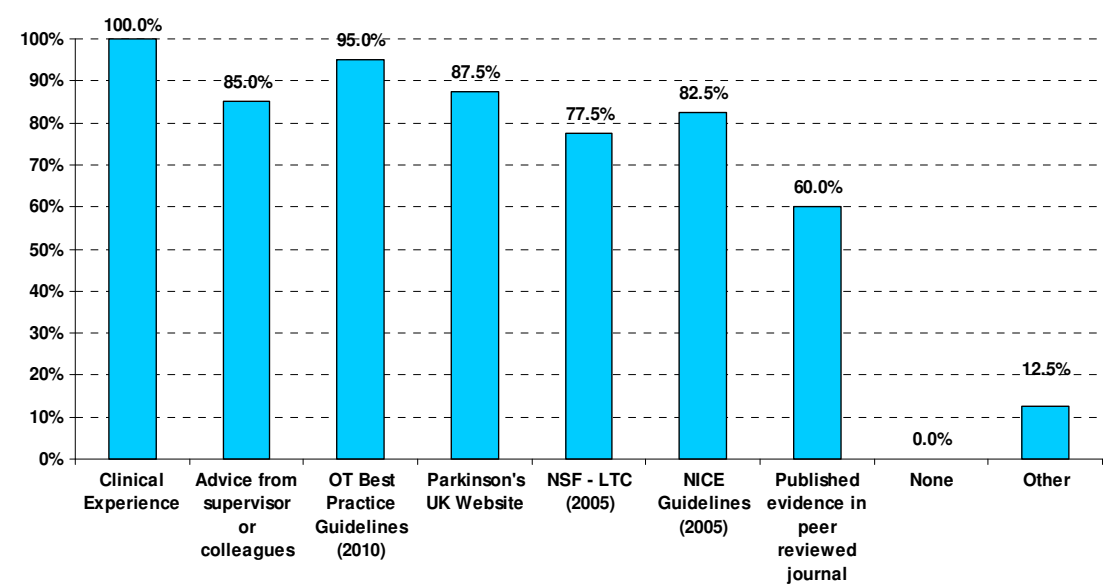


Figure 34. Clinical guidance in occupational therapy

Physiotherapy audit

The physiotherapy audit represented 65 services across the UK, auditing a total number of 1278 patients.

For the purpose of benchmarking, the analysis of this audit is based on the data submitted by 57 services and 1232 patients, where anonymised information for 10 or more patients was submitted.

Patient findings

This section focuses on reviewing the patient findings of the physiotherapy audit.

Referrals

This subsection will focus on analysing the referrals made to physiotherapy for patients with Parkinson's.

Reason for referral

Standard 1: Physiotherapists reviewing people with Parkinson's should give particular consideration to (NICE: R78):

- **gait re-education, improvement of balance and flexibility**
- **enhancement of aerobic capacity**
- **improvement of movement initiation**
- **improvement of functional independence, including mobility and activities of daily living**
- **provision of advice regarding safety in the home environment**

Figure 35 represents the reasons for physiotherapy referrals for 1,175 of the audited patients, based on individual reasoning. 54% of patients were given two or more reasons for referrals. Gait re-education, improvement of balance and flexibility (61%) and improvement of functional independence (44%) are the main reason for referral to physiotherapy services of people with Parkinson's.

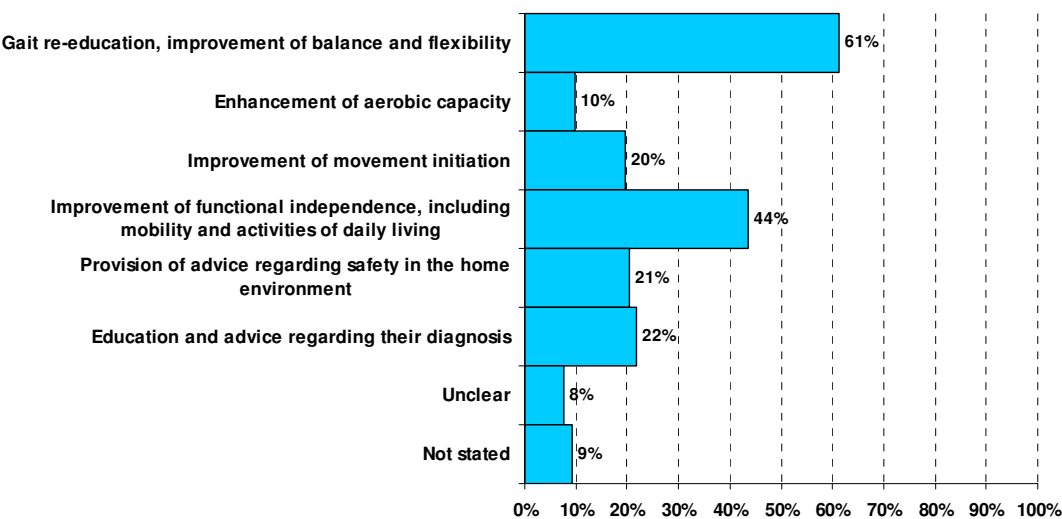


Figure 35. Reasons for referral to physiotherapy

Average time from Parkinson's diagnosis to first referral to physiotherapy

The average number of years representing the time from the patient's Parkinson's diagnosis to their first referral to physiotherapy services was **3.5 years**. The range lies between 0 and 10.8 years.

The findings above suggest that although early intervention of physiotherapy is recommended most people with Parkinson's are only referred to physiotherapy services in the 'mid phase' of the condition.

Average time from physiotherapy referral to initial assessment

The average number of calendar days representing the time from referral to intervention was **38.8 calendar days**.

The standard Referral To Treatment (RTT) time of 18 weeks (126 calendar days) as mandated by the Department of Health requires patients to be seen within this time frame. The collection of data on RTT has been made mandatory since 1 April 2011.¹⁰

91% (52 services) of the participating physiotherapy services met this criterion.

Three of the participating physiotherapy services were excluded from the analysis of the average duration as they greatly exceeded the recommended RTT (552,273 and 148 calendar days) and their inclusion would have caused discrepancies in the data.

Referrals urgent or routine

Participating physiotherapy services were asked whether the referrals were

urgent or routine. 92% of the referrals were routine and 6% urgent.

The physiotherapy services were then asked whether the referrals met local standards for time from referral to initial assessment for urgent or routine referrals. Only 88% answered 'Yes' and 12% 'No'.

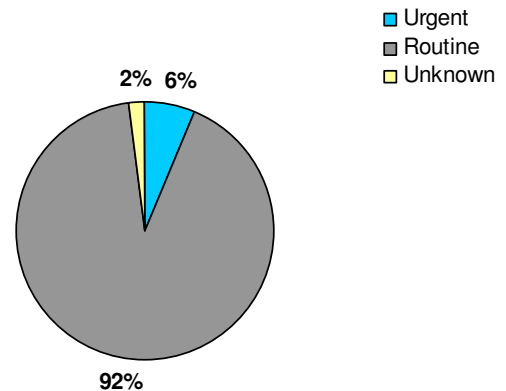


Figure 36. Urgent or routine referrals in physiotherapy

PDR3: All referrals must meet local standards for time from referral to initial assessments.

Previous physiotherapies

Participating physiotherapy services were asked whether their patients had received previous physiotherapies.

Figure 37 demonstrates that 50% of patients had received previous physiotherapies.

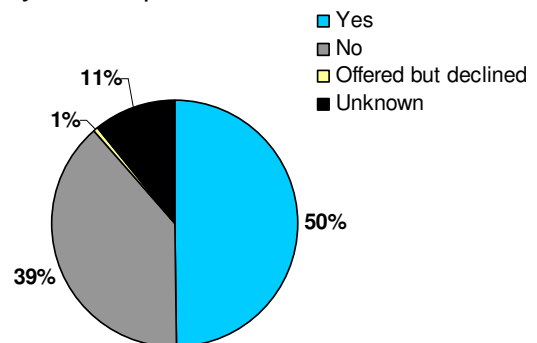


Figure 37. Previous physiotherapists

Initial assessments

This subsection assesses the initial assessments and outcome measures carried out by physiotherapists in the care of patients with Parkinson's.

Identification of intervention in initial assessment

Participating physiotherapists were asked whether the notes identified the area(s) of anticipated intervention in the initial assessment. 97% of patients' notes recorded this information and 3% did not.

Patients' notes which recorded the areas of anticipated intervention were asked to specify the intervention used. This was to see whether the reason for referral matched with the anticipated intervention.

Out of the 1232 audited patients, 93% (1,144 patients) had both a reason for referral combined with a specified intervention specified in the patients' notes.

Further analysis found that 96% of patients received the correct anticipated intervention related to their initial reason for referral.

Treatment strategies and techniques

The physiotherapists were also asked whether the initial notes recorded treatment strategies and techniques to be used for interventions. 94% of patients' notes recorded this information.

Patients' notes which recorded treatment strategies were asked to specify the intervention used (Table 7).

Treatment and strategies		
Treatments	n	%
Gait	514	37%
Balance	217	16%
Flexibility	30	2%
Aerobic capacity	43	3%
Improving functional independence	32	2%
Advice about safety at home	8	1%
General Advice	115	8%
Education	140	10%
Exercises	290	21%
Total	1389	100%
Strategies	n	%
Cueing	70	16%
Transfers inc. bed mobility	113	25%
Posture	268	59%
Total	451	100%

Table7. Treatment strategies and techniques used in physiotherapy

1,840 sets of data were returned where the vast majority listed more than one technique and strategy for intervention.

Balance and falls are most frequently documented as areas of intervention followed by, in terms of most documented, gait, posture and transfers.

Exercise was the most frequent mode for delivering physiotherapy, which including group sessions. Education and advice on Parkinson's was planned for 255 patients. 12 patients' notes documented interventions that are not directly physiotherapy related (e.g. speech and language therapy).

Outcome measures

This subsection discusses the use of outcome measures in physiotherapy assessments.

Participating physiotherapists were asked whether the assessments used specific outcome measures. Only 77% of patients' notes recorded this information and 23% did not.

Outcome Measures		
	n	%
10-minute timed walk	149	14%
180° turn	97	9%
360° turn	25	2%
4 Score Balance	52	5%
6m timed walk	97	9%
Berg Balance	172	16%
EQ5D	36	3%
Lindop Scale	98	9%
Tragus to Wall	76	7%
Timed Up And Go	152	15%
Timed Unsupported Stand	50	5%
UPDRS	39	4%
Total	1043	100%

Table 8. Outcomes measures used in physiotherapy

Patient's notes that recorded assessments using outcome measures were asked to specify the intervention used.

Table 8 shows that Berg Balance and 10-minute timed walk were the most commonly recorded outcome measures for people with Parkinson's. When reporting on the Lindop Scale as an outcome measure, it included some of the listed outcomes measures such as timed up and go, timed unsupported stand and 180° turn.

However, it is also necessary to highlight that many physiotherapies recorded treatment strategies, not standard outcome measures or physiotherapy- related intervention measure (e.g. cognitive assessments) in this question, instead of outcome measures, which reduced the total number of outcome measures used.

PT1: All physiotherapists should be educated on the differences between treatment strategies and outcome measures.

Service findings

This section of the physiotherapy audit consists of general questions about the Parkinson's service of the participating healthcare services.

Service description

Participating physiotherapists were asked where they usually see patients with Parkinson's (Figure 38).

Physiotherapists most often see patients with Parkinson's through community rehabilitation services (48%, 27 services) and in 'Other' settings (39%, 22 services).

On being asked to specify the 'Other' settings, the majority of participants answered 'Day hospital' and 'Outpatients'.

75% (41 services) of participating healthcare services specialised in the treatment of patients with neurological conditions and 63% (34 services) specialised in the treatment of patients with Parkinson's.

Out of the 41 services that specialised in the treatment of patients with neurological conditions, 11 reported that they did not specialise in the treatment of Parkinson's.

14 services reported that they did not specialise in the treatment of patients with neurological conditions, yet, paradoxically five of these services reported that they specialised in the treatment of Parkinson's.

It should be highlighted that Parkinson's is one of the most prevalent neurological conditions in the UK (Ref National Audit Office, Dec 2011), specialist neurological services should be at least aware of its treatment.

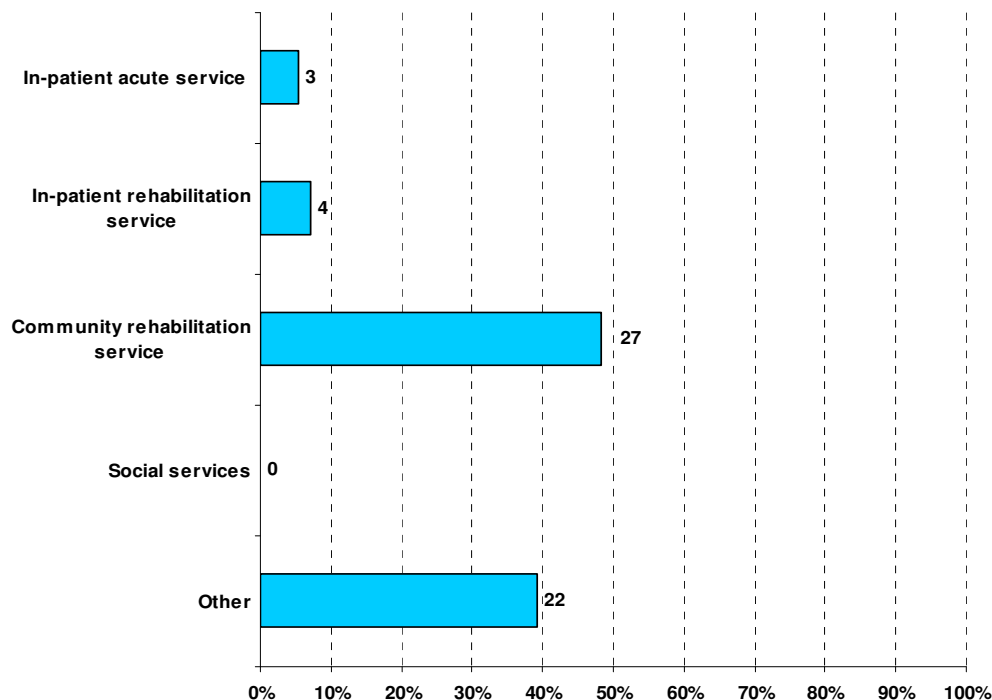


Figure 38. Work settings for physiotherapists

PDR2: All healthcare professionals working for services specialising in neurological conditions and/or in the treatment of Parkinson's should be educated/attend appropriate and regular training in the management of Parkinson's.

