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NATIONAL PARKINSON'S AUDIT 2012

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Foreword

The Parkinson's Audit provides a key benchmark of the quality of care provided to people living with Parkinson's across the UK.

This report, outlining the results of the 2012 audit, continues to illustrate that healthcare professionals are working to evidence-based standards on the care of people with Parkinson's and reveals many examples of good practice.

For instance, more than 97% of patients managed by an elderly care or neurology service were reviewed by a doctor or nurse specialist within the previous year. 87% of patients were referred to occupational therapy at an appropriate time. 85% of patients referred to physiotherapy were seen within the time specified by local standards. 91% of speech and language therapy services provided a full service for people with Parkinson's for communication issues.

However, there are areas for improvement. Less than half (48.2%) of elderly care services and only 36.2% of neurology services have information about Parkinson's available in all their clinics. This is a major barrier to patients taking control of their own condition and being enabled to make informed choices about their care. And 5.5% of Parkinson's patients in the audit did not have access to a Parkinson's nurse specialist.

Parkinson's UK is committed to working with the professional community to address these gaps and drive up standards of care. As part of this activity, we are now working to strengthen the audit, so it becomes a central tool in driving quality improvement. We are revising the structure and process of the audit to better reflect the needs of the Parkinson's community and ensure timely reporting. We are also determining how best to use the resources of Parkinson's UK to address inequalities in care.

Crucially, service users are now involved at all stages of the audit, and a Patient Reported Experience Measure (PREM) will ensure their voices are heard and acted on.

The audit would not be possible without the help of the hundreds of doctors, nurses, occupational therapists, physiotherapists and speech and language therapists who supply the data we request. We are grateful for their continued commitment to the audit, and for their desire to provide the best possible services.

Steve Ford, Chief Executive

Acknowledgements

This national clinical audit would not be possible without the commitment and support of the healthcare professionals who care for people living with Parkinson's. Those professionals who agreed to take part in the audit provided data on the quality of care provided to people with Parkinson's, which enables us to provide a national picture of the quality of care that people living with Parkinson's receive. We thank all the professionals who contributed to the audit.

This report has been prepared by the National Parkinson's Audit Clinical Steering Committee at Parkinson's UK. The Steering Committee has served as the governance body for the design and management of the national clinical audit.

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Executive summary

This report summarises the findings of the National Parkinson's Audit carried out in 2012-13. The audit is intended to measure the quality of care provided to people living with Parkinson's in comparison to a range of published national guidance relating to the care of people with the condition.

This national audit is unique in that it has an entirely integrated multiprofessional approach, involving elderly care and neurology consultants who care for people with movement disorders, Parkinson's nurse specialists, and occupational therapists, physiotherapists and speech and language therapists who also care for people with Parkinson's. The audit involves all these professions in measuring the quality of their practice, within their model of care provision.

This audit reports on the care provided to 4,079 people with Parkinson's. Data were submitted from 59 elderly care services, 51 neurology services, 43 occupational therapy services, 52 physiotherapy services and 35 speech and language therapy services.

Key findings

Good practice

The main findings of the national audit reveal many areas of good practice in the care of people with Parkinson's by all professions involved in the audit. A summary of good practice is in the box.

Good practice revealed by the national audit on the care of people with Parkinson's

Medical and specialist nursing care

Review within a year **–** 98.5% of patients managed in an elderly care service and 97.4% of patients managed in a neurology service were reviewed by a doctor or Parkinson's nurse specialist within the previous year.

Medication prescribed **–** 98.5% of patients in an elderly care service and 98.8% of patients in a neurology service had drugs prescribed in compliance with national prescribing guidelines for initial therapy. When drugs are changed in early and later stages of disease, 97.3% of patients in an elderly care service and 97.5% of patients managed in a neurology service had drugs prescribed in compliance with national guidelines.

Assessment **–** Four services (Two elderly care services and two neurology services) achieved 100% compliance with three domains of assessment – non-motor function, motor and activities of daily living assessment function, and education and multidisciplinary involvement.

Occupational therapy

Timing of referrals **–** 87.5% of patients were referred to occupational therapy at an appropriate time in their treatment. Patients referred to occupational therapy were seen within four to seven weeks of referral.

Information for assessment **–** For 93.2% of patients with Parkinson's that are referred to occupational therapy, most or some of the information essential for occupational therapy assessment

and intervention is available.

Use of evidence base **–** occupational therapy services access a very wide range of evidence to inform clinical practice or guide intervention for people with Parkinson's.

Wide range of interventions **–** occupational therapy services address a wide range of needs of people with Parkinson's, and use a wide range of interventions and treatment strategies.

Physiotherapy

Physiotherapy notes **–** 97.9% of patients had physiotherapy notes that identified the area/s of anticipated intervention in the initial assessment. 90.8% of patients in the physiotherapy audit had initial assessment notes that recorded the treatment strategies and techniques to be used for intervention.

Timing of appointments **–** 85.9% of patients referred to physiotherapy were seen in accordance with the local standard for time from referral to initial assessment.

Consistency with national guidance **–** Physiotherapists demonstrated that they are using treatment interventions for people with Parkinson's that are consistent with national guidance.

Speech and language therapy

Speech and language service for communication issues **–** 91.0% of speech and language therapy services in the audit provide a full speech and language therapy service for people with Parkinson's for issues with communication.

Acceptance of self-referrals for communication issues **–** 94.3% of speech and language therapy services in the audit accept patients with Parkinson's who self-refer or refer to the service for communication issues.

Availability of services **–** Video fluoroscopy services are accessible for all speech and language therapy services in the audit, either on site or via another service.

Access to continuing development on Parkinson's **–** In 90.9% of speech and language therapy services, speech and language therapists have access to continuing development related to the management of people with Parkinson's at least yearly.

Meeting target times for appointments **–** For 90.5% of patients with Parkinson's referred to speech and language therapy services, the target time between referral to appointment was met (or a reason for the delay was documented), and for 93.7% of Parkinson's patients referred, the target time from intention to treat decision to first appointment was met (or a reason for the delay was documented).

Full profiles carried out in assessments **–** 92.6% of patients have a full profile of communication skills carried out at first referral to a speech and language therapy service (or a reason given for why the assessment would be inappropriate) and 90.4% of patients have a full profile of communication skills carried out at each review (or a reason given for why the profile is not done).

Use of the evidence base **–** 97.0% of speech and language therapy services in the audit said the choice of speech and language therapy assessments are informed by the evidence base and speech and language therapy services access a very wide range of evidence to inform clinical practice or guide intervention for people with Parkinson's.

Management plan **–** For 90.4% of patients, there was documentation of a management plan based on assessment detailed in the patient's notes.

Onward referrals **–** Of the patients with Parkinson's for whom an onward referral was appropriate,

Good practice revealed by the national audit on the care of people with Parkinson's
referrals were documented for 92.4% of the patients.

Shortcomings in care of people with Parkinson's

The national audit also revealed aspects of practice that could be improved to enhance the care provided to people living with Parkinson's. A summary of the main issues is in the box.

Shortcomings in care of people with Parkinson's revealed by the national clinical audit

Medical and specialist nursing care

Lack of access to a Parkinson's nurse specialist – 135 (5.5%) of Parkinson's patients (82 managed by an elderly care service and 53 by a neurology service) had no access to a Parkinson's nurse specialist because the service is not available.

Lack of availability of information about Parkinson's in clinics – Only 48.2% of elderly care services and 36.2% of neurology services have information about Parkinson's available in all their clinics.

Lack of provision of written information on adverse effects of new medications **–** The provision of written information on potential adverse effects for new medications was documented for only 58.1% of elderly care patients and 55.3% of neurology patients.

Lack of advice on driving for patients experiencing daytime sleepiness – Of the 900 patients with Parkinson's who drive and who experience daytime sleepiness, only 215 (59.9%) of elderly care services and 368 (68.0%) of neurology services patients were given advice about driving and asked to consider occupational hazards.

Lack of monitoring for impulse control disorders **–** 29.9% (37.7% of elderly care patients and 23.6% of neurology patients) taking dopamine agonist medication were not monitored for impulse control disorders during the preceding year.

Lack of monitoring of patients on an ergot-derived dopamine agonist **–** Of the 63 patients on an ergot-derived dopamine agonist, only 54.0% (62.5% of elderly care and 39.1% of neurology) of patients were properly monitored.

Lack of discussion of end-of-life issues **–** Only 26.8% of patients with markers of advanced disease were given the opportunity to discuss end-of-life care issues with appropriate healthcare professionals.

Occupational therapy

Lack of integration **–** Only 25.6% (10) of occupational therapy services reported being members of a Parkinson's specialist multidisciplinary team, while another 25.6% (10) of occupational therapy services reported being members of neurology or an elderly care specialist service.

Lack of access to continuing professional development about Parkinson's **–** 22.0% of occupational therapy services reported that occupational therapists don't have access to continuing professional development related to the management of people with Parkinson's at least yearly. 14.6% (six services) reported no availability of induction and support strategies for new occupational therapists working with people with Parkinson's.

Shortcomings in care of people with Parkinson's revealed by the national clinical audit

Lack of standardised assessments **–** Overall, few occupational therapy services regularly use standardised assessments with people with Parkinson's. The most frequently used standardised assessment is the Canadian Occupational Performance Measure, used by 14 (32.6%) of occupational therapy services. All other standardised assessments referred to in the audit data collection tool, were used by about 20% of occupational therapy services.

Lack of consistent use of occupational therapy guidance – Six (14.0%) of occupational therapy services reported not following the recommendations in occupational therapy Best Practice Guidance published by Parkinson's UK in 2010.

Physiotherapy

Lack of training and education for physiotherapists – Not all physiotherapists (51.1% responded 'no') appear to have access to training in the management of people with Parkinson's. Only 28.3% of physiotherapists reported having training in the management of people with Parkinson's on a regular basis.

Lack of integration and time between diagnosis and referral – 32.6% of physiotherapists reported that they work as members of a multidisciplinary team. In some services, patients are referred early and are seen by a physiotherapist as part of a multidisciplinary assessment. However, some patients may not be referred for assessment for nearly three years following diagnosis.

Lack of access to evidence of good practice for the assessment and management of people with Parkinson's – Not all physiotherapists access the evidence that is readily available for the assessment and management of people with Parkinson's, specifically the UK Quick Reference Cards. The UK Quick Reference Cards were reported as being used for 46.0% of patients.

Speech and language therapy

Lack of working in an integrated approach – Only six (19.4%) of the 35 speech and language therapy services participating in the audit reported working in a specialist clinic for patients with Parkinson's**.** Only eight (24.2%) of speech and language therapists were members of Parkinson's specialist multidisciplinary teams. Another seven (21.2%) of speech and language therapists were members of general neurology or elderly care specialist services.

Lack of availability of speech language therapy services for people with Parkinson's –18 (54.5%) services are able to offer Lee Silverman Voice Treatment (LSVT) as required and another six services (18.2%) are able to offer a variant of LSVT. Assistive technology (AAC) is restricted in 11 (33.3%) of speech and language therapy services.

Lack of use of standardised speech and language therapy assessments of people with Parkinson's – Overall, eight (24.2%) speech and language therapy services regularly use standardised assessments of speech, voice and language variables with people with Parkinson's and fewer (three or 9.1%) regularly use standardised assessments of swallowing.

Lack of reviews by speech language therapy services of people with Parkinson's – Only four (12.1%) of speech and language therapy services routinely review people with Parkinson's within six–12 months. For one-third of speech and language therapy services, patients are reviewed on request of a multidisciplinary team or a Parkinson's nurse specialist, and for another third of speech and language therapy services, patients are not automatically reviewed.

Lack of audio recordings and assessments of people with Parkinson's – For only 48 (12.4%) people with Parkinson's, audio recordings of initial assessment and follow-up were available. In some Trusts this may be due to Trust confidentiality policy.

Lack of recording of drug state **–** Only 67 (17.4%) of Parkinson's patients had a speech and

Shortcomings in care of people with Parkinson's revealed by the national clinical audit
language therapy assessment that included documentation of the patient's drug cycle state. For only 56 (14.4%) patients, the documentation included reference to the 'off' or 'on' state. This may be ameliorated by the fact that recent developments in administration of drugs means that a sharp peak dose effect is avoided. ***Lack of completeness of assessments*** **–** Initial assessments and review assessments included all subsystems in both stimulated and unstimulated conditions for only 84 (23.0%) Parkinson's patients. ***Reports by speech language therapy services*** – For 55 (15.4%) patients with Parkinson's, speech and language therapists did not provide a report. Reports did not routinely include the required contents of speech and language therapy reports.

Actions needed for improvement of the care of people with Parkinson's

Integration of services needed by people living with Parkinson's

Elderly care and neurology services, and commissioners of these services, need to consider how medical, specialist Parkinson's nursing, occupational therapy, physiotherapy and speech and language therapy services can be organised to support an integrated multiprofessional approach to service delivery for people with Parkinson's.

Such an approach supports the recognition that Parkinson's is a complex condition with many varied symptoms and the potential for complications from treatment. An integrated approach to the care of these patients' aims to facilitate and support the provision of a full range of on going assessments and therapies, including those relating to the psychological and psychiatric issues patients and carers may face. The approach can also facilitate the development of expertise within the healthcare professional team to focus more effectively on the clinical and therapeutic needs of people with Parkinson's.

Professionals providing care to people with Parkinson's should arrange to meet with local managers and commissioners, presenting the evidence of good practice concerning an integrated model of service delivery and the findings of this audit. They need to consider any barriers to changing the service delivery model for people with Parkinson's and overcoming any local barriers to an integrated service delivery approach.

Improvement of clinic processes to support the care of people with Parkinson's by elderly care and neurology services

Elderly care and neurology services that provide care for people with Parkinson's should consider how to improve a number of processes that support the care of people with Parkinson's. Key actions needed are to:

Review how services can be organised to support an integrated multiprofessional approach to service delivery for people with Parkinson's in order to focus on the full range of

clinical and therapeutic needs of people with the condition.

Improve clinic accessibility to facilitate the review by a specialist of every patient with Parkinson's at least every year.

Provide suitable written information on Parkinson's in all clinics in which people with Parkinson's are seen, including information on adverse effects of new medications prescribed for people with the condition.

Provide advice on the impact of driving for all patients experiencing daytime sleepiness.

Monitor for impulse control disorders for all patients on dopamine agonists.

Appropriately monitor all patients on ergot-derived dopamine agonists.

Support with symptom control and end-of-life care planning for people with markers of advanced Parkinson's.

Provide organisational support for ongoing professional training of staff caring for people with Parkinson's.

Review of use of standardised assessments and evidence-based practice

Professionals involved in the assessment and management of people with Parkinson's need to consider the availability of standardised tools relevant to the assessment of people with the condition. Professionals should consider the regular use of such tools to support the provision of a full range of care and services to people with Parkinson's.

Occupational therapists and physiotherapists need to access evidence of best practice relevant to the assessment and treatment of people with Parkinson's, particularly guidelines published by professional bodies and Parkinson's UK.

Training and continuing professional development for therapists assessing and treating people with Parkinson's

Medical, nursing and therapy services need to consider how the on-going training and development of all professionals caring for people with Parkinson's can be maintained.