Patients with Parkinson's

This subsection discusses questions related to patients with Parkinson's in participating physiotherapy services.

Percentage of patients with Parkinson's reviewed by physiotherapists

Participating physiotherapy services were asked to provide the percentage of patients with Parkinson's they see (Figure 39).

Participants were provided with the options stated on the legend of Figure 39 and the percentages around the pie chart represent the percentage of services that chose a particular option.

The highest proportion of people with Parkinson's seen by the audited physiotherapy services spans a figure between 20 and 39%.

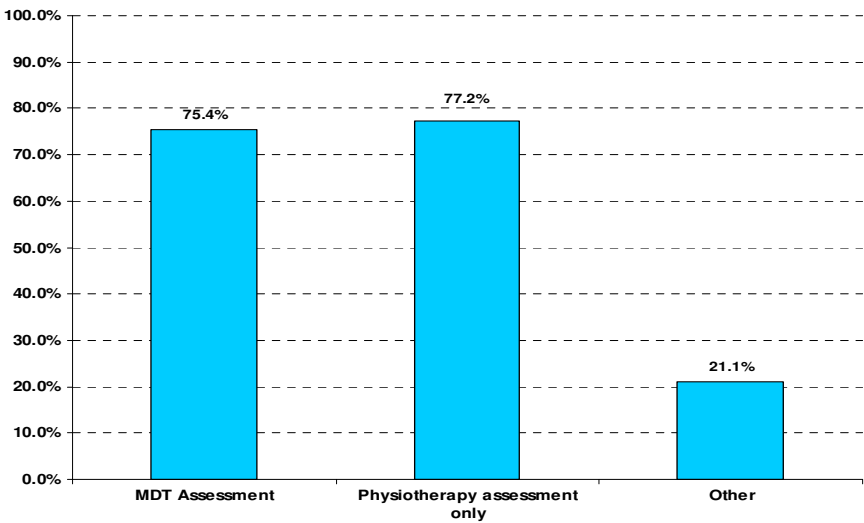


Figure 40. Method of review of patients with Parkinson's in physiotherapy

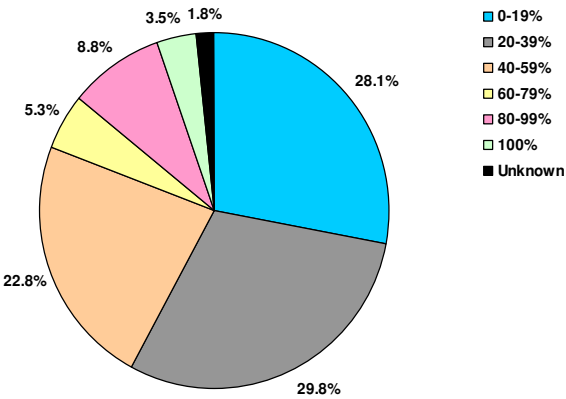


Figure 39. Percentage of patients with Parkinson's reviewed by physiotherapists

12.3% (7 services) of the participating 57 healthcare services see around 80-100% of patients with Parkinson's.

Services where less than 19% of their patients are patients with Parkinson's make up 28.1% (16 services) of the healthcare services see between 0 and 19% of patients with Parkinson's.

Figure 39 illustrates the lower proportion of patients with Parkinson's seen by physiotherapy services.

Method of review of patients with Parkinson's

Participating physiotherapists were also asked how their services offered assessment to people with Parkinson's (Figure 40).

Figure 40 shows that most physiotherapy services carry out physiotherapy assessment only or multidisciplinary assessment (44 services and 43 services respectively). Of the services that reported to use 'Other' assessments, the majority specified to use the following types of assessments:

- joint assessment/visit with occupational therapy
- therapy review list

Physiotherapy professionals

This subsection discusses the expertise and continuing development of physiotherapists within the participating services.

NHS pay band and continuing professional development (CPD)

The NHS pay band of the physiotherapists that took part in this audit ranged between Grade 5 and 8a (Table 9). These are often specialist or advanced physiotherapists.¹²

NHS pay band	No. of healthcare services	
	n	%
5	3	5.4%
6	26	46.4%
7	25	44.6%
8a	2	3.6%
Total	56	100.0%

Table 9. NHS pay band of physiotherapists

Participating physiotherapists were asked whether they attended training in the management of people with Parkinson's (Figure 41).

While 100% of participating physiotherapists do attend training specific to Parkinson's, only 39% (22 services) of them attend on a regular basis.

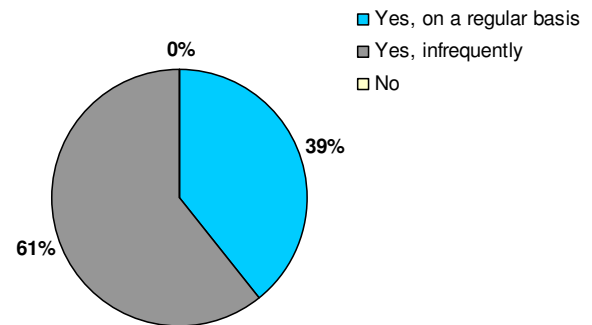


Figure 41. Training in the management of patients with Parkinson's in physiotherapy

The recommendation PDR2 links closely with this question.

Clinical practice

This subsection discusses the guidance documents used in physiotherapy to influence clinical practice.

Participating physiotherapists were asked which of the following guidance documents and advisory sources were used to inform clinical practice (Figure 42).

The results indicate that clinical experience (100%) and advice from colleagues or supervisors (88%) are most commonly used to inform clinical practice.

In relation to the guidance documents, it is evident that the NICE Guidelines for Parkinson's (84%) is used the most, followed by UK Quick Reference Cards (72%) and the recommendations from the Dutch Guidelines (63%) and NSF guidelines (61%).

11% of participating physiotherapists used a combination of all known guidance documents.
It is appropriate to highlight here that although approximately three quarters of physiotherapists reported they were aware of UK Quick Reference Cards, they were not used by 26% of them.

PT2: All physiotherapists should uptake the use of the UK Quick Reference Cards. This can be done through the provision of training and courses to encourage implementation.

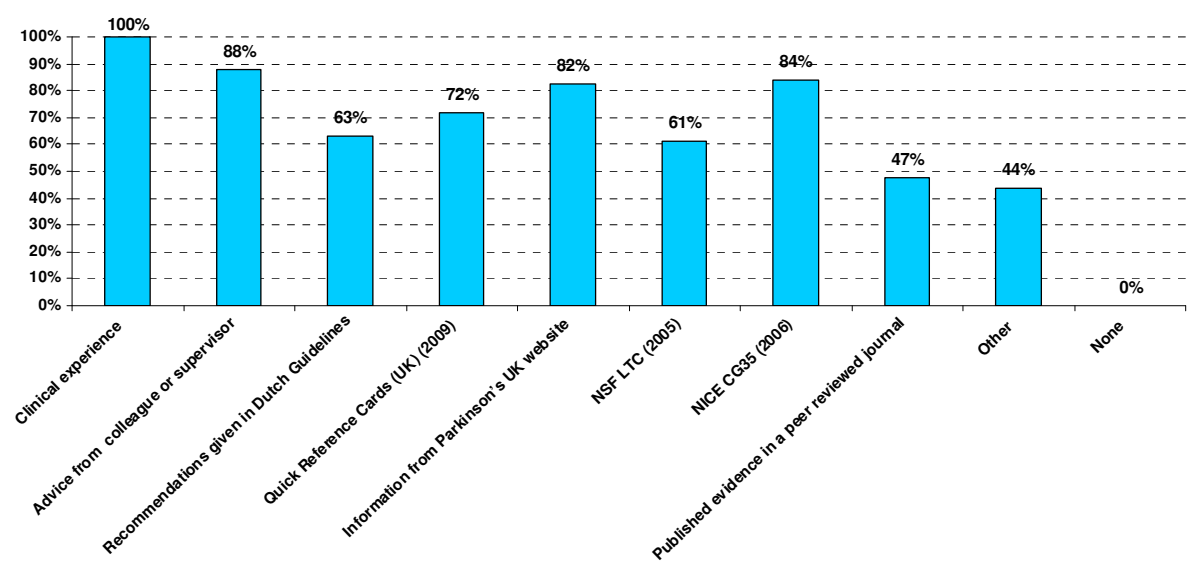


Figure 42. Guidance documents used to inform clinical practice in physiotherapy

Speech and language therapy audit

The speech and language therapy audit represented 44 services across the UK, auditing a total number of 635 patients.

For the purpose of benchmarking, the analysis of this audit is based on the data submitted by 34 services and 579 patients, where anonymised information for 10 or more patients was submitted.

Patient findings

This section focuses on reviewing the patient findings of the speech and language therapy audit.

Referral

This section analyses the different aspects of referrals made to speech and language therapy for people with Parkinson's.

Phase of Parkinson's at initial speech and language therapy referral

Participating speech and language therapists were asked at which stage of Parkinson's each of their audited patients were at, at the first speech and language therapy referral. Four phases were identified, as described below:

- **Diagnosis:** Initial Parkinson's signs and symptoms are present but the diagnosis may not have been confirmed, or accepted by the individual.
- **Maintenance:** The person with Parkinson's has an established diagnosis and is reconciled to this diagnosis. They may not have started medication or are on a

simple drug regime. There is absence of postural instability.

- **Complex:** The person with Parkinson's is receiving an increasingly complex regimen of Parkinson's drugs (at least two drugs) which may have a reduced effect on symptoms and an increasing spectrum of side-effects. Cognitive issues are common, with dementia and psychosis management also a potential issue.
- **Palliative:** The person with Parkinson's is increasingly disabled by the condition's progression, with likely advanced co-morbidity. Parkinson's drugs may have been withdrawn in order to reduce side-effects, particularly confusion.

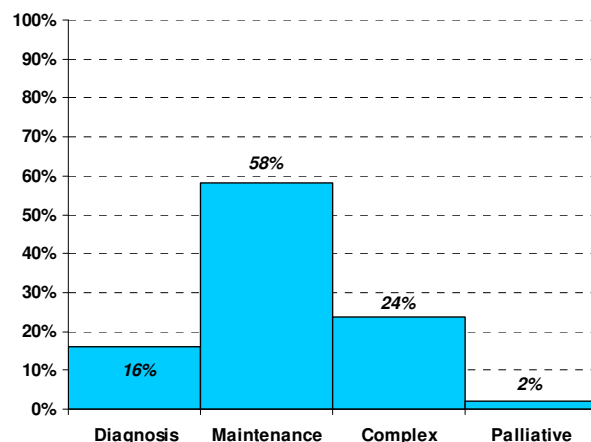


Figure 43. Phase of Parkinson's at initial speech and language therapy referral

Figure 43 indicates that most of the audited patients were referred to a speech and language therapy service during the maintenance phase (58%) and at the complex (24%) phase.

This would suggest that preventive work and education about communication/ swallowing changes, even if the changes are not yet prominent, is not a routine aspect of work in participating services. It is

unclear whether this relates to later referral from feeder services or whether it relates to restrictions within the SLT provision itself.

Source of initial speech and language therapy referral

Participating speech and language therapists highlighted that the source of the initial speech and language therapy referral for the audited patients was as a result of a medical/nurse specialist review appointment (87%) or initial medical appointment (13%).

These further highlights that people with Parkinson’s are often referred to speech and language services at a later stage of their condition.

Reason of initial speech and language therapy referral

Participating speech and language therapists were asked for the original reason of the initial speech and language therapy referral for the audited patients.

Figure 44 shows that the majority of referrals (66%) are made for specific assessment opinion about breathing, voice, speech etc, rather than treatment.

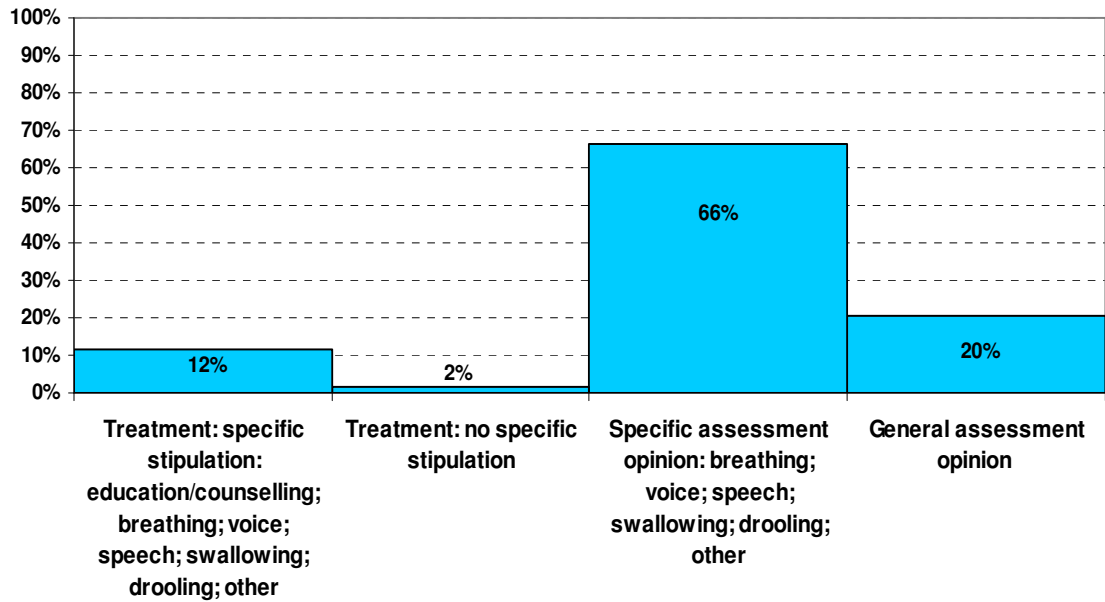


Figure 44. Reason for initial speech and language therapy referral

Referred by

Participating speech and language therapists were asked who referred the audited patients to their services (Figure 45).

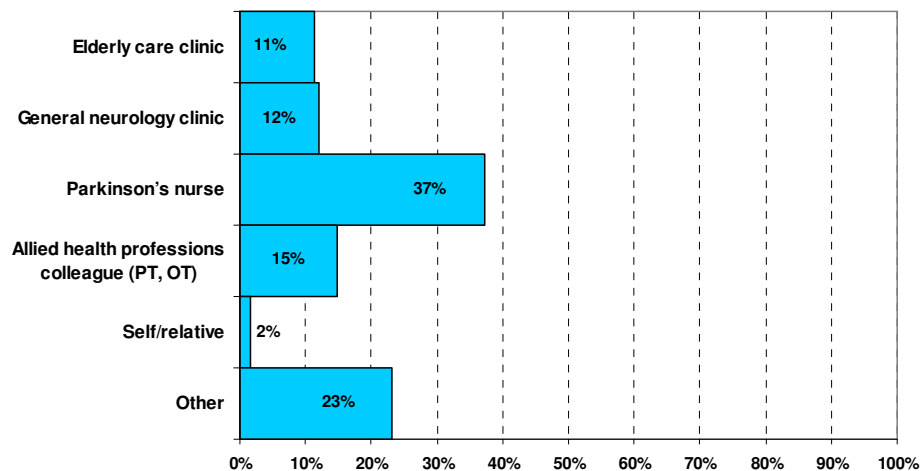


Figure 45. Referred to speech and language therapy by

37% of the audited patients were referred to speech and language therapy services by a Parkinson's specialist nurse and 15% by an elderly care consultant.

Of the 23% that answered 'Other', the majority of referrals were made by other speech and language therapists and/or came from multidisciplinary team review.

Average time from Parkinson's diagnosis to first speech and language therapy referral

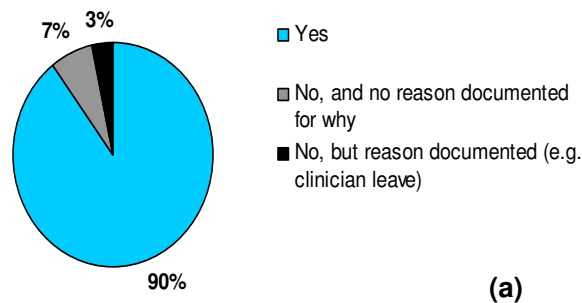
The average time from the Parkinson's diagnosis to the first speech and language therapy referral of the audited patients was **4.9 years**, which strongly supports the interpretation that the lack of early phase input is because people are not referred then.

Target times met

Figure 46 represent whether target times were met for (a) referral to first speech and language therapy appointment and for (b) speech and language therapist intention to treat decision to first appointment. 20 speech and language services met target time for referral to first speech and language appointment in all their patients, and 14 services recorded at least one 'No, no reason documented for why'.

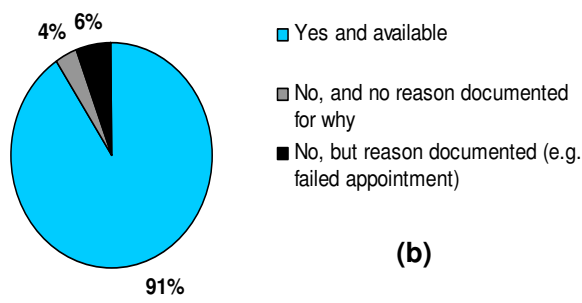
26 speech and language therapy services met target time for speech and language therapist intention to treat decision to first appointment and eight services recorded at least one 'No, no reason documented for why'.

Referral to first SLT appointment



(a)

SLT intention to treat decision to first appointment



(b)

Figure 46. Target times for (a) first appointment and (b) first treatment appointment

Assessments

This subsection reviews assessments used by speech and language therapists.

Full assessment at first referral and each review

Figures 47 and 48 show that communication assessments are carried out more often than swallowing assessments.

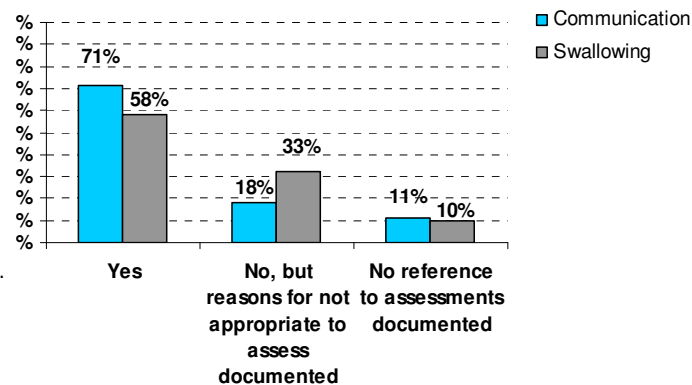


Figure 47. Full communication and swallowing assessments carried out at initial review in speech and language therapy

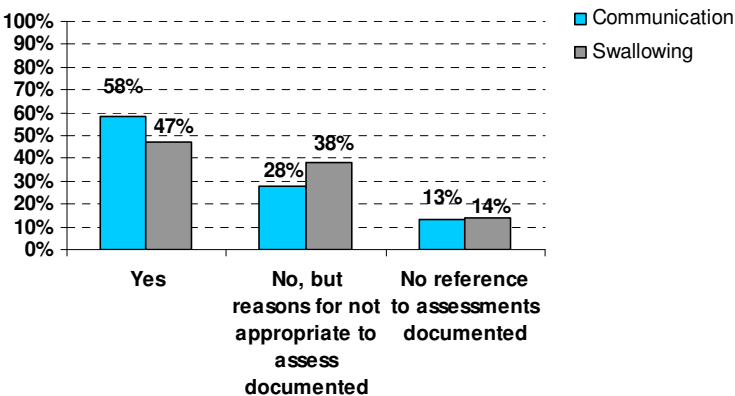


Figure 48. Full communication and swallowing assessments carried out at each review in speech and language

This is due to swallowing assessments being not appropriate to be assessed, for example, reasons for not appropriate to assess are documented in approximately 18% of patients seen for communication assessments and 33% of patients seen for swallowing assessments at initial assessment.

Standard 1: It is recommended to make audio or video recordings of spontaneous speech (Dutch Guidelines: R9a).

84% of speech and language therapy patients did not have an audio recording made at the initial or any other follow up referrals and 15% did have an audio recording.

SLT1: There should be at least one audio recording made throughout a person with Parkinson's journey with the speech and language therapy team.

Augmentative and alternative communication (AAC) needs

Participants were asked whether AAC needs were addressed. It found that these needs were not addressed in 89% of speech and language therapy patients. 6% of patients had AAC needs fully addressed and 3% was restricted due to limited availability.

Standard 2: It recommended that the speech and language therapist expressly takes note of the individual's 'on/off' periods during treatment (Dutch Guidelines: R6, R19b).

Only 15% of patients (n=569) notes highlighted the 'on/off' states/periods of the patients during assessments.

SLT2: All assessments notes should record whether patients with Parkinson's are assessed during an on/off period.

Standard 3: Patients with Parkinson's, their carers and relatives should be provided with the information and should have the opportunity to make informed decisions about their care and treatment (NICE: R1-5, NSF: Q1).

Participating speech and language therapists were asked whether:

- results and rationale for resulting actions (e.g. review period; intervention plans) conveyed and explained to patients and carers?
- information supplied to make informed decisions about care and treatment?

87% of speech and language therapists documented those explanations of causal/maintaining factors were conveyed to patients and carers, similarly 89% of patients were documented to have been given education and advice on self management.

Assessments of speech subsystems and communication

Standard 4: A perceptual assessment should be made, including respiration, phonation, resonance, articulation, prosody and intelligibility, to acquire an accurate profile for analysis (RCSLT Clinical Guidelines).

Participating speech and language therapists were asked the following questions for each audited patient:

- What tasks/contexts did assessment cover?
- Which voice respiration parameters were assessed?
- Which prosody parameters were assessed?

Figure 49 to 51 represent the findings from the above questions.

It is evident that assessments mainly cover loudness.

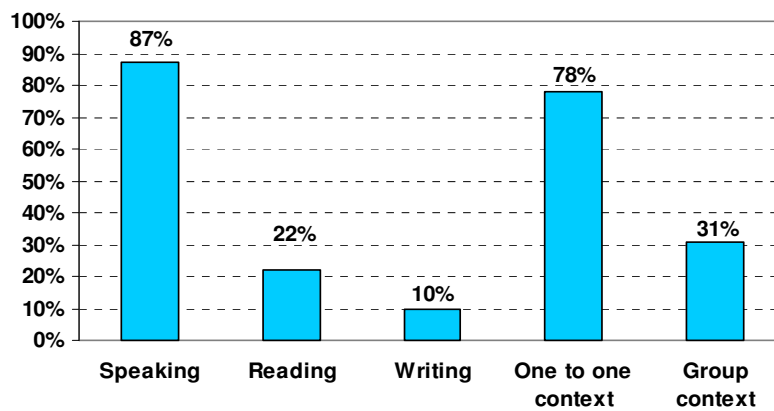


Figure 49. Communication contexts assessed in speech and language therapy

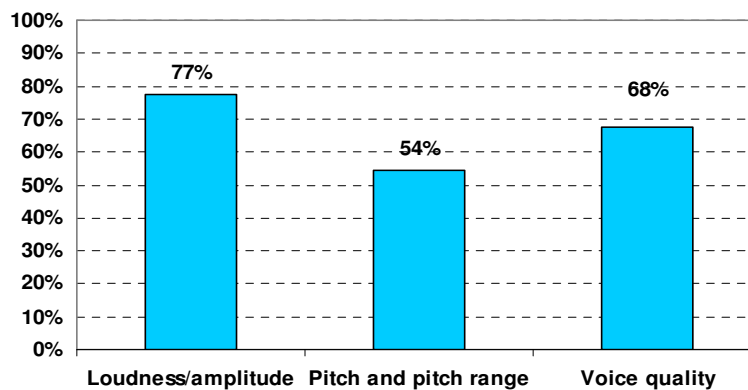


Figure 50. Voice respiration parameters assessed in speech and language therapy

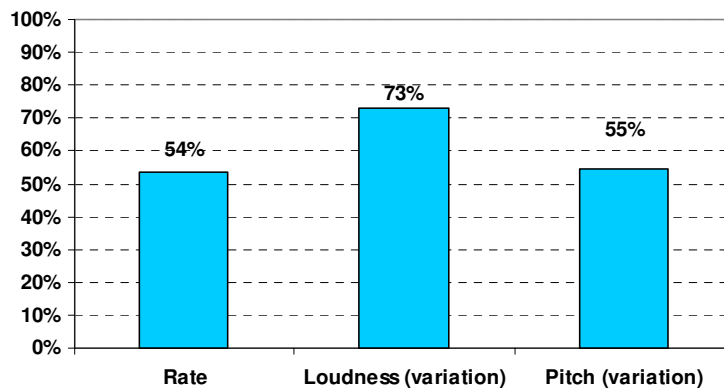


Figure 51. Prosody parameters assessed in speech and language therapy

Intelligibility

71% of the total number of audited patients were assessed for intelligibility using informal assessments such as non standardised tools (rating scales) and 9% of patients were completed a standardised diagnostic intelligibility test with a score given.

Contrary to the evidence base, informal assessment of intelligibility with rating scales appears to remain prevalent.

Standard 5: People with Parkinson's should be asked explicitly about difficulties with word finding and conversations (Dutch Guidelines: R11).

Participating speech and language therapists were asked whether assessments for the audited patients covered:

- communication participation?
- the impact of Parkinson's on communication?
- the impact of communication changes on partner/carer?

Figure 52 highlights that speech and language therapists do assess people with Parkinson's informally about the different impacts of communication, but there is a lack of standardised formal assessment.