Availability of speech and language therapy (SLT) services for patients with Parkinson's

Limitations in the availability of speech and language therapy services for people with Parkinson's should be addressed so that all speech and language therapy services are able to offer Lee Silverman Voice Treatment (LSVT) or a variant, assistive technology (AAC) and fibreoptic endoscopic evaluation of swallowing (FEES) to patients with Parkinson's when these services are indicated.

Improvements in professional practices

All professional groups participating in the audit should review the audit

findings in detail and act to improve professional practices where the audit has demonstrated shortcomings.

The role of Parkinson's UK in acting on the audit findings

Working with relevant professional groups, Parkinson's UK and the Parkinson's National Audit Governance Group should consider:

creating a professional forum in which examples of information for people with Parkinson's and assessment tools and checklists can be shared among the professions involved in the care of people with the condition

providing and promoting standardised validated information on Parkinson's medications that specialist services can refer to and use for Parkinson's patients when they are prescribed new Parkinson's medications

the provision of current evidence-based advice on the use of assessment tools

the role of the specialist doctor and Parkinson's nurse specialist in supporting the patient with Parkinson's in end-of-life care and the provision of advice for specialist teams on these roles

amending the data collection directions and tools for future national Parkinson's audits for the areas for which data provided could not be collated because of the lack of consistency in reporting

ensuring that the national audit participants include services for people with Parkinson's in Scotland, Northern Ireland and Wales

recruiting the participation of care homes in the National Parkinson's Audit, given the number of people living with Parkinson's who are cared for in care homes, and also third party or private sector services for people with Parkinson's

Background

This report provides the findings of the 2012 National Parkinson's audit. This is the fourth year the audit has been carried out.

The national clinical audit was developed originally because of concern by professionals and patients and their representatives about the quality of care provided to people living with Parkinson's. The audit uses the 2006 NICE guideline on *Parkinson's disease – Diagnosis and management in primary and secondary care* and other evidence described in the section on Standards, as the basis for measuring the quality of care.

Changes have been made in the design of the national audit from year to year. The changes have reflected a shift in focus from early diagnosis and intervention for people newly diagnosed with Parkinson's to effective continuous management of these patients. Changes also have been based on learning about the best ways to collect reliable data about the care provided to people with Parkinson's from a diverse group of healthcare professionals working in diversely organised healthcare organisations.

The national audit consists of separate audits on the services and care available to people with Parkinson's from doctors, specialist nurses, occupational therapists, physiotherapists and speech and language therapists. The objectives of the audits are described in the report.

Each of the audits consists of two parts: a **service audit** and a **patient management audit**.

Service audits – These audits identify if people with Parkinson's have access to the full range of multiprofessional care and resources recommended by national guidance, including medical, nursing and therapy professionals, and therapies known to be of benefit to people with Parkinson's. The service audits also identify the models of delivery of services used for people with Parkinson's.

Patient management in elderly care services and
Patient management in neurology services – These audits are intended to measure the quality of assessment and management of patients with Parkinson's who are referred by their general practitioners to elderly care specialists in movement disorders or to neurologists.

Occupational therapy audit – This audit measures occupational therapy assessment and management of people with Parkinson's.

Physiotherapy audit – This audit measures physiotherapy assessment and management of people with Parkinson's.

Speech and language therapy audit – This audit measures speech and language therapy assessment and management of people with Parkinson's.

How to read this report

This report is organised as follows.

First, the overall designs of the audits, including their aims, bases for the standards used and the methods used to collect data are described.

Then, specific objectives, findings, shortcomings in care and actions indicated by the findings are presented for the individual audits. The findings include the number and type of patients and organisations participating, and service audit and patient management audit findings in comparison to the standards. The audits are described in the following sequence:

Part 1 – The audits involving elderly care services and neurology services, both service audits and patient care management audits

Part 2 – The occupational therapy audit, both service audit and patient management audit

Part 3 – The physiotherapy audit, both service audit and patient management audit

Part 4 – The speech and language therapy audit, both service audit and patient management audit

The summary provides a list of areas of good practice and areas where improvements in care of people with Parkinson's are needed.

Appendix 1 to this report lists the organisations that participated in the audit. Other appendices provide the standards and guidance documents and data collection tools for each audit in the National Audit. Also, guidance documents provided to participating organisations on checking their data prior to submission and using their individual preliminary reports are in appendices.

Prior to the publication of this report, an Individual Preliminary Report for the National Parkinson's Audit was provided to each participating organisation and service. The reports provided each individual organisation's data compared to the national data for all aspects of the audit. The objectives of the individual reports were to:

- enable each organisation or service to compare their performance with the performance of all other organisations and services participating in the audit
- correct any errors in the data submitted to the national audit prior to the publication of the overall report
- identify areas of good practice and areas of practice in which improvement is needed at individual organisation or service level

Guidance accompanying the individual reports advised organisations and services on how to make the best use of the individual report.

Overall design and methods

Participating services

All healthcare services in the UK that provide care for people with Parkinson's were encouraged to participate in the audit through announcements of the audit by relevant professional bodies and Parkinson's UK. Elderly care, neurology, Parkinson's specialist nursing, occupational therapy, physiotherapy, and speech and language therapy services were targeted for participation.

People with advanced Parkinson's are cared for frequently in care homes. Centres with Parkinson's nurse specialists who go into care homes could have included nursing home patients in the audit. Many residential care home patients are able to attend clinic appointments and they could have been included in the audit. 134 (10.3%) elderly care service patients and 49 (4.3%) neurology service patients in the audit were living in residential or nursing care homes. However, it is likely that people with Parkinson's living in care homes are underrepresented in the audit.

Clinical services were asked to complete a simple registration form to participate in the audit. Services that registered to participate were sent detailed descriptions and instructions for participation in the audit, customised to each audit.

Aims of the audits

The overall aims of the audits are to recognise areas of good practice in the care of people with Parkinson's and to drive the improvement of the quality of care provided to patients with Parkinson's in accordance with national guidance.

Specific objectives for each of the audits are described in the sections of the report on each audit.

Standards

Standards for the patient management audits were derived directly from the following national and international guidance:

- Parkinson's disease – Diagnosis and management in primary and secondary care, NICE clinical guideline 35, 2006
- The National Service Framework for Long Term Conditions, Department of Health, 2005
- *Occupational therapy for people with Parkinson's: best practice guidelines*, British Association of Occupational Therapists and College of Occupational Therapists (in association with Parkinson's UK), 2010
- Guidelines for physical therapy in patients with Parkinson's disease, Royal Dutch Society for Physical Therapy, 2004

- *Clinical guidelines for dysarthria*, Royal College of Speech and Language Therapy

- *Communicating Quality 3, Royal College of Speech and Language Therapy's* guidance on best practice in service organisation and provision, Royal College of Speech and Language Therapy, 2006

Patients included in the audits

The data needed to demonstrate compliance with the standards for the patient management audits tend to be recorded in paper patient records and are abstracted from these records for the audit directly by professionals who participate in the audit. The standards used in the audits are derived directly from national and international guidance. Therefore, it is reasonable for patients to expect that every single patient receives care consistent with the standards (not just a statistically derived sample of the population of patients).

In view of these considerations, the minimum number of patients for each medical service (elderly care and neurology) to include in the audit was set at 20 consecutive patients selected from the time period of 1 August 2012 to 11 January 2013. For medical services, patients were to be included in the audit only if the service continued to be responsible for the patient's care – that is, a patient being seen by a tertiary service for advice only was not included in the audit.

The minimum number of patients included in the audit for each therapy service (occupational therapy, physiotherapy, and speech and language therapy) was 10 patients seen by the service between 1 August 2012 and 11 January 2013. The patients included by therapists could include new patients and patients being followed up. However, each patient was included in the audit one time only even if a patient was seen more than once during the data collection period.

The data entry spreadsheet to be completed for each audit allowed for up to 50 patients to enable services that wished to include more cases to do so.

Guidance for data collection and data collection tools

Clear and detailed explanations of the standards and guidance for data collection were developed for each clinical or professional service. Eight individual data collection tools were developed to support the four service audits and the four patient management audits for the clinical or professional services.

The standards and guidance document and the appropriate data collection tools were sent to each clinical service registered to participate in the audit.

Data confidentiality and security

All participants in the national audit were required to remove all patient

identifiable information prior to submission of the data to the Parkinson's UK Clinical Audit Manager.

The data collection spreadsheet to be used by participants in submitting data for the national audit was password protected. In addition, participants were advised to save and use the spreadsheet only on a secure computer in the work setting.
When the data collection spreadsheet was received at Parkinson's UK, the data were checked for completeness and compliance with NHS confidentiality requirements. If data were complete and confidentiality maintained, the data were saved in encrypted password protected files for data analysis.

Data quality control

Centres completing the elderly care and neurology audits were asked to randomly select 15% of their patient entries and have these entries independently verified. If the data submitted were incomplete, the named lead for participation in the audit was contacted and asked to supply missing data.

Data submitted for the national clinical audit were available only to those involved directly in the analysis of the data. Prior to analysis, all data were checked for sensibility. Subsequently, the analysis of all data completed by one data analyst was validated by a second data analyst.

As described earlier, preliminary data were returned to each participating service, prior to publication of a report on the national findings, in a format that enabled the service to compare the individual service's performance with the performance of other equivalent services. A guidance document was provided to each service on how to use the individual preliminary report, including how to review the preliminary findings and individual cases not consistent with quality-of-care measures, and how to report to Parkinson's UK any errors in the data.

Errors in data in the individual service reports that were submitted to Parkinson's UK were corrected before the national data were analysed and presented in this report. Also, some cases that had been submitted but missed in the initial data collation were identified by individual services. These additional cases were added to the preliminary data and are included in this report.

Services and patients in the audit

Description of services and patients

The types and numbers of services and the numbers of patients in each audit are in the table.

Table 1. Number and types of services and characteristics of patients included in the audit

Services and patients	Elderly care		Neurology		Occupational therapy		Physiotherapy		Speech and language therapy		Total	
	59 services		51 services		43 services		52 services		35 services		240 services	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
	1304	31.8	1155	28.2	460	11.2	789	19.2	391	9.5	4099	99.9
	Patient characteristics											
Age*												
Mode	82.0		71.0		74.0		78.0		78.0		—	
Median	78.0		70.0		76.0		75.0		74.0		—	
Mean	78.0		69.2		74.8		73.6		72.8		—	
Gender												
Male	759	58.3	724	62.8	275	59.8	506	64.1	267	68.6	2531	61.8
Female	543	41.7	429	37.2	185	40.2	283	35.9	122	31.4	1562	38.2
Total	1302	100.0	1153	100.0	460	100.0	789	100.0	389	100.0	4093	100.0
No reply	2	—	2	—	0	–	0	—	2	—	6	—
Ethnicity												
White British	1151	88.9	997	87.4	417	91.0	718	91.3	312	80.2	3595	88.4
Other white	35	2.7	34	3.0	11	2.4	14	1.8	11	2.8	105	2.6
Black/Black British	11	0.9	17	1.5	2	0.4	7	0.9	3	0.8	40	1.0
Asian/Asian British	29	2.2	55	4.8	19	4.1	28	3.6	9	2.3	140	3.4
Mixed	3	0.2	2	0.2	0	0.0	1	0.1	1	0.3	7	0.2
Chinese	3	0.2	5	0.4	0	0.0	0	0.0	0	0.0	8	0.2
Other	5	0.4	5	0.4	2	0.4	1	0.1	3	0.8	16	0.4
Not stated	57	4.4	26	2.3	7	1.5	17	2.2	50	12.9	157	3.9
Total	1294	100.0	1141	100.0	458	99.8	786	100.0	389	100.1	4068	100.1
No reply	10	—	14	—	2	—	3	—	2	—	31	—
Duration of Parkinson's (years)												
Mode	1.0		1.0		3.0		0.0		1.0		—	
Median	5.0		4.0		5.0		3.0		4.0		—	
Mean	7.0		6.0		6.4		5.1		6.0		—	
Phase of Parkinson's**												
Diagnosis	160	12.3	157	13.6	—	—	—	—	55	14.3	—	—
Maintenance	640	49.2	576	49.9	—	—	—	—	238	62.0	—	—
Complex	457	35.1	386	33.6	—	—	—	—	85	22.1	—	—
Palliative	45	3.5	34	2.9	—	—	—	—	6	1.6	—	—
Total	1302	100.0	1155	100.0	—	—	—	—	384	100.0	—	—
No reply	2	—	0	—	—	—	—	—	7	—	—	—

* Unreliable data (ages of 0, 1, 2) have been omitted from the calculation.

** For speech and language therapy, the phase of Parkinson's is at the time of referral to the SLT service that is participating in this audit.

Almost exactly half (49.5%) the patients included in the audit by elderly care and neurology services in the patient management audit were in the maintenance phase of Parkinson's. This proportion is almost identical to that found in the 2011 audit.

Only 7.4% of the patients in the medical and nursing audit were care home residents. Therefore, the overall findings of the audit may not be a reliable reflection of the quality of care for this patient group.

Patient living alone												
Services and patients	**Elderly care**		**Neurology**		**Occupational therapy**		**Physiotherapy**		**Speech and language therapy**		**Total**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Yes	339	26.3	214	18.7	—	—	—	—	—	—	—	—
No	816	63.3	882	77.0	—	—	—	—	—	—	—	—
No but at residential home	75	5.8	27	2.4	—	—	—	—	—	—	—	—
No but at nursing home	59	4.6	22	1.9	—	—	—	—	—	—	—	—
Total	1289	100.0	1145	100.0	—	—	—	—	—	—	—	—
No reply	15	—	10	—	—	—	—	—	—	—	—	—

Patients' current medications

The profile of medications prescribed is in the table. The percentages provided refer to patients for elderly care and neurology services. There are multiple entries as some patients had more than one prescription.

Table 2. Medications currently available for patients with Parkinson's

Current medications	**Elderly care**		**Neurology**		**Total**		
	No.	**%**	**No.**	**%**	**No.**	**% pts**	**%Rx**
Levodopa/PDI*	1091	83.7	900	77.9	1991	81.0	48.9
COMT* inhibitor	199	15.3	214	18.5	413	16.8	10.1
Dopamine agonist	395	30.3	496	42.9	891	36.2	21.9
MAO-B* inhibitor	162	12.4	196	17.0	358	14.6	8.8
Amantadine	39	3.0	79	6.8	118	4.8	2.9
Anticholinergic	28	2.1	32	2.8	60	2.4	1.5
Other, eg research trial drug	13	1.0	18	1.6	31	1.3	0.8
Untreated	108	8.3	102	8.8	210	8.5	5.2
Total patients	1304	—	1155	—	2459	—	—
Total prescriptions	2035	—	2037	—	4072	—	—

* PDI stands for peripheral decarboxylase inhibitor, COMT stands for catechol-O-methyltransferase, and MAO-B stands for monoamine oxidase-B.

Part 1 – Medical and specialist nursing care

Patient service audit

Objectives

The objectives of the patient service and patient management audits were to:

compare local Parkinson's medical and nursing services and care for people with Parkinson's with national guidance

enable local Parkinson's medical and nursing teams to compare their performance with the performance of other Parkinson's services participating in the audit

identify areas of good practice in the care of people with Parkinson's and shortcomings in care

suggest actions indicated by the audit findings

In addition, an objective was to explore the relationship between models of service provision and the provision of some aspects of quality of care for people with Parkinson's.