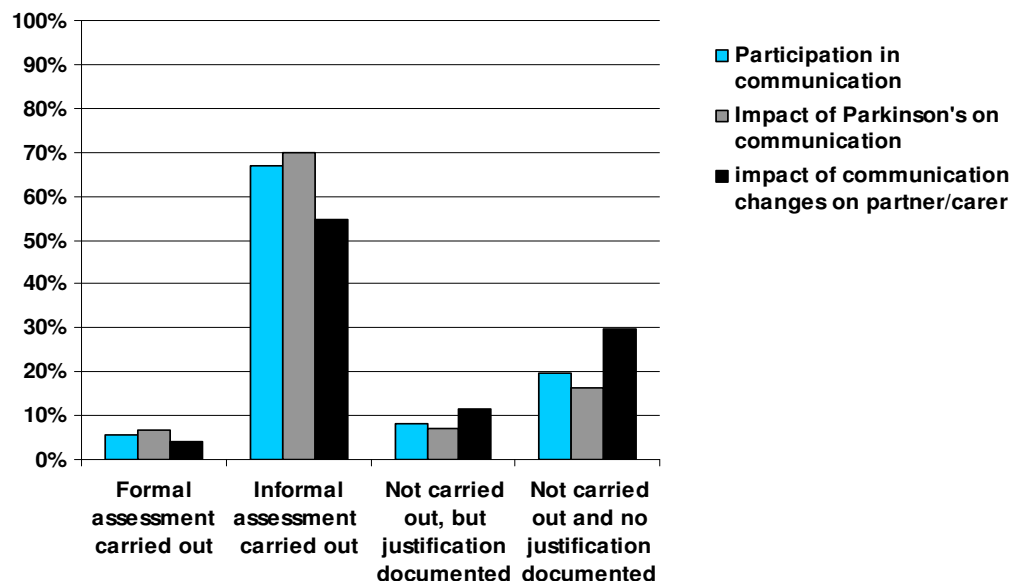


Figure 52. Formal and informal assessments of communications for patients with Parkinson's in speech and language therapy

Interventions

Standard 6: 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).

Participating speech and language therapists were asked the following questions about reports:

- 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)?
- Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?

91% of reports of the audited patients were provided back to the referrer and 83% of reports provided recommended details.

Standard 7: Speech and language therapists should give particular attention to improvement of vocal loudness, pitch range and intelligibility (NICE: R81).

Participating speech and language therapists were asked whether interventions for the audited patients targeted:

- improvement of vocal loudness
- pitch (range)
- prosody
- strategies to optimise intelligibility

Figure 53 indicates that interventions target vocal loudness and intelligibility more than pitch/range and prosody, though this may simply reflect that for the majority of referrals increasing voice loudness may be the best strategy for increasing intelligibility.

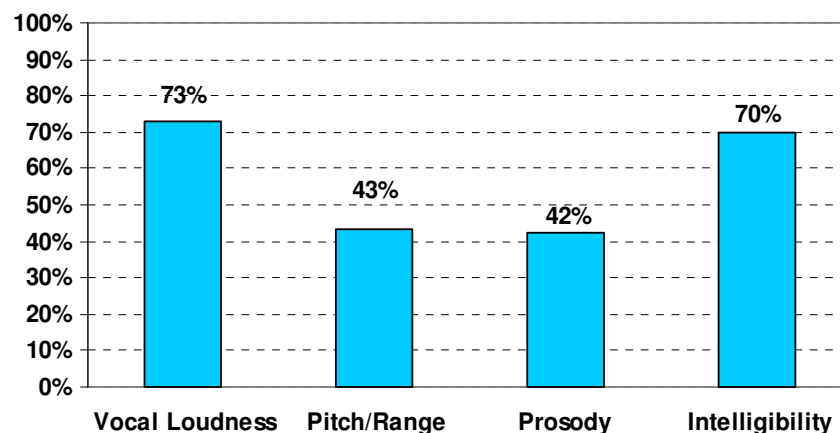


Figure 53. Targeted interventions in speech and language therapy

Service Findings

This section of the speech and language therapy audit consists of general questions about the Parkinson's service provided by the participating speech and language services.

Service description

Participating speech and language therapy services were asked where they usually see patients with Parkinson's.

Table 10 represents the different settings where speech and language therapists see people with Parkinson's.

Setting	No. of healthcare services	
	n	%
In a specialist clinic for patients with Parkinson's	7	21%
In more general specialist neurology clinics	2	6%
In more general specialist elderly care clinics	2	6%
In SLT adult/acquired disorders service mainly based in a hospital	4	12%
In SLT adult/acquired disorders service mainly based in a community clinic	5	15%
In SLT adult/acquired disorders service mainly domiciliary based	11	33%
In generalist SLT service mainly based in a hospital	0	0%
In generalist SLT service mainly based in a community clinic	2	6%
In generalist SLT service mainly domiciliary based	0	0%
No contact with patients with Parkinson's	0	0%
Total	33	100%

Table 10. Work settings of speech and language therapists

45% (15 services) of services for people with Parkinson's are provided in a hospital clinic setting, 33 % (11 services) in domiciliary-based speech and language therapy adult/acquired setting and 15% (five services) in community- clinic based. A small number of services (7%) provided people with Parkinson's with treatment as part of a generalist speech and language service.

Service provision for communication, eating/swallowing/drooling issues

Participating healthcare services were asked whether speech and language therapy was available for all patients with Parkinson's who had problems with communication and eating/swallowing/drooling, irrespective of what stage of the course of their Parkinson's the referral was made.

97% (32 services) of participating healthcare services stated that full service was available for all referrals regarding communication issues and 94% (31 services) of participating healthcare services provided a full service for all referrals were regarding eating/swallowing/drooling issues.

One service highlighted that this type of service was not available for either communication or eating/swallowing/drooling issues.

Service involvement in provision/delivery of palliative care services

45% (15 services) of participating speech and language therapy services have fully planned routine inputs for the provision/delivery of palliative care services (restricted to hospital or community based settings) and 27% (9 services) do not have planned routine inputs.

Patients with Parkinson's

This subsection of the speech and language service findings discusses questions related to patients with Parkinson's in participating speech and language therapy services.

Percentage of patients with Parkinson's seen per year

Participating speech and language therapists were asked the average percentage of patients with Parkinson's that they see per year. This was 39% across all speech and language therapy services.

Estimated number of referrals per year

It is estimated that the number of referrals range from 5 to 270 annual referrals with a median of 60 referrals (Table 11).

No. of referrals per year	No. of healthcare services	
	n	%
1 to 50	14	44%
50 to 100	13	41%
100 to 200	3	9%
≥ 200	2	6%
Total	32	100%

Table 11. Number of referrals per year to speech and language therapy

Review of people with Parkinson's at between 6-12 months

Participating speech and language therapy services were asked whether patients with Parkinson's were attending the clinic for review after 6-12 months. This is illustrated in Figure 53

Only 30% of speech and language therapy services review their Parkinson's patients routinely within 6-12 months and 15% are not automatically reviewed.

45% of speech and language therapy services indicated that some of their

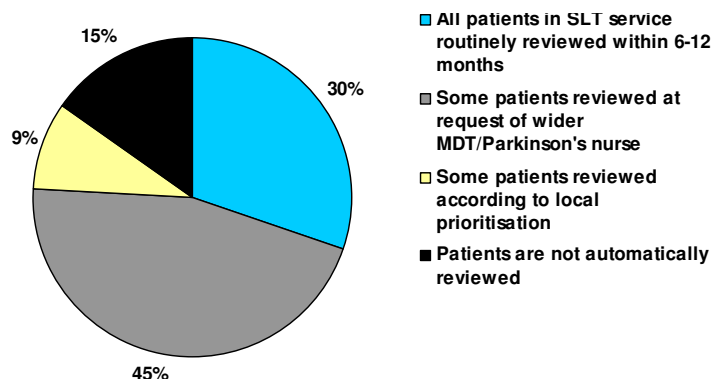


Figure 54. Patients with Parkinson's review by speech and language therapy within 6-12 months

patients with Parkinson's are reviewed at the request of wider multidisciplinary team or Parkinson's specialist nurse.

Self referral/re-referral of patients

Participating speech and language therapy services were asked whether patients with Parkinson's can self refer and/or re-refer themselves to the services, for communication and/or swallowing assessments.

Figure 55 represents the outcomes for this.

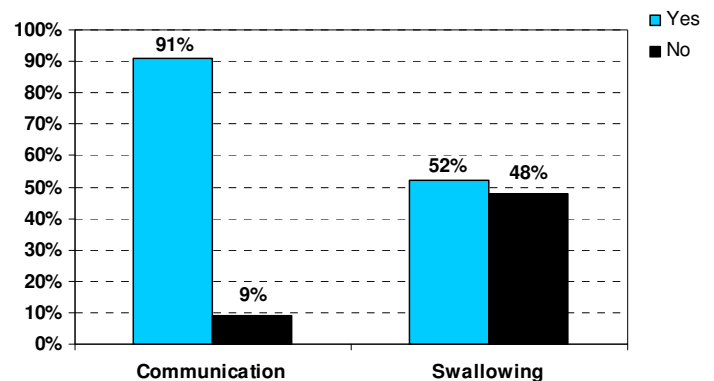


Figure 55. Self referral/re-referral to speech and language therapy services

While the majority of patients with Parkinson's can refer themselves for communication problems (91%), only 54% of speech and language therapy services allow patients with Parkinson's to self refer and/or re-refer themselves for problems with swallowing.

This is of concern as swallowing changes pose a significant risk for people with Parkinson's and any changes should ideally be investigated immediately.

SLT3: All patients with Parkinson's attending speech and language therapy services should be able to self refer and/or re-refer themselves

for communication and swallowing assessments.

Availability of Lee Silverman Voice Treatment (LSVT)

Participating speech and language therapy services were asked of about the availability of LSVT for patients with Parkinson's who meet the inclusion criteria.

Figure 56 shows that 41% of speech and language therapy services do offer LSVT as required, while it is not available for 28%.

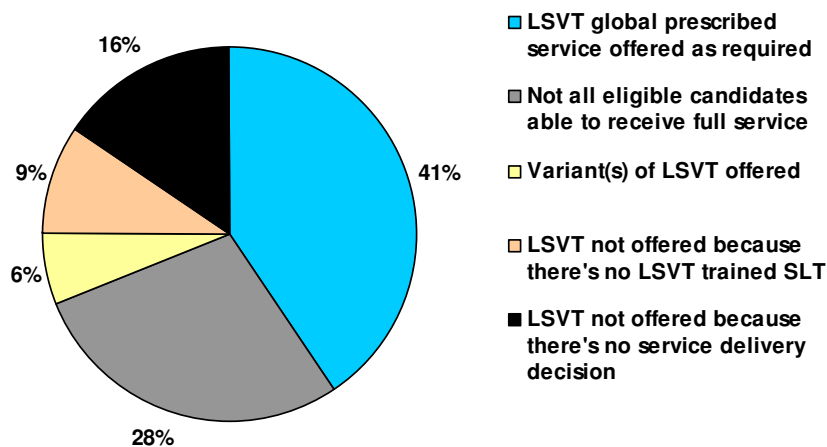


Figure 56. Availability of Lee Silverman Voice Treatment (LSVT) in speech and language therapy services

SLT4: For speech and language therapy services that do not offer LSVT due to the absence of a LSVT-trained SLT, education should be provided.

SLT5: For those speech and language therapy services who are not able to provide full LSVT services to all eligible candidates, the delivery of their service should be reconsidered.

Needs of carers in relation to communication and swallowing

Participating services were asked whether there was a Parkinson's-specific provision that addressed the needs of carers in relation to communication and swallowing contexts.

Figure 57 evidences that more than 40% of speech and language therapy services do not have a specific service addressing the needs of carers of patients with Parkinson's.

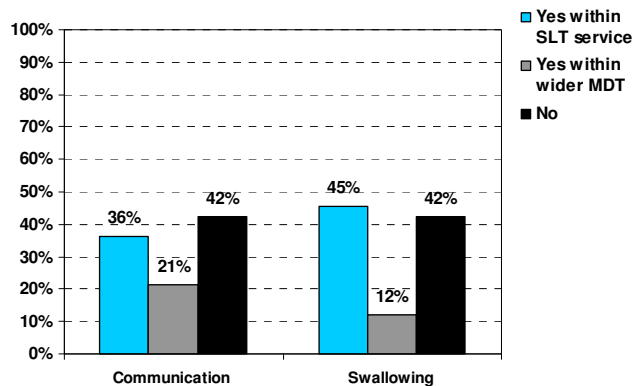


Figure 57. Needs of carers addressed in speech and language therapy services

Provision of information in an appropriate and accessible format

Participating services were also asked whether information provided was culturally appropriate and in a form that is accessible to patients who do not speak or read English.

Figure 58 indicates that 52% of services do not provide information tailored to people who do not speak or read English. 27% of services indicated that they provide this sort of information within their speech and language therapy services.

Given that returns were blind to addresses of participating services it remains unclear whether this reflects the number of services where there are small numbers of people who speak languages other than English. Nevertheless, it is an aspect requiring further attention.

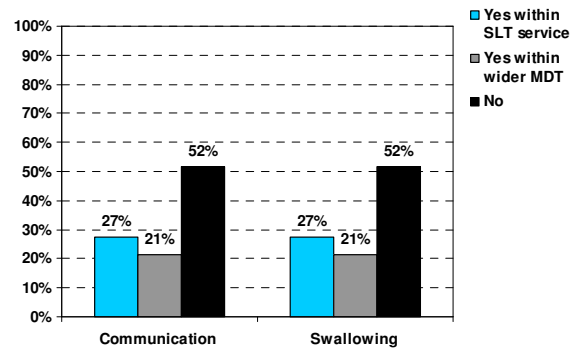


Figure 58. Provision of information in an appropriate and accessible format for patients in speech and language therapy services

Speech and language professionals

This subsection discusses the expertise and continuing development of speech and language within the participating services.

Job description

Participating speech and language therapists were asked to describe their position (Table 12). 61% (20 services) described themselves to be specialist speech and language therapists who see patients with Parkinson's and only 12% (4 services) were Parkinson's specialist speech and language therapists.