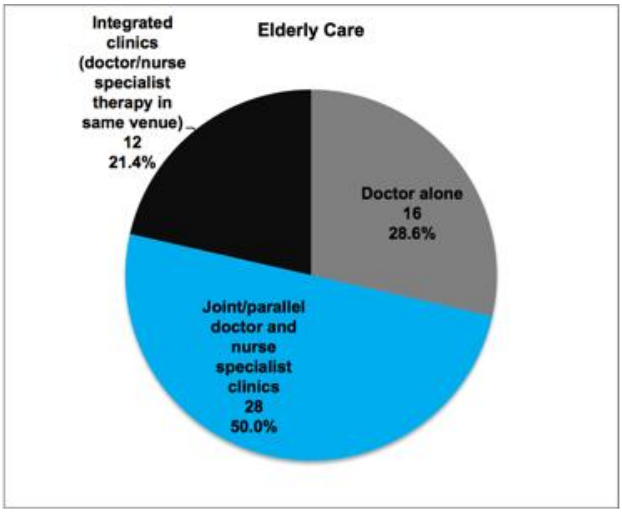
Findings

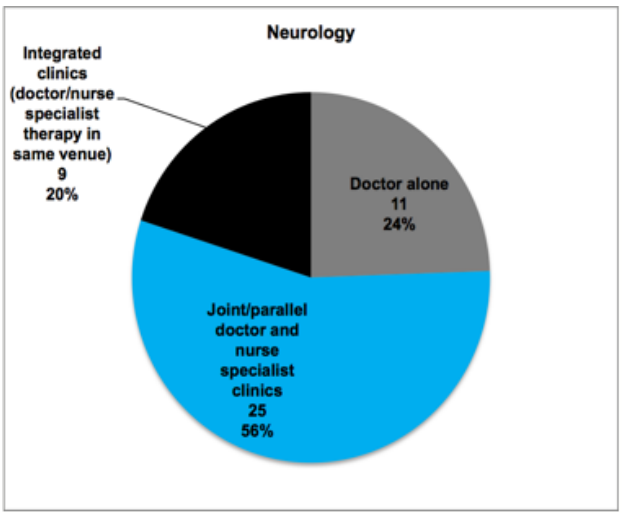
Three elderly care services and four neurology services did not provide information for the service audit, so the total elderly care services for the service audit is 56 and the total neurology services in the service audit is 47.

Model of service provision

The distribution of the main models of service by specialties for people with Parkinson's is in the pie charts.

Figure 1. Pie charts showing the distribution of models of service for people with Parkinson's





The distribution for elderly care services is substantially different from what was reported in the previous year, in which 53% of patients seen by elderly care consultants were seen in a doctor alone clinic setting. The numbers of services following the integrated clinic model are very small (12 elderly care services, 21.4% of all elderly care services and nine neurology services, 20.0% of neurology services).

87.5% of elderly care services, but only 59.6% of neurology services see all or most (≥75%) patients in a specific Parkinson's or movement disorder clinic.

Table 3. Number of patients seen in a specific Parkinson's or Movement Disorder clinic

Patients	Elderly care		Neurology		Total	
	No.	%	No.	%	No.	%
All	29	51.8	10	21.3	39	37.9
Most (≥75%)	20	35.7	18	38.3	38	36.9
Some (25–74%)	5	8.9	4	8.5	9	8.7
Few (≤25%)	0	0.0	3	6.4	3	2.9
None	2	3.6	12	25.5	14	13.6
Total	**56**	**100.0**	**47**	**100.0**	**103**	**100.0**

Information available to patients

The percentage of clinics in which written information regarding Parkinson's is routinely available when patients attend a clinic is in Table 4.

Table 4. Number of clinics having information on Parkinson's routinely available when patients attend clinics

Clinics	Elderly care		Neurology		Total	
	No.	%	No.	%	No.	%
All	27	48.2	17	36.2	44	42.7
Most (>75%)	17	30.4	18	38.3	35	34.0
Some	6	10.7	8	17.0	14	13.6
Not routinely available	6	10.7	4	8.5	10	9.7
Total	**56**	**100.0**	**47**	**100.0**	**103**	**100.0**

Use of assessment tools

The routine use of tools to assess Parkinson's patients varies considerably. The tools explored if a formal activities of daily living assessment tool or checklist and a Parkinson's non-motor symptoms questionnaire or other form of checklist to screen for non-motor symptoms was used in reviews and assessments of patients. In addition, data on the routine availability of a standardised assessment tool to assess and monitor cognitive function in clinic venues and a standardised assessment tool to assess mood in clinic venues were captured.

Table 5 shows whether or not tools are used or available in all, most or some clinics for elderly care and neurology services.

Table 5. Use and availability of assessment tools for Parkinson's patients in clinic venues

Type of assessment tool	All clinics				Most clinics				Some clinics				Not routinely available			
	Elderly care		Neurology		Elderly care		Neurology		Elderly care		Neurology		Elderly care		Neurology	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
An activities of daily living assessment checklist is used when patients are reviewed	12	21.4	6	12.8	13	23.2	9	19.1	14	25.0	15	31.9	17	30.4	17	36.2
Patients are screen for non-motor symptoms using a non-motor symptoms questionnaire or checklist	13	23.2	8	17.0	13	23.2	6	12.8	18	32.1	18	38.3	12	21.4	15	31.9
A standardised tool to assess cognitive function is routinely available	30	53.6	17	36.2	19	33.9	11	23.4	4	7.1	9	19.1	3	5.4	10	21.3
A standardised tool to assess mood is routinely available	18	32.1	12	26.1	17	30.4	5	10.9	7	12.5	10	21.7	14	25.0	19	41.3

Doctor and Parkinson's nurse specialist participation in continuing medical education on movement disorders

The data collection for the audit requested information on the percentage of consultants who provide medical input to the service for Parkinson's patients *and* who have attended movement disorder specific external continuing medical education during the previous year.

However, the data were submitted in various formats, such as fractions, percentages and integers. Therefore, it is not possible to summarise the data on this question.

Availability of Parkinson's nurse specialist

For 51 (92.7%) elderly care services and 46 (97.9%) neurology services, patients can access a Parkinson's nurse specialist.

47 (97.9%) Parkinson's nurse specialists associated with elderly care services and 40 (90.9%) Parkinson's nurse specialists in neurology services attended Parkinson-specific external continuing education in the year prior to data collection.

The main arrangement for contact between consultants and Parkinson's nurse specialists is in Table 6.

Table 6. Number of services with types of arrangements for contact between consultants and Parkinson's nurse specialists

Main arrangement	Elderly care		Neurology		Total	
	No.	%	No.	%	No.	%
Regular contact in multidisciplinary meeting, joint or parallel clinic	35	67.3	18	39.1	53	54.1
Regular face-to-face contact outside clinic	6	11.5	12	26.1	18	18.4
Regular telephone/email contact with occasional face-to-face contact	7	13.5	15	32.6	22	22.4
Telephone/email contact only	3	5.8	1	2.2	4	4.1
No or rare contact	1	1.9	0	0.0	1	1.0
Total	**52**	**100.0**	**46**	**100.0**	**98**	**100.0**
No reply	7	—	5	—	12	—

Patient management audit

Objectives

The objective of the patient management audit was to compare local practice in the care of people with Parkinson's with the eight standards relating to the quality of care for people with Parkinson's. These were derived from national and international guidance and guidance from professional bodies.

Findings

Overall compliance with the standards is summarised in the table. The percentages are based on 2,459 patients in the audit, 486 patients for whom a Parkinson's drug was started for the first time during the year, 900 patients who experienced daytime sleepiness and are drivers, 891 patients for whom a dopamine agonist was prescribed of which 63 patients were prescribed an ergot-derived dopamine agonist.

Table 7. Compliance with medical and specialist nursing standards for the care of people with Parkinson's

Standard	Elderly care		Neurology		Total	
	No.	%	No.	%	No.	%
1. 100% of people with Parkinson's are reviewed by a specialist (doctor or nurse) at six–12 month intervals *(Parkinson's NICE R12, R77; NSF LTC QR2)*	1284	98.5	1123	97.4	2407	97.9
2. 100% of people on medications for Parkinson's are prescribed drugs in accordance with national guideline options for initial and later pharmacological therapy *(Parkinson's NICE Table 7.1, Table 7.4; SIGN Guideline 2.2.1, 2.2.2)*						
a. The choice of first line prescription complies with national prescribing guidelines for initial therapy	255	98.5	242	98.8	497	98.6
b. Medication changes comply with PD NICE guidelines for prescribing in early and later disease	215	97.3	232	97.5	447	97.4
3. 100% of people with Parkinson's are provided with written information regarding potential adverse effects for any new medications *(derived from Parkinson's NICE R3)*	162	58.1	156	55.3	318	56.7
4. 100% of people who have daytime sleepiness and who are drivers are given advice about driving and asked to consider occupational hazards *(Parkinson's NICE R72)**	215	59.9	368	68.0	583	64.8
5. 100% of patients on dopamine agonists are monitored for impulse control disorders including dopamine dysregulation syndrome *(Parkinson's NICE R54)*	279	62.3	425	76.4	704	70.1
6. If an ergot-derived dopamine agonist is prescribed, 100% of patients have a minimum of renal function tests, erythrocyte sedimentation rate (ESR) and chest radiograph (CXR) performed before starting treatment and annually thereafter (*Parkinson's NICE R30 and 40)*	15	37.5	14	60.9	29	46.0
7. For 100% of people with Parkinson's, end-of-life care requirements are considered throughout all phases of the disease *(Parkinson's NICE R82)*	*See text for details*					
8. 100% of people with Parkinson's and their carers are given the opportunity to discuss end-of-life issues with appropriate healthcare professionals *(Parkinson's NICE R83)*	89	26.7	52	26.9	141	26.8

* The wording of the original standard was changed to daytime sleepiness rather than sudden onset of sleep to identify potential quality of life and medication issues.

Review by a specialist

Of the 98.5% of patients in elderly care services and the 97.4% of patients in neurology services that were reviewed within the last year, a doctor reviewed 94.1% of patients in elderly care services and 90.1% of patients in neurology services.

The 76 patients in elderly care services that were not reviewed by a doctor in the past year included eight who were reported as never having had a consultant review. 65 patients in neurology services had not had a medical review in the past year, 44 were not reviewed in more than two years and five were reported as never having a consultant review.

A Parkinson's nurse specialist reviewed 885 patients (69.4%) in elderly care services and 908 patients (78.8%) in neurology services within the last year. 82 patients managed by an elderly care service and 53 patients managed by a neurology service have no access to a Parkinson's nurse specialist because the service is not available. Details about reviews of patients are in Table 8.

Table 8. Time since patients had their most recent medical review and Parkinson's nurse specialist assessment for elderly care and neurology services

Timing	Medical review				Parkinson's nurse Specialist assessment			
	Elderly care		Neurology		Elderly care		Neurology	
	No.	%	No.	%	No.	%	No.	%
Less than six months	1033	79.3	824	71.5	681	53.4	745	64.7
six–12 months	193	14.8	215	18.6	204	16.0	163	14.1
More than one year	47	3.6	65	5.6	92	7.2	60	5.2
More than two years	21	1.6	44	3.8	38	3.0	21	1.8
Never	8	0.6	5	0.4	179	14.0	110	9.5
No service	—	—	—	—	82	6.4	53	4.6
Total	1302	99.9	1153	99.9	1276	100.0	1152	99.9
No reply	2	—	2	—	28	—	3	—

New and current medication

263 patients in elderly care services and 223 patients in neurology services were started on a Parkinson's medication for the first time during the past year. The drugs started for people with Parkinson's are in Table 9.

Table 9. Medications initiated for the first time for people with Parkinson's

Medications started	Elderly Care		Neurology	
	No.	%	No.	%
Levodopa/PDI	196	74.5	140	62.8
COMT inhibitor	4	1.5	7	3.1
Dopamine agonist	32	12.2	55	24.7
MAO-B inhibitor	20	7.6	35	15.7
Amantadine	0	0.0	2	0.9
Anticholinergic	2	0.8	1	0.4
Other, eg research trial drug	5	1.9	1	0.4
Total patients	263	—	223	—
Total prescriptions	259	—	241	—

206 patients in elderly care services and 226 patients in neurology services had their Parkinson's medication altered during the previous year. The drugs involved in the change are in Table 10.

Table 10. Medications used when people with Parkinson's have their drugs changed

Medications used in changes	Elderly Care		Neurology	
	No.	%	No.	%
Levodopa/PDI	53	25.7	62	27.4
COMT inhibitor	44	21.4	37	16.4
Dopamine agonist	72	35.0	65	28.8
MAO-B inhibitor	35	17.0	38	16.8
Amantadine	6	2.9	19	8.4
Anticholinergic	5	2.4	5	2.2
Other, eg research trial drug	3	1.5	5	2.2
Total patients	206	—	226	—
Total prescriptions	218	—	231	—

For 255 (98.5%) of elderly care patients and 242 (98.8%) of neurology patients started on a Parkinson's medication for the first time, the prescription was consistent with national guidance. For 97.3% of elderly care patients and 97.5% of neurology patients for whom a change was made in medication, the prescription was consistent with national guidance. One neurology patient was on a drug being used in a research trial.

Adverse effects monitoring

The aspects of monitoring of adverse effects that were included in the audit included enquiring about daytime sleepiness and advising patients experiencing daytime sleepiness about driving, monitoring of compulsive behaviour in patients taking dopamine agonists, and monitoring for fibrosis-related adverse effects for patients taking ergot-derived dopamine agonists.

Action on daytime sleepiness

Overall, 69.4% of Parkinson's patients were asked about daytime sleepiness, as shown in Table 11. For 33.2% (424) of elderly care patients and 27.5% (310) of neurology patients, there is no evidence that patients were asked about daytime sleepiness. These patients are at potential risk if they are unaware of the potential dangers of driving or using machinery during an episode of sleepiness. Excess daytime sleepiness also impacts on quality of life and should be considered when patients are reviewed, as a change in medication may be indicated.

Table 11. Number of patients for whom there is evidence of enquiry about daytime sleepiness				
Enquiry about daytime sleepiness	**Elderly care**		**Neurology**	
	No.	**%**	**No.**	**%**
Yes	852	66.8	817	72.5
No	424	33.2	310	27.5
Total	1276	100.0	1127	100.0
No reply	28	—	28	—

Table 12 shows the number and percentage of patients who are drivers and with whom driving was discussed and advice given.

Table 12. Number of patients who are drivers and who experience daytime sleepiness and for whom discussion about the impact on driving and advice was documented				
Discussion about driving	**Elderly care**		**Neurology**	
	No.	**%**	**No.**	**%**
Yes	215	59.9	368	68.0
No	144	40.1	173	32.0
Total	359	100.0	541	100.0
No reply	259	—	204	—

In elderly care services, there were 359 drivers among the Parkinson's patients and in neurology services, there were 541 drivers. Of these Parkinson's patients who are drivers, for only 59.9% (215) of elderly care patients and 68.0% (368) neurology patients was there evidence of discussion of daytime sleepiness and advice given. The number of no reply responses is attributable to the way the question was stated, which advised participants in the audit to skip the question if the patient did not experience daytime sleepiness.

Monitoring of patients on dopamine agonists

Of the 1,004 patients for whom dopamine agonists were reported as prescribed, only 70.1% (59.6% of elderly care service patients and 76.4% of neurology service patients) were monitored for the development of compulsive behaviour.