Job description	No. of healthcare services	
	n	%
Overall Speech and Language Therapy Service Manager	5	15%
Parkinson's specialist SLT	4	12%
Specialist SLT who sees patients with Parkinson's	20	61%
Generalist SLT who sees patients with Parkinson's	2	6%
Other	2	6%
Total	33	100%

Table 12. Job description of participating speech and language therapists

Number of full time speech and language therapists

Participating services were asked to state how many full time equivalent speech and language therapists s work with people with Parkinson's in their service.

Figure 59 shows that 42% of services have less than one speech and language therapist (this means that the speech and language therapist only sees people with Parkinson's as a subpart of their job) working with people with Parkinson's. 12% of services have more than five speech and language therapists.

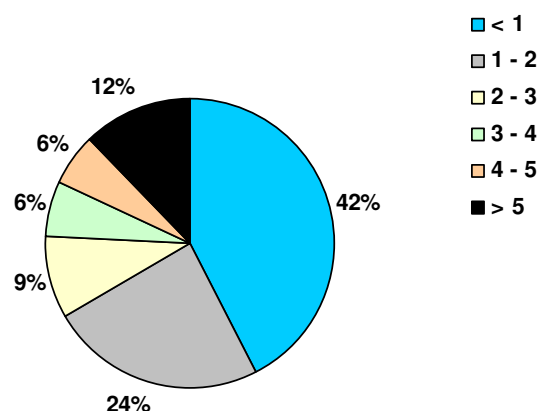


Figure 59. Number of full time speech and language therapists

NHS pay band and continuing professional development (CPD)

The NHS grading band of the speech and language therapists that took part in this audit ranged between Grade 5 and 8b.¹²

59% of therapists are on specialist bands, but 41% more junior colleagues constitute part of the workforce here.

NHS pay band	No. of healthcare services	
	n	%
5	2	5.9%
6	12	35.3%
7	15	44.1%
8a	4	11.8%
8b	1	2.9%
Total:	34	100.0%

Table 13. NHS pay band of participating speech and language therapists

Participating speech and language therapists were asked whether in-service educational support was available.

64% (21 services) of participating speech and language therapy services have in-service educational support as

part of more general competencies however only 30% (10 services) of these services have CPD specifically related to Parkinson's. 6% (2 services) did not provide any in-service education support.

PDR2 links closely with this question. (Please refer to Recommendation chapter)

Level of support within service

Participating therapists were asked where they obtain the best level of support to enable them to provide an appropriate level of treatment to people with Parkinson's.

38% (12 services) of participating speech and language therapists obtain support from a member of the Parkinson's multidisciplinary team. And 31% (10 services) of participating speech and language therapists who do not work for specialist clinics answered that they can readily access a Parkinson's multidisciplinary team and Parkinson's specialist nurse.

Two services did not have access to more specialised advice.

Overall, it is encouraging that 69% of speech and language therapists had received support from Parkinson's specialist colleagues.

Documentation of competencies and induction and support strategies

None of the participating speech and language therapy services documented competencies for speech and language therapists specifically related to people with Parkinson's. 67% of speech and language therapy services documented this as part of more general competencies and 33% services did not document competencies at all.

Participants were also asked whether there were any documented induction and support strategies for therapists new to working with people with Parkinson's. 64% of services reported they have such specific documentation, of which 21% were specifically related to people with Parkinson's.

Clinical practice

This section provides an analysis of the clinical practice and assessments used to influence speech and language therapy practice within the participating services.

Pathways for referral to speech and language therapy

70% (23 services) of services stated that they have clear pathways for referrals to the speech and language therapy service laid out as part of more general care pathway and 24% (8 services) services stated that they have pathways specifically for people with Parkinson's.

Participants were also asked whether the pathways included waiting time targets from referral to speech and language therapy to first appointment. 81% (26 services) of participating SLT services did have waiting time targets from referral to speech and language therapy to first appointment and 18% (6 services) did not.

All of the eight services who had pathways specifically related to people with Parkinson's incorporated waiting time targets from referral to speech and language therapy to first appointment within their services.

Pathways for journey through speech and language therapy

48% (16 services) of services stated that they have clearly pathways for the journey through the speech and language therapy service as part of more general care pathway and 30% (10 services) of service specified that they have pathways specifically for people with Parkinson's.

Participants were also asked whether the pathways included waiting time targets from speech and language therapist decision to treat to first appointment.

52% (17 services) of participating speech and language therapy services did have waiting time targets from referral to speech and language therapist decision to first treatment appointment and 48% (16 services) did not.

Only six out of the 10 services who had pathways for the journey through speech and language therapy, specifically related to people with Parkinson's incorporated waiting time targets from referral to speech and language therapy, to first appointment within their services.

Two of the participating speech and language therapy services did not have pathways for referral to therapy nor for the journey through therapy.

It is appropriate to highlight here that the recording of Referral To Treatment (RTT) has been made mandatory since 1 April 2011 and therefore all service should have this standard incorporated in their services.

PDR3: All services must have waiting time targets incorporated in their care pathways.

Speech and language therapy assessments informed by evidence base

Participants were asked whether the choice of speech and language therapy assessments was informed by the evidence base for current practice. 97% (22 services) of services answered 'Yes', with 45% (15 services) of services reporting that all choice of speech and language therapy assessments were informed by evidence base for their current best practice.

Only one speech and language therapy service reported their choice of assessments not to be informed by evidence base for current practice.

Standard assessment measures at initial assessment and each review

Table 14 indicates that only 6% of services use standardised assessments for all communication assessments and 9% for swallowing assessments.

Possibility of referral to further swallowing assessments

Participating speech and language therapy services were asked whether patients can be referred for further swallowing assessments such as video fluoroscopy and fiberoptic endoscopic evaluation of swallowing (FEES). 90% of services provide video fluoroscopy assessments. 52% of services do not provide a service for the FEES assessment.

Specific stipulated measures that must be carried out at initial assessment and at each review	No. of healthcare services			
	Communication		Swallowing	
	n	%	n	%
Standardised assessments of all speech/voice and language variables are carried out at first assessment and at each major review	2	6%	3	9%
Selective range of speech-voice and/or language formal assessments is carried out	17	52%	8	24%
Assessments are restricted to non-standardised informal assessments	3	9%	15	45%
No assessments stipulated	11	33%	7	21%
Total	33	100%	33	100%

Table 14. Standardised assessment measures for communication and swallowing assessment at initial and each review

Possibility of referring for further swallowing assessments	No. of healthcare organisations			
	Video Fluoroscopy		FEES	
	n	%	n	%
Yes, referral possible on site	14	42%	6	18%
Yes, referral possible via other service	16	48%	7	21%
Restricted access due to financial restrictions	0	0%	0	0%
Restricted access due to postcode	1	3%	0	0%
No service available	1	3%	17	52%
Service exists but unable to access	1	3%	3	9%
Total	33	100%	33	100%

Table 15. Availability of referral for video fluoroscopy and fiberoptic endoscopic evaluation of swallowing (FEES).

Service audit

Fifty-six services completed the Service audit, which evaluates patients' access to NICE-recommended services and treatments. Services were asked to provide information from the perspective of the local neurology and elderly care service.

Where appropriate, comparisons of results with previous audits (2009 and 2010) were made.

Parkinson's specialist clinics

Standard 1a: Patients are able to access a neurologist and/or elderly care consultant with specialist Parkinson's expertise (NICE: R11; NSF: QR2.1, 2.2).

A Parkinson's specialist was defined as a clinician who attends movement disorders meetings on a regular or ongoing basis, and Parkinson's patients comprise a significant part of his/her workload. A specialist service would be expected:

- to have an identified lead clinician who liaises for training, service development and specialist opinion, and
- to provide specific Parkinson's/movement disorders clinics.

50% of the audited trusts reported provision of a Parkinson's or movement disorders specialist service via neurology and elderly care (no change since 2010). Figure 60 shows that provision of a Parkinson's or movement disorders specialist service via elderly care only has decreased by 15%, whereas specialist services via neurology only shows a 20% increase since 2010. 50% have a commissioning/referral pathway, which diverts patients to the specialist's service.

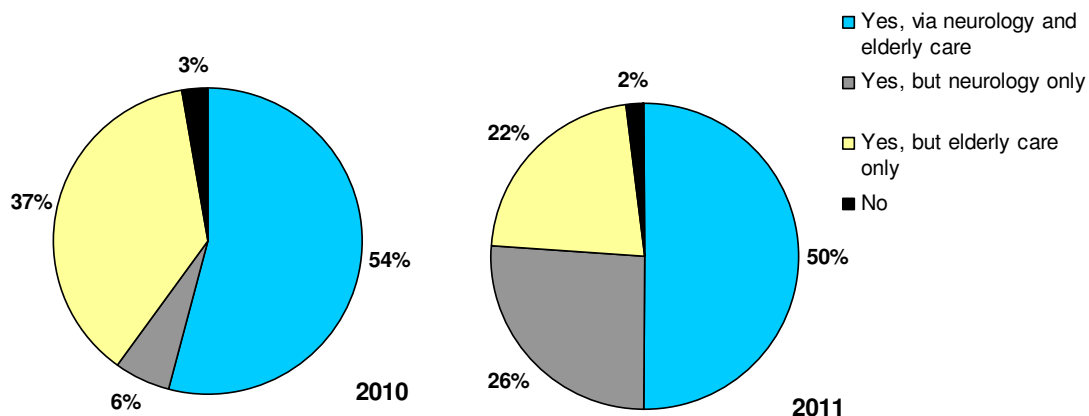


Figure 60. Access of Parkinson's specialist neurology and elderly care consultants

Continuing Medical Education (CME) training

Data was collected on consultant and Parkinson's specialist nurse attendance at external movement disorders specific CME training as supportive evidence of specialist expertise. 83% of consultants who routinely deal with Parkinson's patients had attended such training during the 2010/2011 CME cycle (85% elderly care consultants, a decrease from 97% in 2010 and 80% neurology consultants, an increase from 75% in 2010).

In 2011, participants were also asked whether the Parkinson's specialist nurse attended specific CME training. All (100%) Parkinson's specialist nurses in 80% of services had attended specific CME training.

Standard 1b: Parkinson's patients should have specialist review of diagnosis at 6-12 monthly intervals (NICE: R12, R77; NSF: QR2.5).

94% of services keep their patients under 6-12 monthly specialist review regardless of local patient's postcode (89% in 2010) and 9% of services reported postcode variations in their ability to meet the standard (9% neurology services and 0% elderly care services).

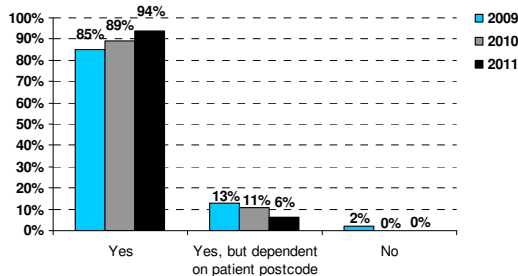


Figure 61. Trends in service delivery of specialist review of diagnosis at 6-12 monthly intervals from 2009 to 2011

Figure 61 represents the trends in service delivery of specialist review of diagnosis at six-12 monthly intervals from 2009 to 2011. It is evident that services are increasingly reviewing their Parkinson's patients within six-12 months. It is encouraging to see a constant decline in provision of service dependent on postcode variations.

46% of audited services can provide specialist review (includes Parkinson's specialist nurse) at home for all patients unable to attend clinic and 18% cannot provide this service. The main limiting factor is the patient's postcode, where 37% of services can only provide specialist review at home depending on the patient's postcode.

Standard 1c: New referrals in later disease with complex problems can access review within two weeks (NSF: QR2.1, 2.4).

80% of services were able to give advice/or review their Parkinson's patients within two weeks, in urgent and complex situations (82% in 2010). Elderly care services were better at providing this service than neurology services (Figure 62).

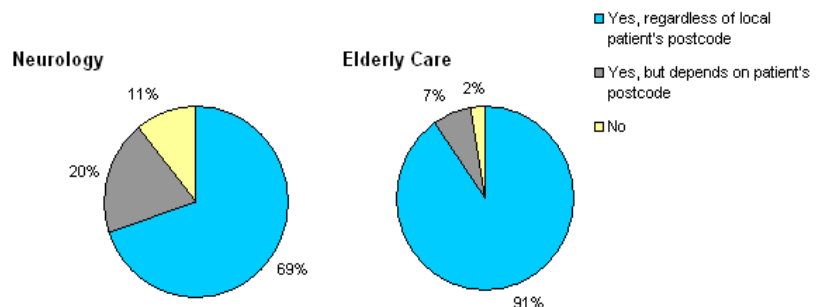


Figure 62. Access to urgent specialist review within 2 weeks

96% of services were able to offer urgent outpatient or home visit support

(93% neurology and 98% elderly care). 9% of services were able to advise only by telephone. There is a significant difference between neurologists (16% in 2010 and 7% in 2011) and elderly care services (9% in 2010 and 2% in 2011).

Assessment of Activities of Daily Living (ADL) function, non-motor symptoms (NMS), cognition and mood

Services were asked if they screen patients for ADL problems and non-motor symptoms and if cognitive and mood assessment scales are available in clinics.

In 22% of elderly care services, a formal ADL tool or checklist is routinely used in all clinics compared with only 7% of neurology (4% in 2010).

Approximately one third (34%) of elderly care services and just over a half (52%) of neurology services do not routinely screen for ADL problems, a decrease from 68% in 2010 (Table 16). It appears that the availability of ADL tool or checklists remains low; however there are improvements in neurology services.

Provided these tools are quick and straightforward to complete, and services should consider how to make them more widely available to increase awareness of ADL issues and to trigger referrals to other healthcare professionals as necessary.

Non-motor symptoms (NMS) have a significant influence on quality of life with Parkinson's and are often under reported in a clinic setting without specific enquiry. Services were asked to indicate if they routinely used a non-motor symptom questionnaire or some form of checklist to screen for these

problems. As a result, 21% of elderly care and 9% of neurology services routinely screen for non-motor symptoms in all their clinics (Table 16). However, 48% neurology (decrease from 54% in 2010) and 33% of elderly care services do not use any written prompts regarding non-motor issues.

Services were asked to indicate if cognitive and mood assessment scales are routinely available for use when clinically indicated. Cognitive assessment tools are generally available in elderly care run clinics with 55% of services having the paperwork in all clinics, this is a decrease from 67% in 2010 (Table 17). Neurology services are less likely to have cognitive assessment tools in the clinic, although 35% of services have them in all clinics.

Mood assessment tools are less likely to be readily available in clinic, possibly reflecting clinicians' uncertainty regarding their validity in Parkinson's. Elderly care services (36%) report greater availability to mood assessment tools compared to neurology (13%) (Table 17).

	ADL				NMS			
	Neurology		Elderly Care		Neurology		Elderly Care	
	n	%	n	%	n	%	n	%
All clinics	3	7%	9	22%	4	9%	9	21%
Most clinics (>75%)	1	2%	3	7%	3	7%	5	12%
Some clinics	18	39%	15	37%	17	37%	14	33%
Not routinely available	24	52%	14	34%	22	48%	14	33%
Total	46	100%	41	100%	46	100%	42	100%

Table 16. Use of ADL and NMS assessment tools or checklist

	Cognitive function				Mood			
	Neurology		Elderly Care		Neurology		Elderly Care	
	n	%	n	%	n	%	n	%
All clinics	16	35%	23	55%	6	13%	15	36%
Most clinics (>75%)	9	20%	7	17%	4	9%	4	10%
Some clinics	11	24%	6	14%	12	26%	12	29%
Not routinely available	10	22%	6	14%	24	52%	11	26%
Total	46	100%	42	100%	46	100%	42	100%

Table 17. Use of cognitive function and mood assessment tools

Standard 2: Patients can access Parkinson's specialist nurse (or neurology nurse with Parkinson's remit) for clinical monitoring continuing point of contact for support, including home visits and as reliable source of information about social and clinical matters (NICE: R77; NSF: QR1.2, 2.4, 2.5).

Participating services were asked whether their patients were able to be referred to a Parkinson's specialist nurse for ongoing support. One third (75%) of services have equitable access to a Parkinson's specialist nurse for neurology and elderly care patients from all postcode areas (no change since 2010). 17% of services provided this service to some patients only (Figure 63). For services where only some patients were able to get support from a Parkinson's specialist nurse, 30% were dependent on the commissioning area of the patient and 35% depended on the neurology services they attended.

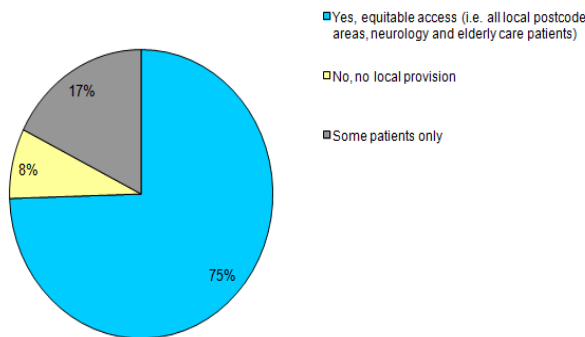


Figure 62
3. Referral to Parkinson's specialist nurse for ongoing support

Therapies

The service audit assumed that non-specialist therapy services would be available in all areas, but in varying amounts. Services were asked about patient access to therapists with specialist knowledge and expertise in Parkinson's chronic management. Expert therapy was defined as services delivering therapy where:

- Parkinson's forms a significant part of the therapists work load, and
- therapists can access Parkinson's related continuing professional development (at least yearly), and
- therapy practice is based on the NICE guidelines for Parkinson's.

84% of the services report some local provision of 'expert' physiotherapy, with 72% for occupational therapy and 80% for speech and language therapy, in relation to swallowing function and speech respectively. Further analysis on individual therapy results are discussed below.

Standard 3a: Physiotherapy is available at diagnosis and at each regular review and appropriate referral activated for people with Parkinson's (NICE: R78; NSF: QR4.1, 4.2, 5.1, 5.2, 5.3)

Of the 84% of services that had access to expert physiotherapy, 55% had universal access. Of the services without universal access, 48% were dependent on the commissioning area (i.e. patient postcode) (a decrease from 64% in 2010), 38% were restricted by both commissioning area and service specialty (increase from 21% in 2010), and 14% were only able to access expert physiotherapy through elderly care services.

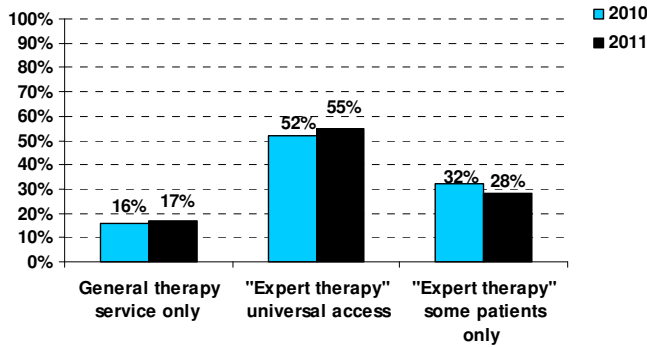


Figure 64. Provision of expert and general therapy in physiotherapy services

Standard 3b: Occupational therapy is available at diagnosis and at each regular review and appropriate referral activated for people with Parkinson's (NICE: R80; NSF: QR4.1, 4.2, 5.1, 5.2, 5.3).

Of the 72% of services that had access to expert occupational therapy, 46% had universal access. Of the services without universal access (26%) (i.e. some patients only), 28% were dependent on the commissioning area, 46% were able to access expert occupational therapy through neurology services (0% in 2010) and 26% through elderly care services (17% in 2010). There were no services identified to be restricted by both commissioning area and service specialty.

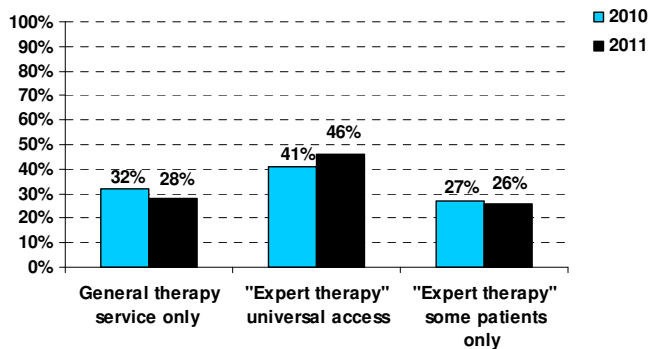


Figure 65. Provision of expert and general therapy in occupational therapy services

It is promising to see that occupational therapy can now be accessed through neurology services.

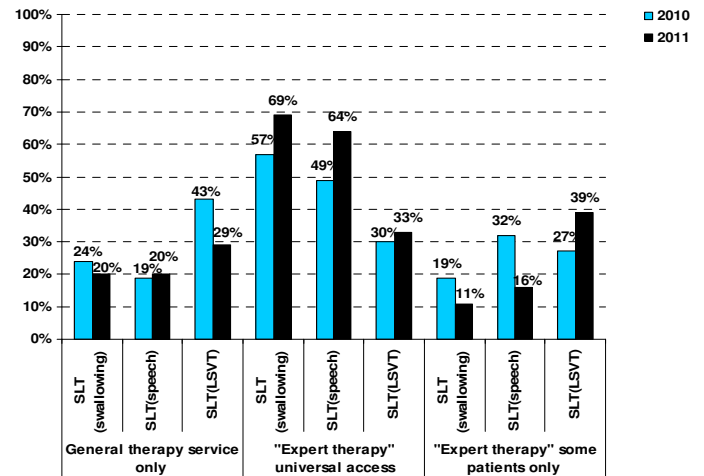


Figure 66. Provision of expert and general therapy in speech and language therapy services

Standard 3c: Speech and language therapy is available at diagnosis and at each regular review and appropriate referral activated for people with Parkinson’s (NICE: R81; NSF: QR4.1, 4.2, 5.1, 5.2, 5.3)

Figure 66 represents access to expert therapy against general therapy for speech and language therapy for speech, swallowing and Silverman voice therapy treatment.

It is evident that increases have been highlighted in all three aspects of

speech and language. Decreases in services without universal access (i.e. some patient only) in speech and swallowing functions are also encouraging.

Factors influencing the lack of universal access to ‘expert’ therapy

Table 18 represents the reasons behind the lack of universal access to expert therapy in the different therapy services and shows great variances when comparing the previous audit.

	Physiotherapy		OT		SLT speech		SLT swallowing		SLT Lee Silverman	
	2010	2011	2010	2011	2010	2011	2010	2011	2010	2011
Commissioning area (patients postcode)	57%	48%	50%	28%	58%	40%	60%	60%	36%	39%
Neurology service only	0%	0%	0%	46%	8%	0%	0%	0%	0%	4%
Elderly care service only	14%	14%	17%	26%	17%	8%	20%	10%	27%	0%
Postcode and specialty dependent variations	29%	38%	33%	0%	17%	52%	20%	30%	37%	57%

Table 18. Factors influencing the lack of universal access to 'expert' therapy

Medication formulary

Standard 4: Patients can access Parkinson's medications allowed by NICE based on clinical need (NICE: R26,28,32,34,35,38,39,43,44,46,47,48, 49,50,68; NSF: QR2.3).

Table 19 represents whether listed Parkinson's medications are available for prescription based on clinical need.

Dopamine agonists

Patients are generally able to access oral and patch dopamine agonist treatment as per clinical need (Table 19). There were no reported formulary restrictions for standard-release ropinirole, pramipexole and cabergoline.

The availability of prolonged-release ropinirole had decreased slightly from 97% services in 2010 to 90% in 2011, and the prolonged-release pramipexole has increased from 82% 2010 to 88% in 2011. The difference in access is likely to continue if ropinirole/pramipexole price discrepancies remain.

Access to the patch-preparation rotigotine has declined slightly compared to the previous audit (95% in 2010 and 93% in 2011).

The use of cabergoline continues to decline (83% in 2009, 74% in 2010 and now 60% in 2011), and is now unavailable in 27% of services (20% in 2010 and 16% in 2009). This reflects its more complex monitoring requirements and the arrival of once daily formulations of ropinirole and pramipexole.

Access to apomorphine has declined since 2010 (61% in 2010), 4% of services are unable to prescribe and 20% now require individual funding approval (5% in 2010).

COMT inhibitors

Entacapone and Stavelo can be prescribed in primary and secondary care. Tolcapone requires intensive monitoring however appropriate restrictions on initial prescribing in primary care are decreasing (9% in 2010 and 4% in 2011) but the proportion of services reporting that they are unable to prescribe has declined to 23% compared to 30% in 2010.

MAOB inhibitors

Standard selegiline is generally available (98% of services). Rasagiline is more likely to be the second line alternative to selegiline, with only 5% of services unable to prescribe compared with 9% of services for Zelapar.

Duodopa

Duodopa is classed as an orphan drug and it is to be expected that 70% of services need to apply for individual funding approval. It is concerning that 16% of trusts are unable to use Duodopa therapy in appropriate patients (increase of 4% since 2010).

Cholinesterase inhibitors

Cholinesterase inhibitor therapy is generally available (81% of services), although there is an increase in its prescription limitation to secondary care from 19% in 2010 to 28% in 2011.

Clozapine

Clozapine is mainly prescribed via mental health (82% in 2011 and 78% in 2010). It is also now only unavailable in 3% of services, compared to its unavailability in 11% of services in 2010.

Access to Parkinson's medication				
	Yes, primary and secondary care*	Yes, secondary care only	Restricted (individual funding approval)	No
Dopamine Agonists				
Ropinirole (Standard)	100%	-	-	-
Ropinirole Prolonged Release	90%	2%	4%	4%
Pramipexole	100%	-	-	-
Pramipexole Prolonged Release	88%	4%	4%	4%
Rotigotine	93%	5%	2%	-
Cabergoline	60%	13%	-	26%
Apomorphine	61%	15%	20%	4%
COMT inhibitors				
Entacapone	100%	-	-	-
Stalevo	100%	-	-	-
Tolcapone	40%	33%	4%	23%
MAOB inhibitors				
Selegiline	98%	-	-	2%
Zelapar	84%	7%	-	9%
Rasagiline	86%	5%	4%	5%
Amantadine	100%	-	-	-
Duodopa	9%	5%	70%	16%
Cholinesterase inhibitors	72%	28%	-	-

Table 19. Access to Parkinson's medication

DaTSCAN and neurosurgery

Standard 5: Patients can be referred by a movement disorder specialist for a DaTSCAN (NICE: R13; NSF: QR2.2)

73% of participating services reported being able to refer their Parkinson's patients for a DaTSCAN and 23% had a limit to the number of scans funded per year and one trust was unable to refer. Figure 67 shows that limitation to access and the unavailability of DaTSCAN is increasing from year-on-year.