Monitoring of patients on ergot-derived dopamine agonists

63 (40 elderly care and 23 neurology) patients were reported as being on ergot-derived dopamine agonists. Of this small number of patients, only 15 (37.5%) patients in elderly care services and 14 (60.9%) patients in neurology services had renal function tests, erythrocyte sedimentation rate (ESR) and chest radiograph (CXR) to monitor for fibrosis-related adverse effects.

Advanced care planning

Of the patients included in the audit, 24.3% (315) of patients in elderly care services and 16.0% (185) of patients in neurology services were reported as having markers of advanced Parkinson's, including dementia, increasing frailty, impaired swallowing or a nursing home level of care being required.

Discussion about end-of-life issues was documented for patients with markers of advanced disease for 26.7% (89) in elderly care services and for 26.9% (52) of patients in neurology services.

A few patients were offered information about or had set up a Lasting Power of Attorney (55 patients in elderly care services and 41 in neurology services). For over 1,000 patients in each of elderly care services and neurology services, the response submitted was 'not applicable' or there was no reply.

A few patients were offered information about or had established an End of Life Care Plan (43 patients in elderly care services and 27 in neurology services). For over 1,000 patients in each of elderly care services and neurology services, the response submitted was 'not applicable' or there was no reply.

Parkinson's assessment and care planning process

Three patient assessment domains were included in the audit, based on NICE guidelines on communication with people with Parkinson's and their carers (section 4), non-motor features of Parkinson's (section 9) and other key interventions including Parkinson's nurse specialists, physiotherapy and occupational therapy (section 10).

In the scoring of the assessments, each 'yes' and 'no but' answer scored 1 and each 'no' answer scored 0.

The assessments were referred to as domains and are described as follows:

Domain 1 is about a non-motor assessment carried out during the previous year, and could score a maximum of 12. Non-motor symptoms include pain, sleep, mood, memory and bowel function, which are known to have a significant impact on quality of life.

Domain 2 is about a motor and activities of daily living assessment carried out during the previous year and could score a maximum of 12.

- Domain 3 is about education and multidisciplinary involvement during the previous year and could score a maximum of 10.

For aspects of care in the domains, the response options recognised that there may be a clinically justifiable explanation for why a particular aspect of care was not evidenced as specified. These explanations were identified as 'no but' options and were 'counted' as acceptable practice when compliance with the domain items was calculated.

It is recognised that there may not be time or a need to cover every aspect of an assessment at every visit, and the guidance for the audit advised participants to base domain answers on whether the problem or issue had been addressed at least once over the previous year, including the current visit by the patient.

The median domain scores and the range of scores for elderly care and neurology services are in Table 13.

Table 13. Median and range of scores on assessment and care planning domains for elderly care and neurology services

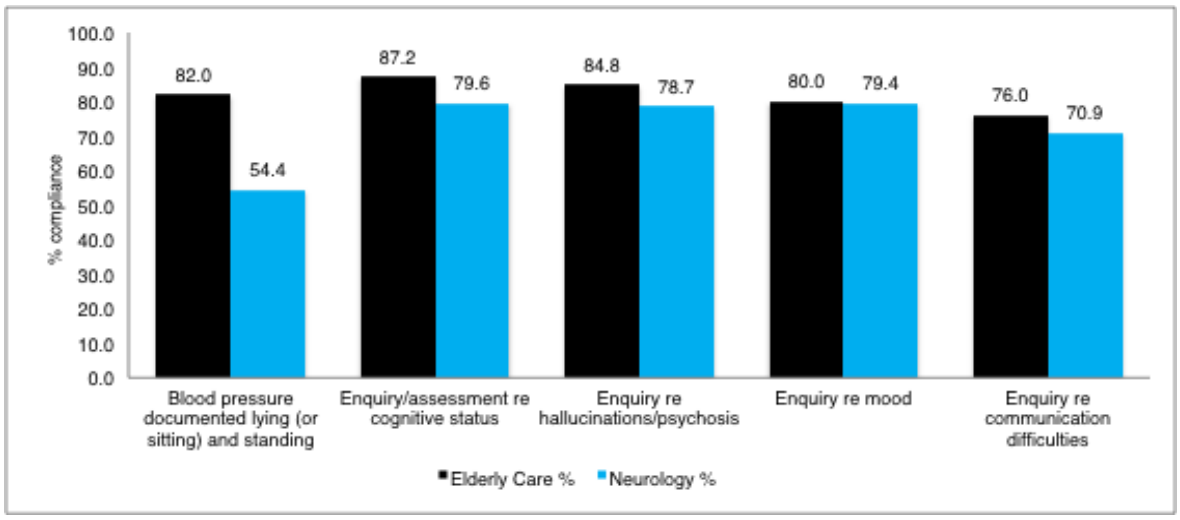
Domain	Elderly Care		Neurology	
	Median	Range	Median	Range
Domain 1 – Non-motor assessment during the previous year (12)	11.0	0.0–12.0	9.0	0.0–12.0
Domain 2 – Motor and activities of daily living assessment during the previous year (12)	11.0	0.0–12.0	10.0	0.0–12.0
Domain 3 – Education and multidisciplinary involvement during the previous year (10)	8.0	0.0–10.0	8.0	0.0–10.0
Total domain score (34)	28.0	0.0–34.0	27.0	0.0–34.0

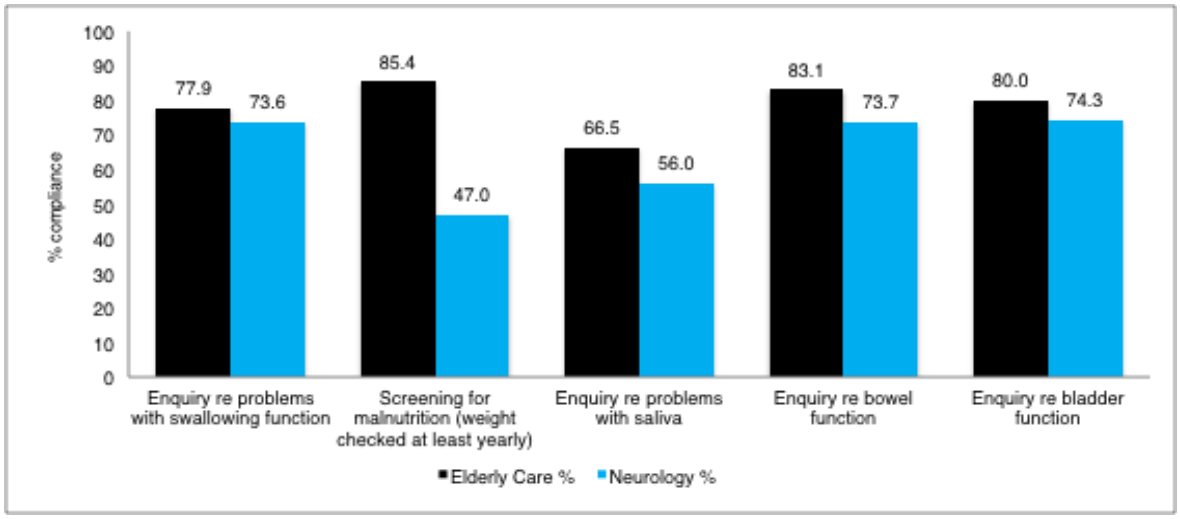
Compliance with assessments included in each domain by elderly care and neurology services are in Figures 2, 3 and 4.

Figures 5, 6 and 7 illustrate domain scores for elderly care services and neurology services by model of service provision. The figures indicate the relationship between completing the aspects of care specified in the domains and the model of service delivery used by a clinical service. The figures also demonstrate the wide range of performance among centres participating in the audit.

The scattergrams seem to suggest that Parkinson's patients receive more thorough assessments on all the domains measured when the care model provides integrated multidisciplinary clinics. More thorough assessments are likely to identify needs for therapy earlier than waiting for individual symptoms to appear.

Figure 2. Compliance with Domain 1 assessments by elderly care and neurology services





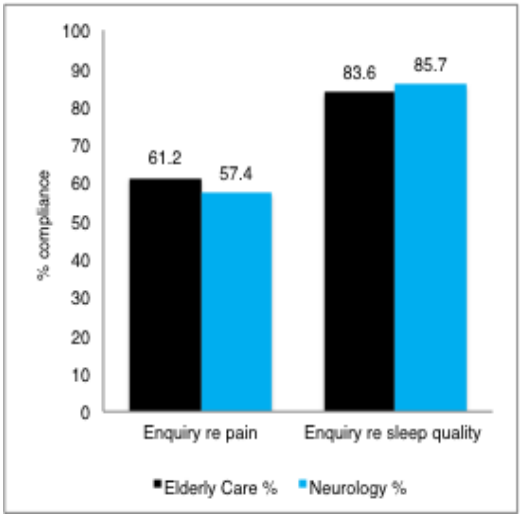
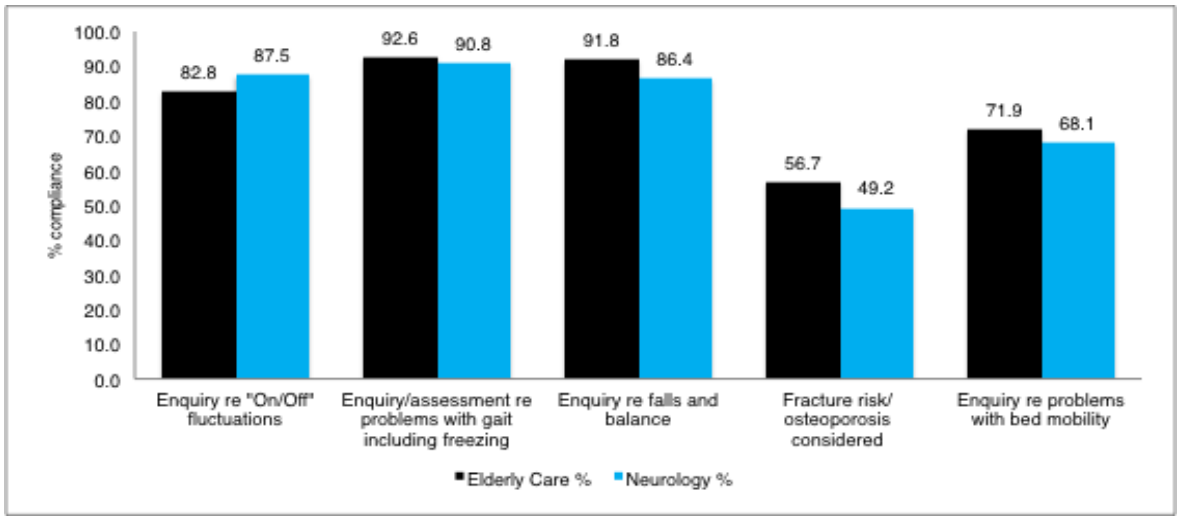
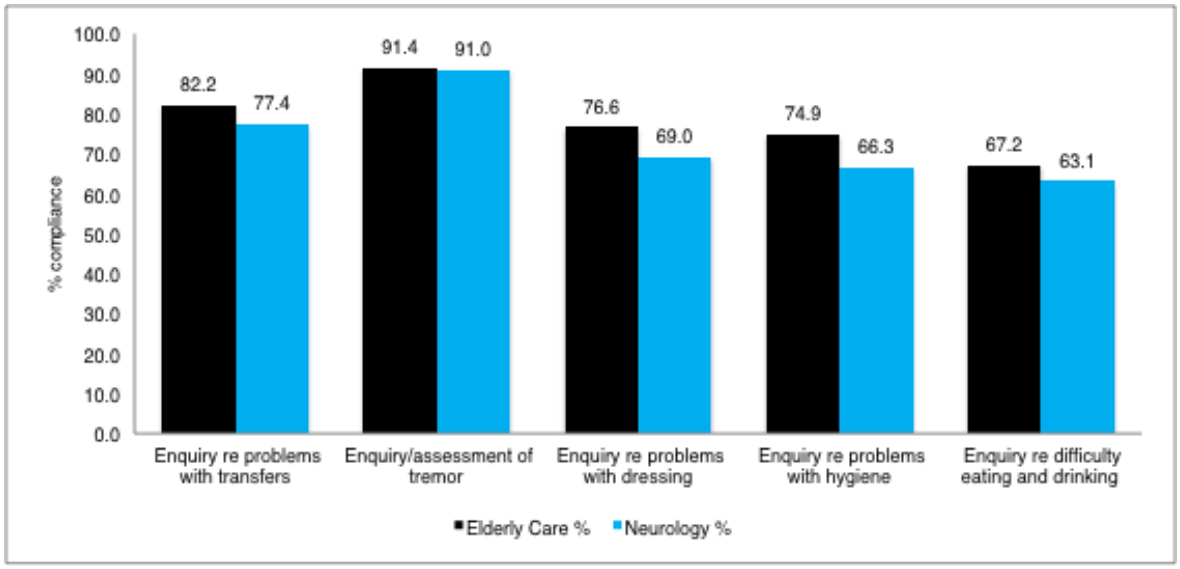


Figure 3. Compliance with Domain 2 assessments by elderly care and neurology services





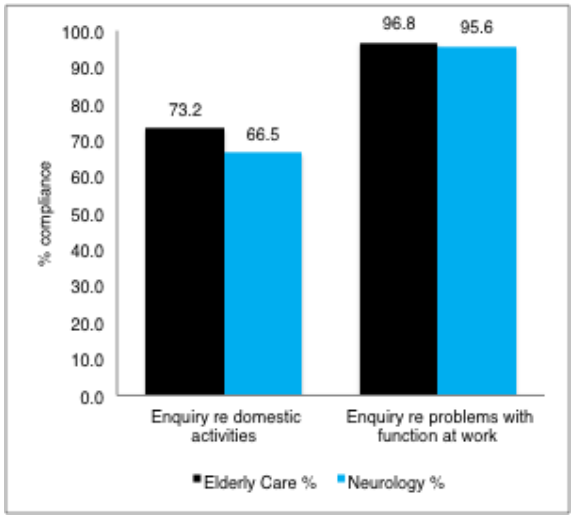
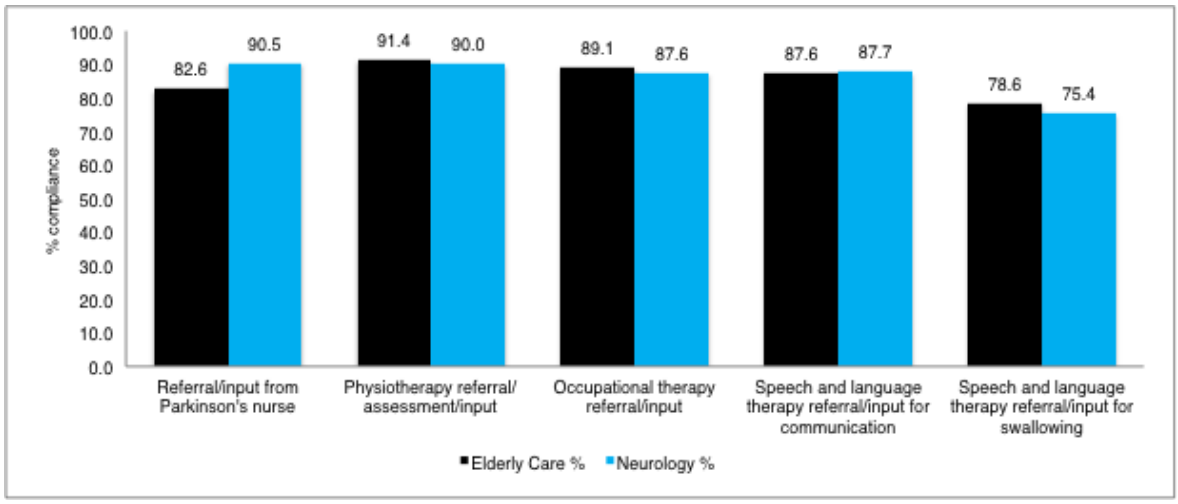