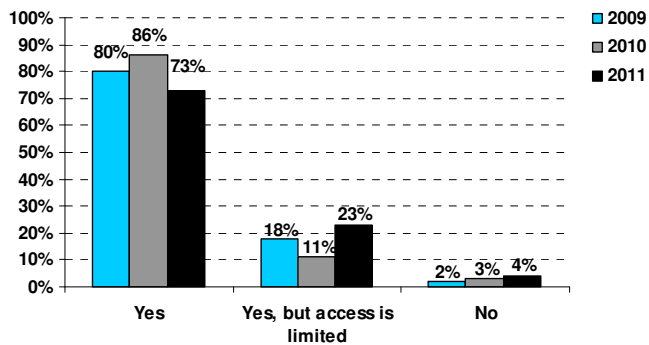


Figure 67. Trends in the availability of referral for a DaTSCAN from 2009 to 2011

Standard 6: Patients can be considered for neurosurgery based on clinical need (NICE: R55, R56, R57, R58; NSF: QR2.3)

13% of participating services can directly provide neurosurgery for Parkinson's, a decrease from 16% in 2010. 85% of patients were able to access neurosurgery based on clinical need. Most of the remaining trusts can refer and access funding for suitable patients regardless of their postcode (Figure 68).

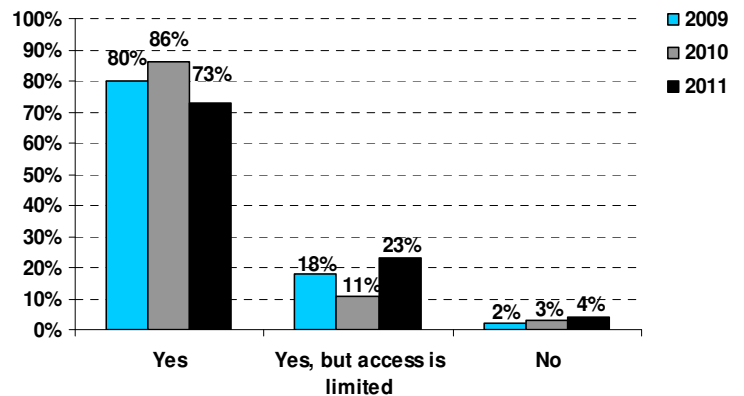


Figure 68. Trends in the availability of referral for neurosurgery from 2009 to 2011

Recommendations

This section of the report summarises all the recommendations made throughout the report for each specialty.

The following acronyms have been used to represent specific recommendations related to each specialty:

- **PDR#** recommendations applicable to all participants of the audit
- **PM#** recommendations applicable to patient management in neurology and elderly care services only
- **OT#** recommendations applicable to occupational therapy only
- **PT#** recommendations applicable to physiotherapy only
- **SLT#** recommendations applicable to speech and language therapy only

All recommendations

PDR1: All information about the person with Parkinson's should be available at any referral. This includes details of Parkinson's history, previous medical history and reason for referral.

- OT audit: 9% of referrals did not provide information such as the reason for referral and details of the client's history of Parkinson's. The majority of these referrals were made by multidisciplinary team, Parkinson's specialist nurse and elderly care consultants

PDR2: All healthcare professionals working for services specialising in neurological conditions and the treatment of people with Parkinson's should be educated/attend appropriate training in the management of Parkinson's

- Speech and language audit: only 30% of speech and language therapists have access to continuing professional development specific to Parkinson's
- Occupational therapy audit: 73% of occupational therapists have access to continuing professional development. Six occupational therapy services that specialised in the treatment of clients with Parkinson's did not have access to CPD related to Parkinson's
- Physiotherapy audit: only 39% of therapists attend training specific to Parkinson's on a regular basis

PDR3: Services without local standards for waiting time from referral to initial assessment/appointment need to consider setting maximum wait time targets

- Physiotherapy audit: 9% of services did not meet RTT targets
- Speech and language audit: 19% of services did not have RTT targets

Patient management in neurology and elderly care recommendations

PM1: 100% of patients with Parkinson's attending services must be reviewed at between 6-12 monthly intervals

- 92% of patients were reviewed in as part of medical review and 74% by Parkinson's specialist nurse review

PM2: 100% of patients with newly diagnosed Parkinson's should be seen within 6 weeks.

- Only 69% of patients were seen within six weeks

PM3: All consultants should provide written information about Parkinson's via signposting to Parkinson's UK (website or local information support worker).

- 39% of newly diagnosed audited patients were not provided with written information about Parkinson's

PM4: All Parkinson's services should provide Parkinson's specialist nurse contact information to newly diagnosed patients, where there is one.

- Only 62% of newly diagnosed audited patients received contact information for a Parkinson's specialist nurse. This is decline from the audit findings of 2010 (75%)

PM5: All patients who drive should have their driving status determined and be advised about DVLA/car insurance.

- Only 70% of newly diagnosed audited patients had their driving status determined and only 54% had been advised about DVLA/car insurance

PM6: All patients must be advised about the risk of impulsive and compulsive behaviour when starting on a dopamine agonist and have ongoing monitoring.

- 16% of newly diagnosed patients and 28% of existing patients on dopamine agonist prescription were not monitored for impulsive and compulsive behaviour

PM7: Services using ergot-derived dopamine agonist should ensure their compliance with baseline investigation and early monitoring standards.

- 40% of audited patients on ergot-derived dopamine agonist prescription are not monitored

PM8: End of life care requirements should be encouraged throughout the stages of Parkinson's.

- Approximately 40% of palliative patients are considered for end of life care requirements

PM9: Participating services recording domain scores should examine their assessment (and documentation) process if they have a low amalgamated domain score and derive an appropriate action plan.

PM10: Integrated doctor, specialist nurse and therapy reviews should be encouraged amongst neurology services.

- No neurology services used the integrated doctor, specialist nurse and therapy reviews as a model of service delivery

Occupational therapy recommendations

OT1: Promote less well-known aspects of the occupational therapy role amongst health professionals working with people with Parkinson's, in particular, mental wellbeing, and management of fatigue and leisure activities, maintenance of family roles and maintenance of work.

- These five aspects were found to be low amongst the reasons for referral to occupational therapy (7.2%, 4.3% and 3.9%3.0%, respectively).

OT2: There is a need to promote the audit among occupational therapy working in social services.

- 37% of occupational therapy referrals are made to social services, however 0% of participants worked in social services

OT3: Explore the use of group work with people with Parkinson's.

- Only 2.5% of occupational therapists saw their clients in a group setting although occupational therapists are trained to use group work skills

OT4: Encourage the use of standardised assessments, as recommended in the Occupational Therapy Best Practice guidelines and explore other standardised assessments which could also be recommended.

- 28% of services did not use any of the recommended standardised assessments
- Only 13% of services used the recommended standardised assessments

OT5: The time between diagnosis and referral to occupational therapy should be reduced.

- The audit found that occupational therapists see people who have had Parkinson's for an average of six years.

OT6: Promote early intervention for people with Parkinson's among occupational therapists themselves.

- Their role at this stage is to establish rapport, to prevent activities and roles restricted or lost and to develop appropriate coping strategies with the person with Parkinson's.

Physiotherapy recommendations

PT1: All physiotherapists should be educated on the differences between treatment strategies and outcome measures

- Although 77% of patients' notes recorded the use of specific outcome measures, many physiotherapists recorded treatment strategies as opposed to standard outcome measures when asked to specify.

PT2: All physiotherapists should use the UK Quick Reference Cards. This can be done through the provision of training and courses to encourage implementation.

PT3: 100% of physiotherapists should record the area of physiotherapy intervention at initial assessment, treatment strategies and techniques and to use outcome measures in patients' notes.

- The audit identified adherence with all three standards was 97%, 94% and 77% respectively.

Speech and language therapy recommendations

SLT1: There should be at least one audio recording made throughout a person with Parkinson's journey with a speech and language therapy team.

- Only 15% of patients have had an audio recording made at initial or any other follow up referrals.

SLT2: All assessments notes should record whether patients with Parkinson's are assessed during an 'on/off' period.

- Only 15% of patients' notes recorded on/off states/period of the patient during assessments.

SLT3: All patients with Parkinson's attending speech and language therapy services should be able to self-refer and/or re-refer themselves for communication and swallowing assessments.

- Only 54% of services allow patients with Parkinson's to self refer and/or re-refer themselves for problems with swallowing

SLT4: For speech and language therapy services who do not offer Lee Silverman Voice Training (LSVT) due to the absence of a LVST-trained speech and language therapist, education should be provided

- 9% of speech and language therapy services did not offer LSVT due to absence of a LVST-trained speech and language therapist.

SLT5: For those speech and language therapy services that are not able to provide full LSVT services to all eligible candidates, the delivery of their service should be reconsidered.

- 28% of services that are not able to provide full LSVT services to all eligible candidates

List of figures and tables

Patient characteristics

Table 1. Patient characteristics

Methodology

Figure 1. Total number of services and patients analysed after benchmarking

Patient management audit

Figure 2. Parkinson's phase

Figure 3. Time since most recent medical review

Figure 4. Time since most recent Parkinson's nurse review

Figure 5. Newly diagnosed patients referred untreated

Figure 6. Newly diagnosed patients seen within six weeks

Figure 7. Newly diagnosed patients who are given written information about Parkinson's

Figure 8. Newly diagnosed patients offered Parkinson's nurse contact information

Figure 9. End of life care requirements

Figure 10. Scatter diagrams of domain 1 average scores

Figure 11. Scatter diagrams of domain 2 average scores

Figure 12. Scatter diagrams of domain 3 average scores

Figure 13. Scatter diagrams of domain 4 average scores

Figure 14. Model of service delivery

Table 2. Current Medication

Table 3. New medication prescribed within the last year

Table 4. Monitoring for impulsive and compulsive behaviour of patients on dopamine agonists

Table 5. Average domain scores of services with medical alone setting

Occupational therapy audit

Figure 15. Referred to occupational therapy by

Figure 16. Referral to occupational therapy at an appropriate time

Figure 17. Referral to occupational therapy triggered by medical review

Figure 18. Essential information available for occupational therapy

Figure 19. Goals identified for optimising activities by client, carer and therapist

Figure 20. Goals identified for supporting participation activities by client, carer and therapist

Figure 21. Goals identified for end of life care by client, carer and therapist

Figure 22. Treatment strategies and techniques for initiating and maintaining movement

Figure 23. Treatment strategies and techniques for engagement, motivation, learning and carryover

Figure 24. Treatment strategies and techniques for environmental adaptations/assistive technologies

Figure 25. Treatment strategies and techniques for ensuring community rehabilitation and social support

Figure 26. Treatment strategies and techniques for providing information to increase client's knowledge
 Figure 27. Treatment strategies and techniques for providing information and support for family and carers
 Figure 28. Treatment strategies and techniques for providing support to facilitate change in attitude
 Figure 29. Work settings of occupational therapists
 Figure 30. Percentage of clients with Parkinson's reviewed by occupational therapists
 Figure 31. Method of review of clients with Parkinson's in occupational therapy
 Figure 32. Type of assessment for clients with Parkinson's in occupational therapy
 Figure 33. Standardised assessments used in occupational therapy
 Figure 34. Clinical guidance in occupational therapy

Table 6. NHS pay band of occupational therapists

Physiotherapy audit

Figure 35. Reasons for referral to physiotherapy
 Figure 36. Urgent or routine referrals in physiotherapy
 Figure 37. Previous physiotherapists
 Figure 38. Work settings for physiotherapists
 Figure 39. Percentage of patients with Parkinson's reviewed by physiotherapists
 Figure 40. Method of review of patients with Parkinson's in physiotherapy
 Figure 41. Training in the management of patients with Parkinson's in physiotherapy
 Figure 42. Guidance documents used to inform clinical practice in physiotherapy

Table 7. Treatment strategies and techniques used in physiotherapy

Table 8. Outcomes measures used in physiotherapy

Table 9. NHS pay band of physiotherapists

Speech and language therapy audit

Figure 43. Phase of Parkinson's at initial speech and language therapy referral
 Figure 44. Reason for initial speech and language therapy referral
 Figure 45. Referred to speech and language therapy by
 Figure 46. Target times for (a) first appointment and (b) first treatment appointment
 Figure 47. Full communication and swallowing assessments carried out at initial review in speech and language
 Figure 48. Full communication and swallowing assessments carried out at each review in speech and language
 Figure 49. Communication contexts assessed in speech and language therapy
 Figure 50. Voice respiration parameters assessed in speech and language therapy
 Figure 51. Prosody parameters assessed in speech and language therapy
 Figure 52. Formal and informal assessments of communications for patients with Parkinson's in speech and language therapy
 Figure 53. Targeted interventions in speech and language therapy
 Figure 54. Patients with Parkinson's review by speech and language therapy within 6-12 months
 Figure 55. Self referral/re-referral to speech and language therapy services

Figure 56. Availability of Lee Silverman Voice Treatment (LSVT) in speech and language therapy services

Figure 57. Needs of carers addressed in speech and language therapy services

Figure 58. Provision of information in an appropriate and accessible format for patients in speech and language therapy services

Figure 59. Number of full time speech and language therapists

Table 10. Work settings of speech and language therapists

Table 11. Number of referrals per year to speech and language therapy

Table 12. Job description of participating speech and language therapists

Table 13. NHS pay band of speech and language therapists

Table 14. Standardised assessment measures for communication and swallowing assessment at initial and each review

Table 15. Possibility of referral to further swallowing assessments (video fluoroscopy and FEES)

Service audit

Figure 60. Access of Parkinson's specialist neurology and elderly care consultants

Figure 61. Trends in service delivery of specialist review of diagnosis at 6-12 monthly intervals from 2009 to 2011

Figure 62. Access to urgent specialist review within 2 weeks

Figure 63. Referral to Parkinson's specialist nurse for ongoing support

Figure 64. Provision of expert and general therapy in physiotherapy services

Figure 65. Provision of expert and general therapy in occupational therapy services

Figure 66. Provision of expert and general therapy in speech and language therapy services

Figure 67. Trends in the availability of referral for a DaTSCAN from 2009 to 2011

Figure 68. Trends in the availability of referral for neurosurgery from 2009 to 2011