Figure 4. Compliance with Domain 3 assessments by elderly care and neurology services



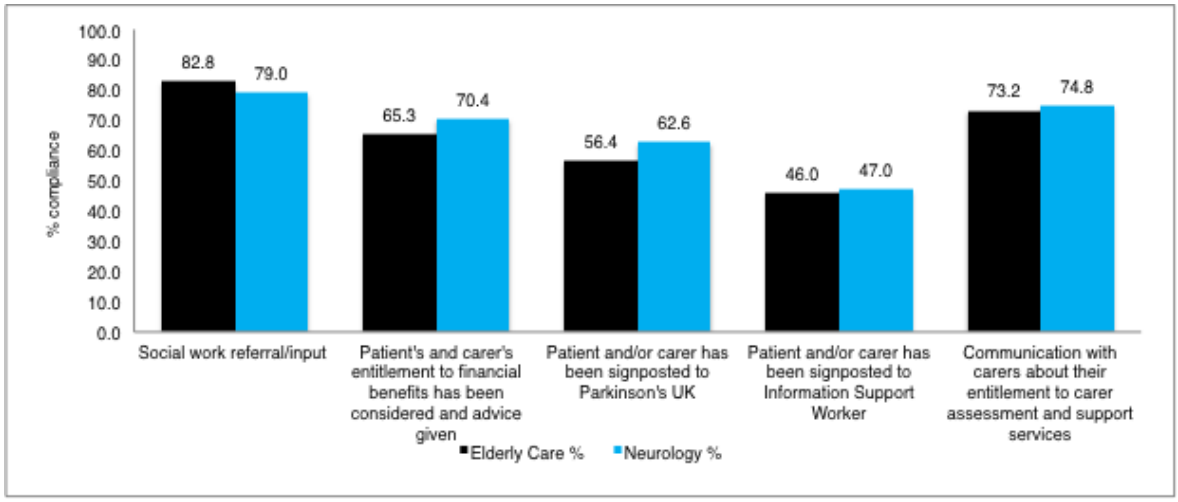


Figure 5. Scattergram of compliance with Domain 1 assessments by model of care provision for elderly care and neurology services

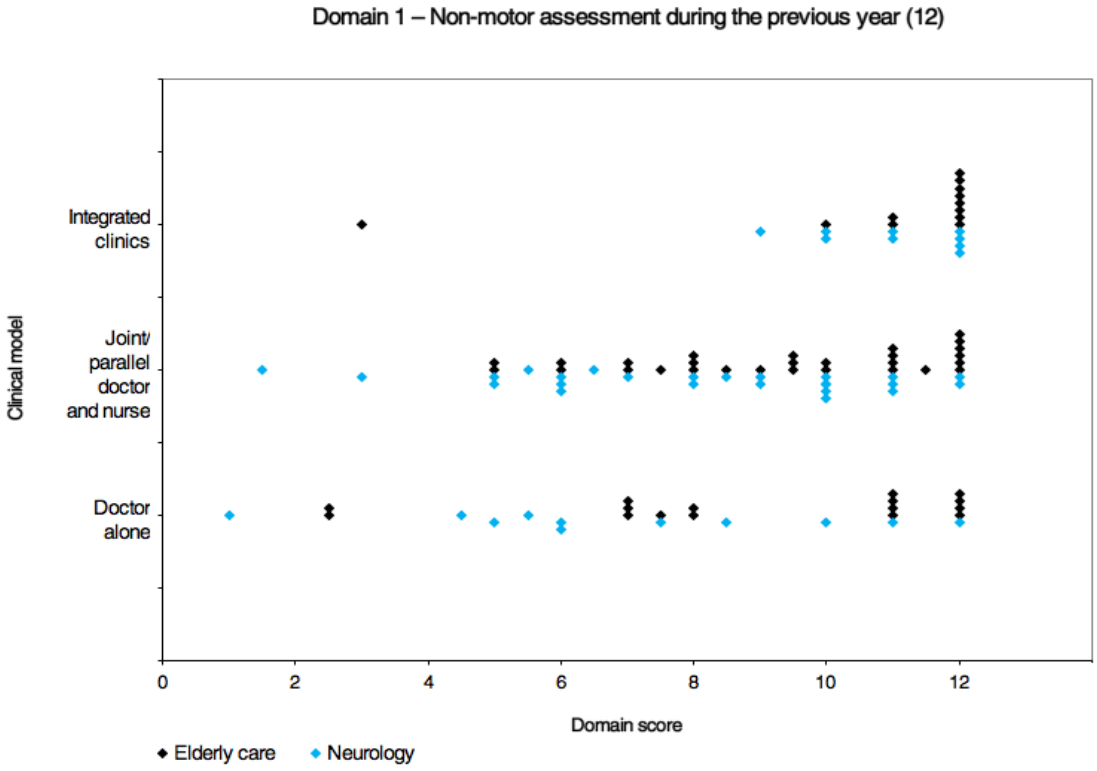


Figure 6. Scattergram of compliance with Domain 2 assessments by model of care provision for elderly care and neurology services

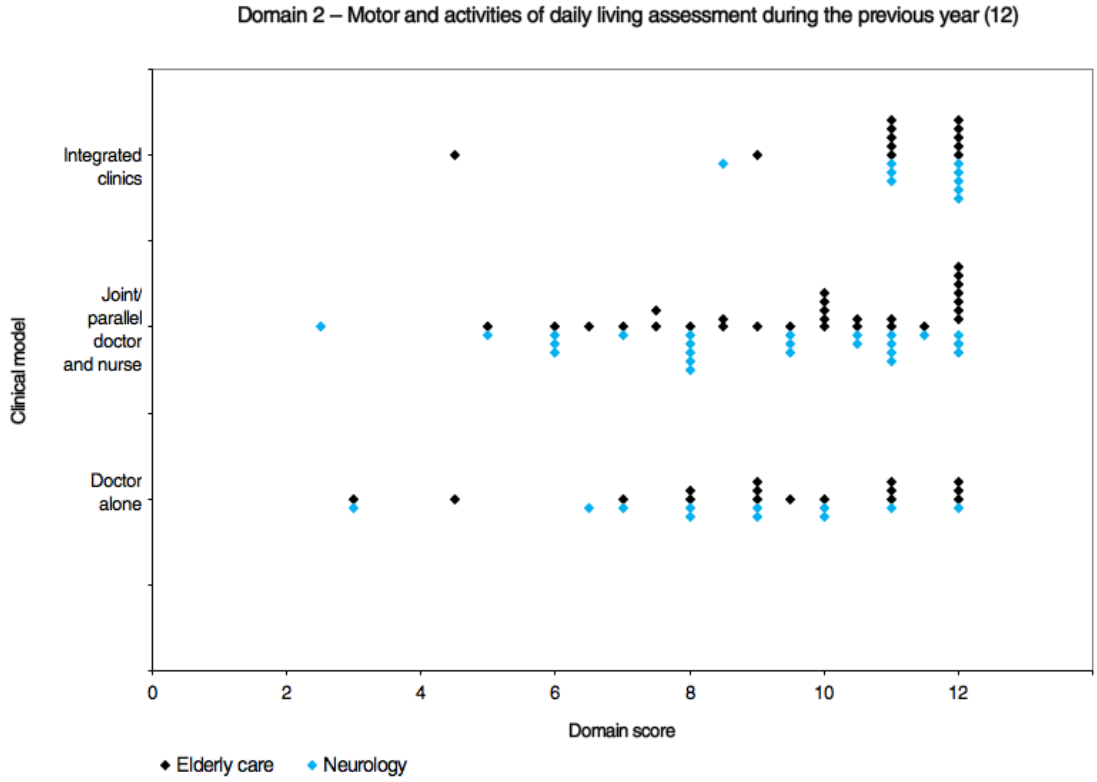


Figure 7. Scattergram of compliance with Domain 3 assessments by model of care provision for elderly care and neurology services

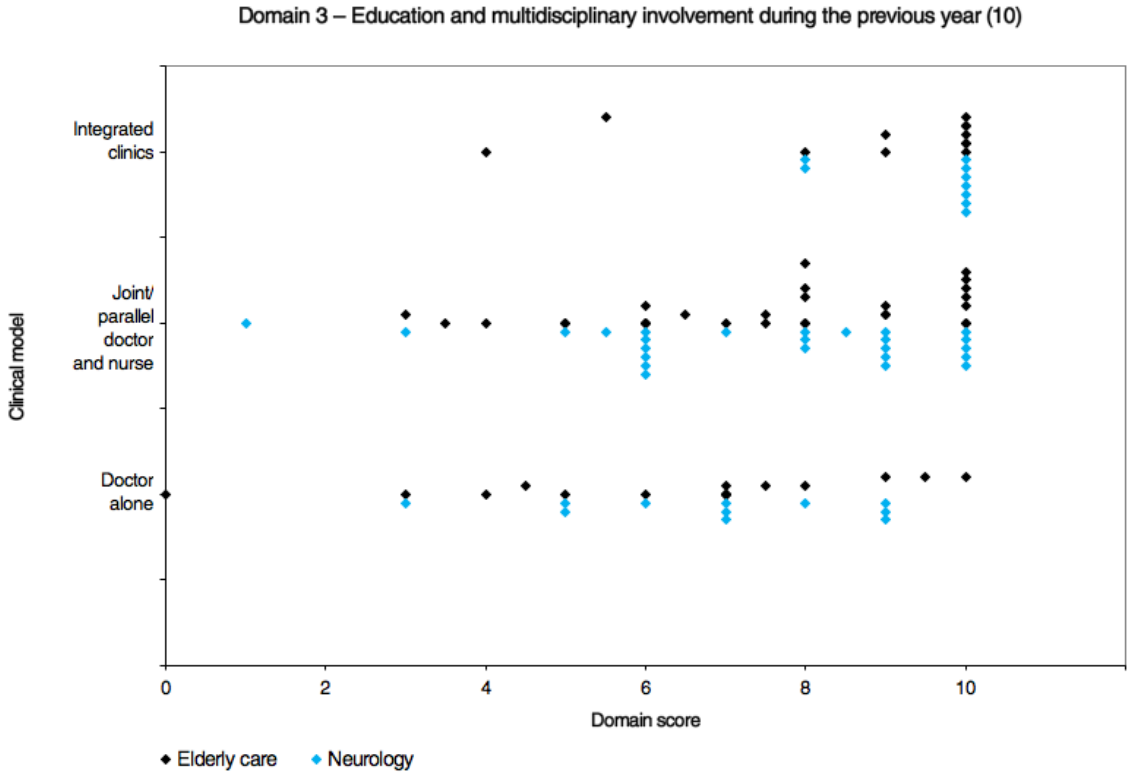
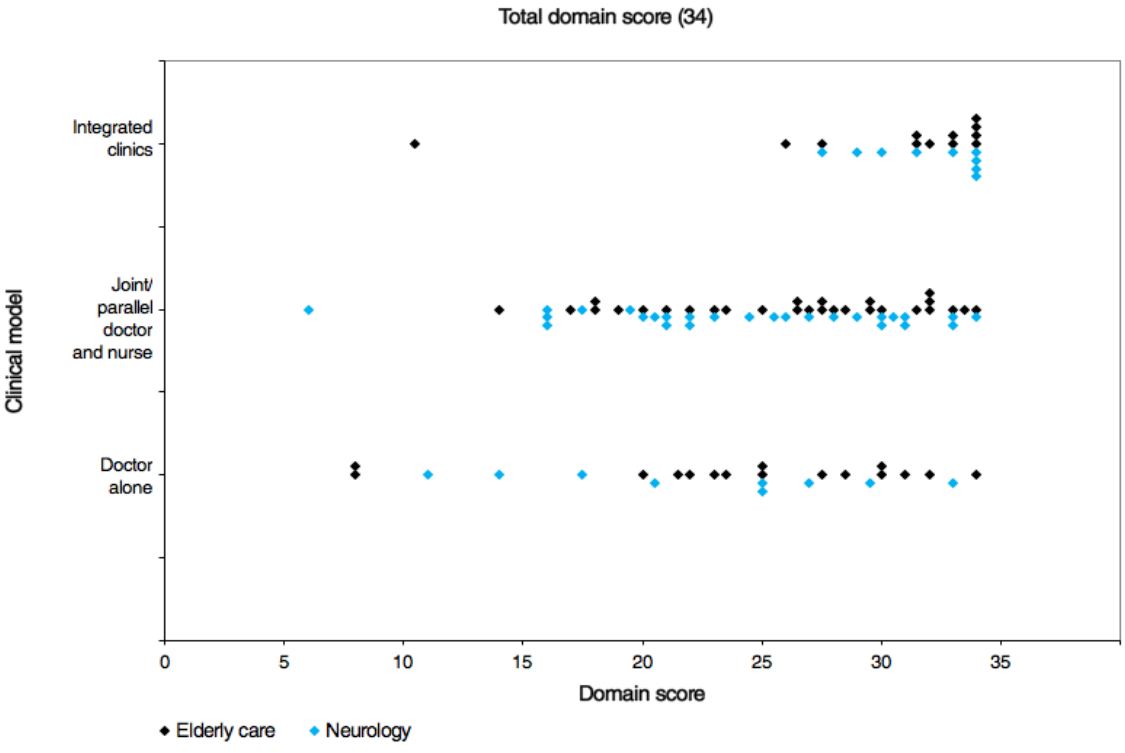


Figure 8. Scattergram of total compliance with all domain assessments by model of care provision for elderly care and neurology services



Good practice involving medical and nursing care demonstrated by the audit

The national audit has demonstrated good practice for patients with Parkinson's being managed by doctors and nurses in the 110 elderly care and neurology services that participated in the audit. The aspects of management that represent good practice include the following:

98.5% of patients managed in an elderly care service and 97.4% of patients managed in a neurology service were reviewed by a doctor or Parkinson's nurse specialist within the previous year.

Nearly all patients in the audit had drugs prescribed in compliance with national prescribing guidelines both for initial therapy (98.5% of patients in an elderly care service and 98.8% of patients in a neurology service) and when drugs are changed in early and later stages of disease (97.3% of patients in an elderly care service and 97.5% of patients managed in a neurology service).

Another aspect of good practice is that 87.5% of elderly care services that manage patients with Parkinson's see all or most (>75%) patients in a specific Parkinson's or movement disorder clinic.

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Some aspects of the Domain 2 on motor and activities of daily living issues are assessed for most patients, including:

91.7% of services assessed patients for problems with gait including freezing.

89.1% of services assessed patients for falls and balance.

91.2% of services assessed patients for tremor.

96.2% of services assessed patients for problems with function at work.

Under Domain 3 on education and multidisciplinary involvement, there are consistently high levels of compliance with referring patients for input by therapies or clear documentation that no therapy is needed or there are no achievable therapy goals.

Shortcomings in medical and specialist nursing care for people with Parkinson's

The findings of the audit identify some areas of practice that represent shortcomings in care in relation to national guidance for the care of people with Parkinson's.

Organisation of neurology services

The national guidance and the evidence base emphasise the value of an integrated approach to the assessment and management of people living with Parkinson's.

Neurology services appear to organise services for people living with Parkinson's differently from elderly care services. Only 21.3% of neurology

services (compared with 51.8% of elderly care services) see all patients in a specific Parkinson's or movement disorder clinic, which can enable and facilitate the provision in clinic of Parkinson specific information and assessment tools as well as a multidisciplinary approach.

Communication patterns between consultants and Parkinson's nurse specialists are different in neurology services. Fewer neurology services (39.1% versus 67.3% of elderly care services) have regular contact in multidisciplinary meetings or joint or parallel clinics. Neurology services tend to use face-to-face contact (26.1% versus 11.5% in elderly care services) and regular telephone or email contact (32.6% versus 13.5% of elderly care services).

Review of Parkinson's patients

82 patients managed by an elderly care service and 53 patients managed by a neurology service have no access to a Parkinson's nurse specialist because the service is not available.

Information about Parkinson's and about potential adverse effects for new medications

Only 48.2% of elderly care services and 36.2% of neurology services have information about Parkinson's available in all their clinics. For 9.8% of medical services seeing patients with Parkinson's, information about Parkinson's is not routinely available. Only 58.1% of elderly care patients and 55.3% of neurology patients had documented provision of written information on potential adverse effects for any new medications. Adverse effects may be verbally explained to patients. However, in view of the serious potential adverse effects of Parkinson's medications, the national guidance advises written information that patients can refer to long after a clinic appointment is appropriate. The audit guidance allowed this information to be included in the clinic letter if the patient was provided with a copy

Advice on driving for patients experiencing daytime sleepiness

Of the 900 patients with Parkinson's who drive and who experience daytime sleepiness, only 215 (59.9%) elderly care services and 368 (68.0%) neurology services patients were advised about driving and occupational hazards.

Given the inherent risks to patients who experience daytime sleepiness and who drive or operate other machinery, there should be documentation that consultants or Parkinson's nurse specialists have provided advice on this issue to relevant patients.

Monitoring for impulse control disorders

Not all Parkinson's patients on dopamine agonists are monitored for impulse control disorders including dopamine dysregulation syndrome (62.3% of eligible elderly care services and 76.4% of neurology patients). In view of the potentially serious impact of impulse control disorders on people with Parkinson's, implementation of the

national guidance on such monitoring is appropriate.

Monitoring of patients on ergot-derived dopamine agonists

Only 37.5% of patients on ergot-derived dopamine agonists in elderly care services and 60.9% of eligible patients in neurology services had monitoring for fibrosis-related adverse effects. Each patient in this small group of 63 patients in the audit should have renal function tests, erythrocyte sedimentation rate and chest radiograph (CXR) before starting treatment and annually thereafter.

Advanced care planning

Although national guidance refers to the expectation that doctors will support patients with Parkinson's in planning for end-of-life care, the audit findings indicate that there is little evidence that this is documented as being done for most or all patients for whom it would be appropriate. The audit included measures related to discussion about end-of-life issues being documented in patients with markers of advanced disease and to the offering of information about a Lasting Power of Attorney and information about an end-of-life care plan.

The audit is not designed to identify why advanced care planning is not evidenced for all or most eligible patients.

Assessment of non-motor, motor, cognitive and mood functions

Assessments of non-motor symptoms, motor symptoms, activities of daily living, and education and multidisciplinary involvement of patients with Parkinson's varies considerably. Assessment tools related to activities of daily living, non-motor symptoms, cognitive function and mood are not used consistently in either elderly care and neurology services.

The domain scores reflect the variation in assessment as well. Although some aspects of some domains appear to be assessed reasonably consistently, other aspects of each of the domains are assessed variably.

For example, there are relatively high levels of compliance regarding enquiring about falls and balance in elderly care (91.8%) and neurology services (86.4%). However, there may be a poor linkage to a management plan to reduce the risk of a fracture resulting from a fall by considering bone strength. Only 56.7% of elderly care service patients and 49.2% of neurology service patients had evidence of fracture risk or osteoporosis considered.

Shortcomings in the audit data collection tool

For a few questions in the audit data collection tool, directions were insufficiently clear to elicit reliable data. For example, respondents provided a variety of forms of answers about continuing medical education of doctors treating people with Parkinson's. For some questions, it was not entirely clear if the respondents intended that the question was 'not applicable' or that

the respondents intended to 'not respond'.

Actions indicated by audit findings for medical and specialist nursing care for people with Parkinson's

Services providing care for people with Parkinson's

Elderly care and neurology services that provide care for people with Parkinson's should act to:

organise services to support an integrated multiprofessional approach to service delivery for people with Parkinson's in order to focus on the full range of clinical and therapeutic needs of people with the condition

improve clinic accessibility to facilitate the review by a specialist of every patient with Parkinson's at least every year

provide written information on Parkinson's in all clinics in which people with Parkinson's are seen, including information on adverse effects of new medications prescribed for people with the condition

change processes to ensure that advice on the impact of driving is provided for all patients experiencing daytime sleepiness

change processes to ensure that monitoring for impulse control disorders takes place for all patients on dopamine agonists

change processes to ensure appropriate monitoring of all patients on ergot-derived dopamine agents

carry out relevant assessments of non-motor, motor, cognitive and mood functions of people with Parkinson's periodically

support with symptom control and end of life care planning for people with markers of advanced Parkinson's

provide organisational support for ongoing professional training of staff caring for people with Parkinson's

Managers and commissioners of services for people with Parkinson's

Neurology and elderly care services that do not currently have an integrated service delivery model in place for the care of people with Parkinson's and commissioners of services for people with Parkinson's should consider the value of organising clinical services for people with Parkinson's to enable an integrated multidisciplinary approach to assessment and management of patients with Parkinson's.

Such an approach supports the recognition that Parkinson's is a complex condition with many, varied symptoms and the potential for complications if medication is poorly managed. An integrated approach facilitates and supports the provision of the full range of assessments and therapies that are needed as the condition progresses, including support for the psychological and psychiatric issues patients and carers face.

Professionals providing care to people with Parkinson's should arrange to meet with local managers and commissioners, presenting the evidence of good practice concerning an integrated model of service delivery and the findings of this audit, considering any barriers to changing the service delivery model for people with Parkinson's and overcoming any local barriers to an integrated service delivery approach.

Parkinson's UK and the Parkinson's National Audit Governance Group

Working with relevant professional groups, Parkinson's UK and the Parkinson's National Audit Clinical Steering Group should consider:

creating a professional forum in which the examples of information for patients on Parkinson's medications and assessment tools and checklists can be shared among the professions involved in the care of people with Parkinson's

providing and promoting standardised validated information on Parkinson's medications that specialist services can refer to and use for Parkinson's patients when they are prescribed new Parkinson's medications

formally considering assessment tools available to assess various functions of a person with Parkinson's, and the provision of current evidence-based advice on the use of assessment tools

formally considering the role of the specialist doctor and Parkinson's nurse specialist in supporting the patient with Parkinson's in end-of-life care and the provision of advice for specialist teams on these roles

amending the data collection directions and tool for future national Parkinson's audits for the areas for which data provided could not be collated because of the lack of consistency in reporting

ensuring the inclusion of patients residing in care homes in the National Parkinson's Audit

recognising the role of the Clinical Steering Group in recruiting services to participate in the National Parkinson's Audit

Part 2 – Occupational therapy care

Occupational therapy service audit

Objectives

The objectives of the occupational therapy (OT) service audit are to:

determine the service delivery models used for assessment by occupational therapists of people with Parkinson's, including the nature of referrals of people with Parkinson's to occupational therapy services

determine if occupational therapists assessing and treating people with Parkinson's have sufficient professional support

Findings

Occupational therapy care setting

The 43 occupational therapy services that supplied data for the service audit see patients with Parkinson's in a variety of care settings as shown in Table 14. Four of 42 (9.5%) occupational therapy services reported working in a setting in which there is an integrated medical and therapy Parkinson's clinic. The majority, 27 (64.3%), of occupational therapy services are in community rehabilitation services.

Table 14. Settings in which OTs see patients with Parkinson's

Setting	No.	%
Integrated medical and therapy Parkinson's clinic	4	9.5
Inpatient acute service	4	9.5
Inpatient rehabilitation service	0	0.0
Community rehabilitation service	27	64.3
Social services	0	0.0
Other	7	16.7
Total	42	100.0
No reply	1	—

Of the 43 occupational therapy services, 26 (61.9%) specialise in the treatment of patients with neurological conditions. 25 (59.5%) specialise in the treatment of people with Parkinson's.

Proportion of patients seen with Parkinson's and number of referrals of people with Parkinson's

Of the 43 occupational therapy services responding in the audit, for 27 (65.9%), the percentage of patients with the diagnosis of Parkinson's that are seen by an occupational therapist ranges from zero to 19%. This is shown in Table 15.

Table 15. Percentage of patients with Parkinson's seen by an OT

% patients seen by an OT	No.	%
0–19%	27	65.9
20–39%	8	19.5
40–59%	0	0.0
60–79%	1	2.4
80–100%	5	12.2
Total	41	100.0
No reply	2	—

The most frequent (mode), middle (median), average (mean) and range numbers of referrals made to occupational therapy services participating in the audit is in Table 16. The same statistics for the number of therapists working with people with

Parkinson's in the occupational therapy service also are in the table.

Table 16. Mode, median, mean and range numbers of referrals of people with Parkinson's to OT services and of OTs working with patients with Parkinson's

Numbers	Mode	Median	Mean	Range
Referrals made of patients with Parkinson's to OT per year	35.0	50.0	93.2	7–300
OTs working with patients with Parkinson's in the service	1.0	3.0	4.1	0–25

Grade of occupational therapist

For the occupational therapy service for which data were collected, the grade (band) of the therapist was requested. Some respondents gave a range of bands. Therefore, it was not possible to calculate accurately the number of therapists working in each band or grade.

Training and support for occupational therapists working with patients with Parkinson's

Most occupational therapists who participated in the audit have access to opportunities for training in the management of people with Parkinson's, as shown in Tables 17–19.

Table 18. Number of OT services for which documented induction and support strategies for new OTs working with patients with Parkinson's are available

Induction and support available	No.	%
Yes, specifically in relation to patients with Parkinson's	8	19.5
Yes, as part of more general competencies	27	65.9
No	6	14.6
Total	41	100.0
No reply	2	—

Occupational therapists identified the best level of support in relation to Parkinson's that individual occupational therapists can receive in their services. Only 10 (25.6%) occupational therapy services were members of Parkinson's specialist multidisciplinary teams (MDT) and another 10 (25.6%) were members of general neurology or elderly care specialist services. Most occupational therapy services participating in the audit said they don't work in specialist clinics but can access a Parkinson's multidisciplinary team or a Parkinson's nurse specialist.

Table 17. Number of OT services having access by OTs at least yearly to continuing professional development (CPD) related to the management of people with Parkinson's

Access to at least yearly CPD on Parkinson's	No.	%
Yes	32	78.0
No	9	22.0
Total	41	100.0
No reply	2	—

Table 19. Number of OT services accessing best level of support available in the service for individual OTs working with people with Parkinson's		
Best level of support available for OTs	**No.**	**%**
Member of Parkinson's specialist MDT	10	25.6
Member of neurology/elderly care specialist service	10	25.6
Do not work in specialist clinics but can readily access Parkinson's specialist MDT/Parkinson's nurse specialist	15	38.5
Do not work in specialist clinics but can readily access specialist neurology or elderly care MDT	4	10.3
No access to more specialised advice	0	0.0
Work alone	0	0.0
Total	39	100.0
No reply	4	—

Model of assessment of patients with Parkinson's

Table 20 shows that occupational therapy services work in a variety of models when delivering assessment for people with Parkinson's. Occupational therapists sometimes provided more than one answer to the options in the data collection form.

Table 20. Number of OT services using models of service delivery of assessment of patients with Parkinson's		
Model	**No.**	**%**
Single OT assessment	30	69.8
MDT assessment	33	76.7
Interview with patients and carer	38	88.4
Assessment during group work	7	16.3
Functional assessment	33	76.7
Other	4	9.3

Of the 43 occupational therapists services participating in the audit, 28 (66.7%) said they usually see patients with Parkinson's individually and none said patients were usually seen in a group setting. The options for usually seeing patients with Parkinson's are in Table 21.

Table 21. Model of OT usually seeing people with Parkinson's		
Model	**No.**	**%**
Individually	28	66.7
In a group setting	0	0.0
Both individually and in groups	14	33.3
Total	42	100.0
No reply	1	–

Needs of people with Parkinson's addressed in group work interventions of occupational therapists

A wide range of needs of people with Parkinson's was identified as being met through interventions by occupational therapists in group work. The distribution of needs being addressed is in Table 22. The table illustrates that multiple needs are being addressed by occupational therapy interventions.

Table 22. Number of OT services with needs of people with Parkinson's being addressed by OT interventions that include group work

Needs addressed with group work	No.	%
Maintenance of work roles	4	9.3
Maintenance of family roles	3	7.0
Domestic activities of daily living	7	16.3
Leisure activities	7	16.3
Improvement and maintenance of transfers and mobility	10	23.3
Improvement of personal self-care activities such as eating, drinking, washing and dressing	10	23.3
Environmental issues to improve safety and motor function	11	25.6
Mental wellbeing, including cognition, emotional and/or neuropsychiatric problems	9	20.9
Management of fatigue	15	34.9
Education	13	30.2
Social interaction/social support	8	18.6
Other	2	4.7

Table 23. Number of OT services using standardised assessments with people with Parkinson's by OTs

Standardised assessments	No.	%
Assessment of Motor and Process Skills (AMPS) (Fisher 2003)	5	11.6
Canadian Occupational Performance Measure (Law et al 2005)	14	32.6
Nottingham Extended Activities of Daily Living Assessment (NEADL) (Noun and Lincoln 1987)	7	16.3
Fatigue Impact Scale (FIS) (Whitehead 2009)	8	18.6
Unified Parkinson's Disease Rating Scale (UPDRS)	7	16.3
Model of Human Occupation Screening Tool (MOHOST)	2	4.7
Non-motor Questionnaire	9	20.9
None	8	18.6
Other	9	20.9

Standardised assessments used by occupational therapists with people with Parkinson's

Occupational therapists use a number of standardised assessments with people with Parkinson's. Table 23 lists the standardised assessments used and the distribution of use. The table illustrates that several standardised assessments may be being used by occupational therapists in combination.

Use by occupational therapists of evidence base on occupational therapy for people with Parkinson's

The range of evidence occupational therapists may use in the management of people with Parkinson's and the percentage of occupational therapists using that evidence to inform clinical practice or to guide intervention are in Table 24.