Table 16. Use of ADL and NMS assessment tools or checklist

Table 17. Use of cognitive function and mood assessment tools

Table 18. Factors influencing the lack of universal access to 'expert' therapy

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Appendices

Appendix A – List of all participating Trusts

Trust	Neurology	Elderly Care	Occupational therapy	Physiotherapy	Speech and language therapy
Abertawe Bro Morgannwg University Health Board					
Aintree University Hospitals NHS Foundation Trust					
Airedale NHS Foundation Trust					
Ashton, Leigh & Wigan Community NHS Trust					
Ayrshire and Arran NHS					
Barking Havering and Redbridge University Trust					
Barts and The London NHS Trust					
Basingstoke and North Hampshire Hospital NHS Foundation trust					
Bath and North East Somerset NHS Trust					
Bedford Hospital NHS Trust					
Berkshire Healthcare NHS Foundation Trust					
Betsi Cadwalader University Health Board-East					
Bolton NHS Foundation Trust					
Brighton & Sussex University Hospitals NHS Trust					
Bristol Community Health					
Buckinghamshire Healthcare NHS Trust					
Calderdale and Huddersfield NHS Foundation Trust					
Cambridgeshire Community Services					
Camden Provider Services					

Central London Community Healthcare NHS Trust					
Chelsea and Westminster NHS Foundation Trust					
Cheshire and Wirral Partnership					
Colchester Hospital University NHS Foundation Trust					
Cornwall and Isles of Scilly PCT					
County Durham and Darlington NHS Foundation Trust					
Croydon Health Services NHS Trust					
Cumbria Partnership NHS Foundation Trust					
Cwm Taf Health Board					
Dartford and Gravesham NHS Trust					
Derby Hospitals NHS Foundation Trust					
Derbyshire Community Health Services NHS Trust					
Dorset Community Health Services					
Dorset County Hospital NHS Foundation Trust					
East and North Hertfordshire NHS Trust					
East Cheshire NHS Trust					
East Kent Hospitals University NHS Foundation Trust					
East Sussex Healthcare NHS trust					
Fife NHS					
Frimley Park Hospital NHS Foundation Trust					
Gateshead Health NHS Foundation Trust					
Gloucestershire Hospitals NHS Foundation Trust					
Grampian NHS					
Great Western Hospitals NHS Foundation Trust					
Great Yarmouth and Waveney PCT					

Greater Glasgow and Clyde					
Guys and St Thomas NHS Foundation Trust					
Guys and St Thomas NHS Foundation Trust, Community Health Services					
Harrogate and District NHS Foundation Trust					
Heart of England NHS Foundation Trust					
Heatherwood & Wexham Park Hospital NHS foundation trust					
Hertfordshire Community Health Services					
Highland NHS					
Hinchingbrooke Healthcare NHS Trust					
Homerton Hospital Foundation Trust					
Hull And East Yorkshire Hospitals NHS Trust					
Hywel Dda Health Board					
Imperial College Healthcare NHS Trust					
Isle of Man Department of Health					
Kettering General Hospital NHS Trust					
Kings College Hospital NHS Foundation Trust					
Kingston NHS					
Kirklees Community Healthcare Service					
Lanarkshire NHS					
Lancashire Teaching Hospitals NHS Trust					
Leeds Teaching Hospitals NHS Trust					
Lewisham Hospital NHS Trust					
Liverpool Community Health NHS Trust					
Luton and Dunstable Hospital NHS Foundation Trust					

Maidstone and Tunbridge Wells NHS Trust					
Medway NHS Trust					
Milton Keynes and Northamptonshire NHS Trust					
Newcastle upon Tyne Hospitals NHS Trust					
NHS Swindon (Care & Support Partnership)					
Norfolk and Norwich University Hospital NHS Trust					
North Cumbria Acute Hospitals NHS Trust					
North Tees and Hartlepool NHS Foundation Trust					
North West London Hospitals					
Northampton General Hospital NHS trust					
Northern Devon Healthcare Trust					
Northern Lincolnshire and Goole NHS Foundation Trust					
Northumbria Healthcare Foundation Trust					
Nottingham University Hospitals NHS Trust					
Outer North East London Community Services					
Pennine Acute Hospital NHS Trust					
Peterborough and Stamford NHS Trust					
Plymouth PCT					
Poole Hospital NHS Foundation Trust					
Portsmouth NHS Trust					
Royal Berkshire NHS Foundation Trust					
Royal Bournemouth and Christchurch hospital NHS Trust					
Royal Devon and Exeter Hospital Foundation NHS Trust					
Royal Free London NHS Foundation Trust					
Royal United Hospital NHS Trust					

Royal Wolverhampton Hospitals NHS Trust					
Salford Royal Foundation Trust					
Salisbury Hospital NHS Foundation Trust					
Sandwell & West Birmingham Hospitals NHS trust					
Scarborough & North East Yorkshire NHS Trust					
Sheffield Health and Social Care Trust					
Sheffield Teaching Hospitals NHS Foundation Trust					
Shrewsbury and Telford Hospital Trust					
Solent NHS Trust					
South Devon Healthcare NHS Trust					
South East Essex Community Healthcare NHS					
South Eastern Health and Social Care Trust					
South London Healthcare NHS Trust					
South Powys Local Health Board					
South Staffordshire PCT					
South Tees Hospital NHS Foundation Trust					
South Warwickshire NHS Foundation Trust					
South West Essex Community Services					
Southern Health and Social Care Trust					
Southport and Ormskirk NHS Trust					
St Georges Healthcare NHS Trust					
St Helens and Knowsley Hospitals NHS Trust					
Staffordshire and Stoke on Trent Partnership NHS Trust					
States of Jersey Health & Social Services					
Stockport NHS Foundation Trust					

Suffolk Community Healthcare					
Sunderland PCT					
Surrey Community Health					
Sutton and Merton Community Services					
Taunton and Somerset Foundation Trust					
Tayside NHS					
The Dudley Group NHS Foundation Trust					
The Hillingdon Hospital NHS Foundation Trust					
The Ipswich Hospital NHS Trust					
The Rotherham NHS FT					
Tower Hamlets Community Health Services					
Trafford Provider Services					
United Lincolnshire Hospitals NHS Trust					
University Hospitals Coventry & Warwickshire NHS Trust					
University Hospital of South Manchester NHS Foundation Trust					
University Hospital Southampton NHS Foundation Trust					
University Hospitals Birmingham NHS Foundation Trust					
University Hospitals Bristol NHS Foundation Trust					
University Hospitals of Leicester NHS Trust					
Walsall Healthcare NHS Trust					
Warrington and Halton Hospitals NHS Foundation Trust					
Warrington PCT					
West Middlesex University Hospital NHS Trust					
Western Isles Health Board					

Western Sussex NHS Trust					
Weston Area Health NHS Trust					
Wirral University Teaching Hospital NHS Foundation Trust					
Wye Valley NHS Trust Hereford					
Yeovil District Hospital NHS Foundation Trust					

Appendix B – List of all standards

Patient management audit standards

Standard 1: Patients with Parkinson's must be reviewed at 6-12 monthly intervals (NICE: R12, R77; NSF LTC: QR2).

Standard 2: People with Parkinson's should be referred quickly and untreated to a specialist with expertise in the differential diagnosis of the condition (NICE: R11).

Standard 3: People with newly diagnosed Parkinson's should be seen within 6 weeks (NICE: R11; NSF LTN QR2.1).

Standard 4: Patients with a new diagnosis of likely Parkinson's should be given written information regarding Parkinson's (NICE: R3; NSF LTN QR1.4).

Standard 5: Patients with a new diagnosis should be offered Parkinson's specialist nurse contact information (NICE: R6; NSF LTN QR1.2, QR2.4).

Standard 6: Driving status should be determined and patients who drive advised of need to inform DVLA and their insurance (NICE: R7).

Standard 7: Clinicians should be aware of dopamine dysregulation syndrome (NICE: R74).

Standard 8: People with Parkinson's who have sudden onset of sleep should be advised not to drive and to consider any occupational hazards (NICE: R72).

Standard 9: If an ergot-derived dopamine agonist is used, the patient should have a minimum of renal function tests, erythrocyte sedimentation rate (ESR) and chest radiograph performed before starting treatment, and annually thereafter (NICE: R30, R40).

Standard 10: End of life care requirement should be considered throughout all phases of the condition and both patient and carers should be given the opportunity to discuss end of life issues (NICE: R82, 83)

Occupational therapy audit standards

Standard 1: Occupational therapy should be available and considered at diagnosis and during each regular reviews for people with Parkinson's. (NICE: R12, R80)

Standard 2: Occupational therapists reviewing people with Parkinson's should give particular consideration to (NICE R80):

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

Standard 3: There is timely integrated assessment involving all relevant health agencies leading to individual care plans, which ensure that staffs have access to all relevant records and background information about the person's condition, test results and previous consultations. (NSF QR1)

Standard 4: People with Parkinson's should have a comprehensive care plan agreed between the individual, their family and/or carers and specialist and secondary healthcare providers (NICE R5)

Principle 3: Development of goals in collaboration with the individual and carer with regular review

Physiotherapy audit standards

Standard 1: Physiotherapists reviewing people with Parkinson's should give particular consideration to (NICE: R78):

- gait re-education, improvement of balance and flexibility
- enhancement of aerobic capacity
- improvement of movement initiation
- improvement of functional independence, including mobility and activities of daily living
- provision of advice regarding safety in the home environment

Speech and language therapy audit standards

Standard 1: It is recommended to make audio or video recordings of spontaneous speech (Dutch Guidelines: R9a).

Standard 2: It recommended that the speech and language therapist expressly takes note of the individual's 'on/off' periods during treatment (Dutch Guidelines:R6, R19b).

Standard 3: Patients with Parkinson's, their carers and relatives should be provided with the information and should have the opportunity to make informed decisions about their care and treatment (NICE: R1-5, NSF: Q1).

Standard 4: A perceptual assessment should be made, including respiration, phonation, resonance, articulation, prosody and intelligibility, to acquire an accurate profile for analysis (RCSLT Clinical Guidelines).

Standard 5: People with Parkinson's should be asked explicitly about difficulties with word finding and conversations (Dutch Guidelines: R11).

Standard 6: 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).

Standard 7: Speech and language therapists should give particular attention to improvement of vocal loudness, pitch range and intelligibility (NICE: R81).

Appendix C – Patient management audit

Appendix C.1 – Patient management: Full Definitions of Parkinson's Phases

Diagnosis	<ul style="list-style-type: none"> • From first recognition of symptoms/sign/problem • Diagnosis not established or accepted
Maintenance	<ul style="list-style-type: none"> • Established diagnosis of Parkinson's • Reconciled to diagnosis • No drugs or single drug 4 or less doses/day • Or 2 drugs but stable medication for >3/12 • Absence of postural instability
Complex	<ul style="list-style-type: none"> • Drugs more than 5 doses or more than 2 drugs • Inability to accept diagnosis despite adequate information and education • Any parenteral medication (apomorphine) • Dyskinesia • Neuro-surgery considered • 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	<ul style="list-style-type: none"> • Inability to tolerate adequate dopaminergic therapy • Unsuitable for surgery • Advanced co-morbidity (life threatening or disabling)

Appendix C.2 – Patient management: Full list of domain questions

	Domain 1: Non-motor assessments during the previous year (Maximum score = 12)
1	Blood pressure documented lying (or sitting) and standing
2	Evidence of enquiry/assessment re cognitive status
3	Evidence of enquiry re hallucinations/psychosis
4	Evidence of enquiry re mood
5	Evidence of enquiry re communication difficulties
6	Evidence of enquiry re problems with swallowing function
7	Evidence of screening for malnutrition (weight checked at least yearly)
8	Evidence of enquiry re problems with saliva
9	Evidence of enquiry re bowel function
10	Evidence of enquiry re bladder function
11	Evidence of enquiry re pain
12	Evidence of enquiry re sleep quality
	Domain 2: Motor and ADL assessment during the previous year (Maximum score = 12)
1	Evidence of enquiry re "On/Off" fluctuations
2	Evidence of enquiry/assessment re problems with gait including freezing
3	Evidence of enquiry re falls and balance
4	Evidence fracture risk/osteoporosis considered
5	Evidence of enquiry re problems with bed mobility (e.g. getting in/out of bed, moving/rolling from side to side once in bed)
6	Evidence of enquiry re problems with transfers (e.g. out of chair/off toilet/car)
7	Evidence of enquiry/assessment of tremor
8	Evidence of enquiry re problems with dressing
9	Evidence of enquiry re problems with hygiene (e.g. washing/bathing/hair/nails)
10	Evidence of enquiry re difficulty eating and drinking (i.e. cutlery/managing drinks etc. not swallowing)
11	Evidence of enquiry re domestic activities (cooking/cleaning/shopping)
12	Evidence of enquiry re problems with function at work
	Domain 3: Multi-disciplinary involvement during the previous year (Maximum score 8)
1	Evidence of referral/input from Parkinson's nurse
2	Evidence of physiotherapy referral/assessment/input
3	Evidence of occupational therapy referral/input
4	Evidence of speech and language therapy referral/input for communication
5	Evidence of speech and language therapy referral/input for swallowing
6	Evidence of social work referral/input
7	Evidence that patient's and carers' entitlement to financial benefits has been considered and advice given
8	Evidence that carers' needs have been considered
	Domain 4: Communication and education (Maximum score 4)
1	Evidence that patient and/or carer has been offered written information about Parkinson's
2	Evidence that patient and/or carer has been signposted to Parkinson's UK

3	Evidence of communication with carers about their entitlement to carer assessment and support services
4	Has the patient and or carer been offered a Parkinson's education/self management course since diagnosis?