Table 24. Number of OT services using sources of evidence to inform clinical practice or guide intervention for people with Parkinson's

Source of evidence	No.	%
Clinical experience	40	93.0
Advice from colleague or supervisor	29	67.4
Recommendations given in OT Best Practice Guidelines (Parkinson's UK 2010)	37	86.0
Information from Parkinson's UK website	28	65.1
National Service Framework for Long Term Conditions (2005)	31	72.1
NICE Clinical Guideline 35 (2006)	37	86.0
Published evidence in a peer reviewed journal	24	55.8
None	0	0.0
Other	5	11.6

Occupational therapy management audit

Objectives

The objectives of the occupational therapy management audit are to:

- determine the proportion of people with Parkinson's who have an appropriate and timely referral to occupational therapy
- determine if occupational therapy services are providing assessment, interventions, strategies and techniques appropriate to the needs of people with Parkinson's, consistent with national guidance

Findings

Overall compliance with the occupational therapy standards for the care of people with Parkinson's is summarised in Table 25. The percentages are based on 43 occupational therapy services and information provided for a total of 460 patients included in the audit. (There were eight no replies for standard 1, seven for standard 2 and three for standard 3.)

Table 25. Compliance with OT standards for people with Parkinson's*

Standard	No.	%
1. Occupational therapy is: *(Parkinson's NICE CG35, R12, R80)*		
• available for 100% of people with Parkinson's	—	—
• considered at diagnosis	—	—
• considered during regular review	257 patients	56.9
2. Occupational therapists reviewing people with Parkinson's give particular consideration to the following for 100% of people with Parkinson's *(Parkinson's NICE CG35, R80):*		
• maintenance of work and family roles, employment, home care and leisure activities	8–110 patients *(see Table 31)*	1.7–23.9
• improvement and maintenance of transfers and mobility	309 patients	67.2
• improvement of personal self-care activities, such as eating, drinking, washing and dressing	195 patients	42.4
• environmental issues to improve safety and motor function	188 patients	40.9
• cognitive assessment and appropriate intervention	92 patients	20.0
3. 100% of assessments are: *(NSF LTNC QR1)*		
• timely	399 patients	87.5
• integrated	—	—
• involve all relevant health agencies	—	—
• leading to individual care plans	—	—
• ensure that staff have access to all relevant records and background information about the person's condition, test results and previous consultations	426 patients	93.2
4. 100% of people with Parkinson's have a comprehensive care plan agreed between the individual, their family and/or carers and specialist and secondary healthcare providers *(Parkinson's NICE CG35, R5)*	—	—

* Explicit data on some aspects of care in the standards were collected in the audit.

Source and nature of referral to occupational therapy

Referrals to occupational therapy for people with Parkinson's are made by a wide variety of sources, as described in Table 26.

Table 26. Number of patients referred by source of referral to OT

Source of referral	No.	%
Speech and language therapist	11	2.4
Physiotherapist	73	16.1
Parkinson's nurse specialist	114	25.1
Neurologist	22	4.8
Geriatrician	70	15.4
GP	41	9.0
Dietician	0	0.0
Social care worker	9	2.0
Self-referral	22	4.8
Other	89	19.6
Don't know	3	0.7
Total	454	99.9
No reply	6	—

Over half the referrals reported in the audit had been triggered as a result of a medical review. The full description of medical review serving as a trigger for referral to occupational therapy is in Table 27.

Table 27. Number of patients referred to OT triggered by a medical review

Referrals	No.	%
Yes	257	56.9
No	177	39.2
Don't know	18	4.0
Total	452	100.1
No reply	8	–

On average, people with Parkinson's had one to two episodes of care, as indicated in Table 28.

Table 28. Mode, median, mean and range number of episodes of OT for people with Parkinson's

Episodes	Mode	Median	Mean	Range
Average episodes of OT for people with Parkinson's	1.0	2.0	2.1	0–16

Previous occupational therapy

A breakdown of whether or not patients received occupational therapy previously for the management of Parkinson's is in Table 29.

Table 29. Number of patients who previously had OT specifically for Parkinson's

Previous OT for Parkinson's	No.	%
Yes	206	44.8
No	188	40.9
Don't know	66	14.3
Total	460	100.0

Time between referral and occupational therapy intervention

People with Parkinson's referred to occupational therapy tended to be seen within a month or two of referral. Time between referral and occupational therapy intervention in calendar days for people with Parkinson's is shown in Table 30.

Table 30. Median, mean and range of time in calendar days between referral and OT intervention

Length of time between … in calendar days	Median	Mean	Range
Referral and OT intervention	20.0	32.3	0–368

Reasons for referrals to occupational therapy for patients with Parkinson's

There can be more than one reason for referral of patients with Parkinson's, which the findings reflect. Occupational therapists often gave multiple reasons for referral in response to the question asked in the audit.

The most commonly occurring reason for referral is improvement and maintenance of transfers and mobility (309 or 67.2%). The full list of reasons for referral to a physiotherapist is in Table 31.

Table 31. Number of patients referred to OT by reason

Reasons for referral	No.	%
Maintenance of work roles	8	1.7
Maintenance of family roles	28	6.1
Domestic activities of daily living	110	23.9
Leisure activities	35	7.6
Improvement and maintenance of transfers and mobility	309	67.2
Improvement of personal self-care activities	195	42.4
Environmental issues to improve safety and motor function	188	40.9
Mental wellbeing, including cognition, emotional and/or neuropsychiatric problems	92	20.0
Management of fatigue	46	10.0
Other	58	12.6
Unclear	2	0.4
Total patients	460	—
Not stated	7	1.5

Availability of information for assessment and intervention

Nearly three-quarters of referrals had most of the required information available for assessment and intervention (Table 32).

Table 32. Number of patients for whom information essential for OT assessment and intervention for referrals for people with Parkinson's is available

Availability of information	No.	%
Yes, most of it	346	75.7
Yes, some of it	80	17.5
No	31	6.8
Total	457	100.0
No reply	3	—

Timeliness of referral of people with Parkinson's to occupational therapy

Of the referrals of people with Parkinson's to occupational therapy, 87.5% were judged by an occupational therapist to be made at the right time, as shown in Table 33.

Table 33. Judgement by an OT of the timeliness of the referral of people with Parkinson's

Timeliness of referral to OT of people with Parkinson's	No.	%
Yes	399	87.5
No	51	11.2
Don't know	6	1.3
Total	456	100.0
No reply	4	—

Goals identified

A large number of goals were identified for the patients with Parkinson's who received occupational therapy intervention and were included in the audit. The goals were identified by people with Parkinson's, their carers, and occupational therapists. The distribution of the goals identified for people with Parkinson's and their carers is in Table 34.

Table 34. Number of people with Parkinson's and their carers and of therapists for whom OT goals were identified						
OT goals identified	**Patients**		**Carers**		**Therapists**	
	No.	**%**	**No.**	**%**	**No.**	**%**
Optimising activities						
Mobility	157	34.1	57	13.3	200	43.5
Falls prevention	112	24.3	70	15.2	237	51.5
Transfers	207	45.0	99	21.5	277	60.2
Bed mobility	132	28.7	63	13.7	195	42.4
Posture and seating, including wheelchair mobility	38	8.3	20	4.3	106	23.0
Eating and drinking	60	13.0	17	3.7	74	16.1
Self-care routines	99	21.5	40	8.7	141	30.7
Domestic skills	48	10.4	11	2.4	62	13.5
Fatigue management	34	7.4	11	2.4	74	16.1
Handwriting and/or computers	43	9.3	4	0.9	41	8.9
Driving	3	0.7	0	0.0	8	1.7
Managing medications	20	4.3	10	2.2	55	12.0
Structuring day	20	4.3	6	1.3	50	10.9
Supporting participation						
Self-efficacy (maintaining a sense of control)	95	20.7	20	4.3	126	27.4
Roles and relationships	35	7.6	22	4.8	49	10.7
Work	10	2.2	1	0.2	10	2.2
Social, recreational and leisure activities	45	9.8	11	2.4	79	17.2
Driving	4	0.9	1	0.2	6	1.3
Community living skills and outdoor mobility	41	8.9	15	3.3	56	12.2
End of life care						
24-hour approach to posture, positioning and pressure care	5	1.1	3	0.7	9	2.0
Manual handling and minimising risk	11	2.4	12	2.6	29	6.3
Alternative living arrangements	3	0.7	2	0.4	8	1.7

Intervention strategies used

A very large number of occupational therapy treatment strategies and techniques are used for people with Parkinson's. The distribution of occupational therapy interventions used is in Table 35.

When intervention strategies were applicable but not used, reasons for the interventions not being used are in Table 36. The results indicate that when particular occupational therapy treatment strategies were not used, the reasons did not relate to lack of training, lack of experience, lack of time or priority, or lack of resources.

Table 35. Number of people with Parkinson's for whom OT treatment strategies and techniques were used		
OT treatment strategies and techniques used	**No.**	**%**
Initiating and maintaining movement		
Promoting functional abilities through trial of intrinsic cueing techniques	141	30.7
Promoting functional abilities through trial of extrinsic cueing techniques	66	14.3
Promoting functional abilities throughout a typical day, taking into account timing of medication	167	36.3
Promoting functional abilities throughout a typical day, taking into account fatigue	166	36.1
None of the above treatment strategies applicable	141	30.7
Engagement, motivation, learning and carryover		
Promoting mental well-being	163	35.4
Promoting new learning	83	18.0
None of the above treatment strategies applicable	203	44.1
Environmental adaptations/assistive technology		
Small aids and adaptations	340	73.9
Wheelchair and seating	81	17.6
Major adaptations	31	6.7
Assistive technology	27	5.9
None of the above treatment strategies applicable	71	15.4
Ensuring community rehabilitation and social support		
Social services OT	53	12.5
Social worker/carers	67	14.6
Other allied health professions	115	25.0
Respite care	9	2.0
Voluntary services	25	5.4
Access to work	1	0.2
Other	71	15.8
None of the above treatment strategies applicable	172	37.4
Providing information to increase patient's knowledge		
Work advice and resources	16	3.5
Specific activities of daily living techniques	219	47.6
Cognitive strategies	113	24.6
Fatigue management	121	26.3
Assertiveness/stress management	27	5.9
None of the above treatment strategies applicable	116	25.2
Providing information and support for family and carers		
Optimising function	166	36.1
Safe moving and handling	171	37.2
Support services	107	23.3
Managing changes in mood, cognition or behaviour	61	13.3
None of the above treatment strategies applicable	128	27.8
Providing support to facilitate change in attitude		
Positive attitude/emotional set	106	23.0
Developing self-awareness/adjustment to limitations	183	39.8
Increasing confidence	147	32.0
Explore new occupations	15	3.3
None of the above treatment strategies applicable	133	28.9

Table 36. Frequency of reasons for OTs not using specific OT treatment strategies										
Strategy	**Reason for not using treatment strategy**									
	Training*		**Experience***		**Time/priority***		**Resources***		**Other***	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Initiating and maintaining movement	2	0.5	1	0.2	6	1.4	0	0.0	38	8.6
Engagement, motivation, learning and carryover	2	0.4	2	0.4	7	1.5	0	0.0	24	5.2
Environmental adaptations/assistive technology	0	0.0	1	0.2	4	0.9	0	0.0	20	4.3
Ensuring community rehabilitation and social support	0	0.0	0	0.0	3	0.7	0	0.0	15	3.3
Providing information to increase patient's knowledge	1	0.2	1	0.2	7	1.5	0	0.0	14	3.0
Providing information and support for family and carers	0	0.0	0	0.0	4	0.9	0	0.0	13	2.8
Providing support to facilitate change in attitude	1	0.2	1	0.2	5	1.1	0	0.0	9	2.0

* Training refers to lack of training, experience refers to lack of experience, time/priority refers to lack of time or lack of priority, and resources refers to lack of resources.

Good practice involving occupational therapy demonstrated by the audit

The national audit has demonstrated good practice for patients with Parkinson's being cared for by occupational therapists in the 43 services that participated in the audit. The aspects of occupational therapy-related services that represent outstanding good practice including the following:

- The timing of the referral to occupational therapy was judged to be appropriate by an occupational therapist for 87.5% of patients referred.
- The median time between referral and occupational therapy intervention was 20.0 calendar days (about one month) and the mean time was 32.3 calendar days (about seven weeks).
- For 93.2% of patients with Parkinson's that are referred to occupational therapy, most or some of the information essential for occupational therapy assessment and intervention is available.
- Occupational therapy services access a very wide range of evidence to inform clinical practice or guide intervention for people with Parkinson's.
- Occupational therapy services address a wide range of needs of people with Parkinson's, and use a wide range of interventions and treatment strategies. The use of occupational therapy treatment strategies is not affected by lack of training, experiences, time or resources.

Shortcomings in occupational therapy for people with Parkinson's

The findings of the audit identify some areas of practice that represent shortcomings in occupational therapy care in relation to national guidance for the care of people with Parkinson's.

Lack of an integrated model of service delivery

Less than 10% of occupational therapy services reported working in an integrated clinic when therapists see patients with Parkinson's. The most prevalent setting in which occupational therapists see people with Parkinson's is in a community rehabilitation service. It is unclear if services provided in this setting provide for integration of contributions from all professionals providing care for people with Parkinson's.

Only 25.6% (10) of occupational therapy services reported being members of a Parkinson's specialist multidisciplinary team, while another 25.6% (10) of occupational therapy services reported being members of a neurology or an elderly care specialist service.

Lack of access to continuing professional development and induction related to the management of people with Parkinson's

22.0% (nine) of occupational therapy services reported that therapists don't have access to continuing professional development related to the management of people with Parkinson's at least yearly. 14.6% (six services) reported no availability of induction and support strategies for new occupational therapists working with people with Parkinson's.

Lack of consistent use of standardised assessments of people with Parkinson's

Overall, few occupational therapy services regularly use standardised assessments with people with Parkinson's. The most frequently used standardised assessment is the Canadian Occupational Performance Measure, used by 14 (32.6%) of occupational therapy services. A non-motor questionnaire was used by nine (20.9%) services. All other standardised assessments referred to in the audit data collection tool were used by less than 20% of occupational therapy services.

Lack of consistent use of occupational therapy guidance

Six (14.0%) of occupational therapy services reported not following the recommendations in *Occupational Therapy Best Practice Guidance* published by Parkinson's UK in 2010.

Actions indicated by audit findings for occupational therapy for people with Parkinson's

Allocation of and training and education for occupational therapists assessing and treating people with Parkinson's

In view of the audit evidence about how occupational therapy services are being delivered for people with

Parkinson's, occupational therapy services and commissioners of occupational therapy services could consider the specialisation of occupational therapists in assessing and providing interventions for people with Parkinson's, given the mastery of the specific evidence base needed to provide effective care for these patients. Such specialisation might enable more appropriate and early interventions provided more uniformly for people with Parkinson's.

Such specialisation could have the effect of promoting the investigation of standardised assessments of people with Parkinson's and the wider adoption of assessments shown to be useful and effective in the occupational therapy management of people with Parkinson's.

Part 3 – Physiotherapy care

Physiotherapy service audit

Objectives

The objectives of the physiotherapy service audit are to:

- determine the proportion of people with Parkinson's who have an appropriate and timely referral to physiotherapy
- determine if physiotherapists assessing and treating people with Parkinson's are likely to have sufficient expertise in the assessment and management of people with Parkinson's

Findings

Physiotherapy care setting

The 52 physiotherapy services that participated in the audit see patients with Parkinson's in a variety of care settings are shown in Table 37. Of the physiotherapy services that participated in the audit, 36 (76.6%) are in a service that specialises in the treatment of people with neurological conditions and 32 (68.1%) are in a service that specialises in the treatment of people with Parkinson's.

Table 37. Settings in which physiotherapists see patients with Parkinson's

Setting	No.	%
Inpatient acute service	3	6.4
Inpatient rehabilitation service	2	4.3
Acute outpatient rehabilitation	14	29.8
Community rehabilitation service	22	46.8
Social services	0	0.0
Other	6	12.8
Total	47	100.0
No reply	5	—

Number of physiotherapists and number of referrals

The average number of physiotherapists in a physiotherapy service who work with patients with Parkinson's and the average number of referrals made to the physiotherapy service per year are in the table.

Table 38. Mode, median, mean and range number of physiotherapists in a physiotherapy service working with patients with Parkinson's and of number of referrals to the physiotherapy service per year for patients with Parkinson's

Numbers	Mode	Median	Mean	Range
Physiotherapists in a physiotherapy service working with patients with Parkinson's	3.0	4.0	4.8	1–25
Referrals of patients with Parkinson's made to the physiotherapy service per year	60.0	60.0	91.7	0–400

Training and support for physiotherapists working with patients with Parkinson's

Some physiotherapists who participated in the audit have access to opportunities for training in the

management of people with Parkinson's, as shown in Tables 39-41.

Table 39. Number of physiotherapy services in which physiotherapists attend training at least yearly in the management of people with Parkinson's

Attendance at training	No.	%
Yes on a regular basis	13	28.3
Yes infrequently	26	56.5
No	7	15.2
Total	46	100.0
No reply	6	—

Table 40. Number of physiotherapy services for which documented induction and support strategies for new physiotherapists working with patients with Parkinson's are available

Availability of induction and support strategies	No.	%
Yes	23	48.9
No	24	51.1
Total	47	100.0
No reply	5	—

Table 41. Number of physiotherapy services for which education, training and support for physiotherapists working with people with Parkinson's are available

Availability of education, training and support	No.	%
Member of Parkinson's specialist multidisciplinary (MDT)team	15	32.6
Member of neurology/elderly care specialist service	14	30.4
Do not work in specialist clinics but can readily access Parkinson's specialist MDT/Parkinson's nurse specialist	14	30.4
Do not work in specialist clinics but can readily access specialist neurology or elderly care MDT	0	0.0
No access to more specialised advice	2	4.3
Work alone	0	0.0
Total	45	97.7
No reply	6	—

Model of assessment of patients with Parkinson's

Table 42 shows that physiotherapists work in a variety of models when delivering assessment for people with Parkinson's. Physiotherapists sometimes provided more than one answer to the options in the data collection form.

Table 42. Number of physiotherapy services using a model of service delivery of assessment of patients with Parkinson's

Model	No.	%
MDT assessment	35	74.5
Physiotherapy assessment only	27	57.4
Other	4	8.5

Previous physiotherapy

A breakdown of whether or not patients received physiotherapy previously specifically for the management of Parkinson's before the current referral is in Table 43.

Table 43. Number of patients with Parkinson's who previously had physiotherapy specifically for Parkinson's before the current referral

Previous physiotherapy	No.	%
Yes	303	38.5
No	349	44.3
Offered but declined	5	0.6
Unknown	131	16.6
Total	788	100.0
No reply	1	—

Time between diagnosis and first referral to physiotherapy

There is considerable variation concerning the length of time between the diagnosis and first referral to

physiotherapy in days for people with Parkinson's, as shown in Table 44.

Table 44. Length of time in days between diagnosis and first referral for physiotherapy and between referral and initial physiotherapy assessment

Length of time between … in days	Mode	Median	Mean	Range
Diagnosis and first referral	0.0	464.0	1073.6	0–14268
Referral and initial physiotherapy assessment	—	23.0	35.6	0–1309

The median wait is over 15 months after diagnosis and the mean wait to first referral is nearly three years. The wide variation in first referral times to physiotherapy suggest that some people with Parkinson's are referred to physiotherapy services sooner than others. Some consultants refer patients with Parkinson's immediately for assessment and education about potential movement problems and how to handle them. Others may wait until patients actually experience movement or gait problems and then refer patients at the time actual symptoms appear. It is not possible to draw firm conclusions about the explanations for the referral patterns from the data collected.

Some people with Parkinson's are seen reasonably promptly following referral for an initial physiotherapy assessment. However, the 35.6–day mean suggests that other patients wait significantly longer than two months to be assessed by a physiotherapist.

85.9% (678) of patients referred to physiotherapy were seen in accordance with the local standard for time from referral to initial assessment for urgent or routine referrals. 10.8% of patients were not seen in accordance with a local standard and for 3.3% of patients, there is no local standard for the time interval between referral and assessment for physiotherapy.

Nature of referrals to physiotherapy for patients with Parkinson's

89.0% (701) of referrals to physiotherapists were routine referrals. Only 9.9% (78) were urgent and 1.1% (nine) was unknown.

Reasons for referrals to physiotherapy for patients with Parkinson's

There can be more than one reason for referral of patients with Parkinson's, which the findings reflect. Physiotherapists often gave multiple reasons for referral in response to the question asked in the audit.

The most commonly occurring reasons for referral are gait re-education, improvement of balance and flexibility (555 or 70.3% of patients) and improvement of functional independence, including mobility and activities of daily living (432 or 54.8% of patients). The full list of reasons for referral to a physiotherapist is in Table 45.

Table 45. Frequency of reasons for referral to physiotherapy of people with Parkinson's		
Reasons for referral	**No.**	**%**
Gait re-education, improvement of balance and flexibility	555	70.3
Enhancement of aerobic capacity	123	15.6
Improvement of movement initiation	235	29.8
Improvement of function independence, including mobility and activities of daily living	432	54.8
Provision of advice regarding safety in the home environment	213	27.0
Education and advice regarding the diagnosis	193	24.5
Unclear	17	2.2
Not stated	41	5.2
Total patients	789	—
No reply	0	

Grade of physiotherapist

For the patients for whom data were collected about physiotherapy, the grade (band) of the physiotherapist who assessed the patient was recorded. The distribution of banding of physiotherapists in the audit is in Table 46.

Table 46. Grade of physiotherapist assessing the patient reported on for the audit		
Grade	**No.**	**%**
Band 5	100	12.7
Band 6	308	39.0
Band 7	342	43.3
Band 8a	18	2.3
Band 8b	1	0.1
Band 8c	0	0.0
Other	20	2.5
Total	789	99.9

In summary, 82.4% of patients in the audit were assessed by physiotherapists in band 6 or 7, 12.7% were seen by band 5, and 2.4% by band 8. The results show that 2.5% of patients were assessed by a member of the physiotherapy staff in a different band, which may indicate that, for some patients, an assessment has been carried out by a physiotherapy assistant rather than a qualified physiotherapist.

Percentage of people with Parkinson's seen by the physiotherapist in a year

The audit questioned how many patients with Parkinson's are seen by the physiotherapist responding to the audit. The findings are in Table 47.

Table 47. Percentage of patients with Parkinson's seen by a physiotherapist in a year		
% of patients	**No.**	**%**
0–19%	215	27.2
20–39%	231	29.3
40–59%	170	21.5
60–79%	74	9.4
80–99%	28	3.5
100%	10	1.3
Unknown	61	7.7
Total	789	99.9
No reply	0	—

Physiotherapy management audit

Objectives

The objectives of the physiotherapy management audit are to:

- determine if physiotherapy services are providing assessment and interventions appropriate to the needs of people with Parkinson's, consistent with national guidance
- drive the increase of the proportion of people with Parkinson's who have an appropriate timely and effective assessment following referral and appropriate interventions compliant with national guidance
- determine if physiotherapists assessing and treating people with Parkinson's are aware of the *UK Quick Reference Cards for Physiotherapy* and are using these cards
- determine if there is a match between 'reason for referral' and 'areas identified for physiotherapy intervention' at the point of initial assessment

Findings

Overall compliance with the physiotherapy standards for the care of people with Parkinson's is summarised in the table. The percentages are based on responses provided for a total of 789 patients included in the audit, although there were no replies for 23, four and 84 patients for standards 1, 2 and 3.

Table 48. Compliance with physiotherapy standards for people with Parkinson's

Standard	No.	%
1. 100% of physiotherapy notes identify the area(s) of physiotherapy intervention on which to work at the point of initial assessment *(Parkinson's NICE CG35, the NSF LTC and the Quick Reference Cards (UK))*	750	97.9
2. 100% of notes record the treatment strategies and techniques to be used for intervention *(Parkinson's NICE CG35, the NSF LTNC and the Quick Reference Cards (UK))*	713	90.8
3. 100% of all assessments use outcome measures (Parkinson's NICE CG35, the NSF LTNC and the Quick Reference Cards (UK))	600	85.1

Documentation of anticipated intervention

For 97.9% of patients in the audit, the physiotherapy notes identified the area/s of anticipated intervention in the initial assessment.

The actual interventions were categorised as summarised in Table 49. As a patient may have had multiple planned interventions as a result of the initial assessment, the table includes multiple answers.

Table 49. Number of patients for whom anticipated interventions in the initial assessment were identified in physiotherapy notes

Interventions	No.	%
Gait	644	85.9
Balance	541	72.1
Posture	497	66.3
Transfers	413	55.1
Reaching and grasping	143	19.1
Physical activity	391	52.1
Positioning	103	13.7
Chest care	13	1.7
Other	174	23.2

Documentation of treatment strategies and techniques to be used for intervention in initial assessment notes

90.8% of patients in the physiotherapy audit had initial assessment notes that recorded the treatment strategies and techniques to be used for intervention.

For 85.1% of patients, physiotherapists used outcome measures. An extensive number of outcomes measures were used as shown in Table 50.

Table 50. Number of people with Parkinson's for whom outcome measures are used by physiotherapists

Outcome measure	No.	%
UPDRS	44	7.3
MDS–UPDRS	19	3.2
Lindop Parkinson's Assessment (LPAS)	223	37.2
Berg	163	27.2
Six-minute walk test	35	5.8
10-meter walk text	152	25.3
Time Up and Go (TUG)	273	45.5
Time UnSupported Stand (TUSS)	231	38.5
Parkinson's activity scale retropulsion test	27	4.5
Tragus to wall	138	23.0
Freezing of Gait Questionnaire	31	5.2
History of Falls Questionnaire	28	4.7
PDQ39	56	9.3
Phone FITT	0	0.0
General Practice Physical Activity Questionnaire (GPPAQ)	4	0.7
The Falls Efficacy Scale–International (Short FES–1)	40	6.7
EQ–5D tool	23	3.8
Other	301	50.2

Use by physiotherapists of evidence base on physiotherapy for people with Parkinson's

The range of evidence physiotherapists may use in the management of people with Parkinson's and the percentage of physiotherapists using that evidence to inform clinical practice or to guide intervention are in Table 51.

Table 51. Number of patients for whom sources of evidence are used by physiotherapy services to inform clinical practice or guide intervention for people with Parkinson's

Evidence sources	No.	%
Clinical experience	737	93.4
Advice from colleague or supervisor	321	40.7
Recommendations given in Dutch guidelines	326	41.3
Quick Reference Cards (UK, 2009)	363	46.0
Information from Parkinson's UK website	254	32.2
NSF LTC (2005)	259	32.8
NICE CG 35 (2006)	365	46.3
Published evidence in a peer reviewed journal	158	20.0
Other	37	4.7
None	1	0.1
No reply	0	—

Good practice involving physiotherapy care demonstrated by the audit

The national audit has demonstrated that there are areas of good practice in physiotherapy for patients with Parkinson's. The aspects of management that represent good practice include the following:

- 97.9% of patients had physiotherapy notes that identified the area/s of anticipated intervention in the initial assessment.
- 90.8% of patients in the physiotherapy audit had initial assessment notes that recorded the treatment strategies and techniques to be used for intervention.
- 85.9% of patients referred to physiotherapy were seen in accordance with the local standard for time from referral to initial assessment for urgent or routine.
- Physiotherapists who took part in this audit demonstrated that they are using treatment interventions for people with Parkinson's that are consistent with national guidance.

Shortcomings in physiotherapy care for people with Parkinson's

Lack of training and education for physiotherapists

Not all new physiotherapists (51.1% responded 'no') appear to have access to training in the management of people with Parkinson's. Only 28.3% of physiotherapists reported having training in the management of people with Parkinson's on a regular basis. 32.6% of physiotherapists reported that they work as members of a multidisciplinary team. It should be noted that 12.7% of physiotherapists providing intervention for people with Parkinson's are band 5.

Time between diagnosis and referral

The data about the time between diagnosis and referral of people with Parkinson's suggest variation in the way people with Parkinson's are referred to physiotherapists. In some services, patients appear to be referred early and are seen by a physiotherapist as part of a

multidisciplinary assessment. However, some patients may not be referred for assessment for nearly three years following diagnosis. The variation suggests that there may be shortages of physiotherapists skilled in assessment and management of patients with Parkinson's or there may be different referral models followed by consultants.

Lack of access to evidence of good practice for the assessment and management of people with Parkinson's

Not all physiotherapists access the evidence that is readily available for the assessment and management of people with Parkinson's, specifically the *UK Quick Reference Cards* (46.0%).

Actions indicated by audit findings for physiotherapy care for people with Parkinson's

Early referral to physiotherapy for people with Parkinson's

People diagnosed with Parkinson's should be offered an early referral to physiotherapy in order to get advice about what physiotherapy can do to address symptoms that may develop later.

Allocation of and training and education for physiotherapists assessing and treating people with Parkinson's

Physiotherapy services and commissioners of physiotherapy services could consider the specialisation of physiotherapists assessing and managing patients with Parkinson's, given mastery of the specific evidence base needed to provide effective care for these patients. Such specialisation might enable more appropriate and early interventions provided more uniformly for people with Parkinson's.

Promotion of available evidence of good practice

Professional bodies, particularly the Chartered Society for Physiotherapists, should actively promote the availability of evidence on the management of patients with Parkinson's, particularly the *Dutch guidelines for physiotherapy for people with Parkinson's*, the *UK Quick Reference Cards*, the *NICE clinical guideline* related to Parkinson's and the European guidelines related to Parkinson's.

Physiotherapists need to use outcome measures for people with Parkinson's, as these measures were not used for 14.9% of patients whose care was reported in the audit.

Part 4 – Speech and language therapy care

Speech and language therapy service audit

Objectives

The objectives of the speech and language therapy service audit are to:

- determine the service delivery models for speech and language therapy services that see people with Parkinson's, including the nature of referrals to these services
- determine if speech and language therapists assessing and treating people with Parkinson's have sufficient professional support in the assessment and management of the speech, language and communications needs of people with Parkinson's

Findings

Speech and language therapy care setting

The 35 speech and language therapy services that supplied data for the service audit see patients with Parkinson's in a variety of care settings as shown in Table 52. Of the speech and language services that participated in the audit, six (19.4%) reported working in a specialist clinic for people with Parkinson's. Nearly half (15, 48.4%) of the speech and language therapy services that provided data for the audit are mainly domiciliary based.

Table 52. Settings in which speech and language therapists usually see patients with Parkinson's

Setting	No.	%
In a specialist clinic for patients with Parkinson's	6	19.4
In more general specialist neurology clinics	0	0.0
In more general specialist elderly care clinics	0	0.0
In speech and language therapy adult/acquired disorders service mainly based in a hospital	5	16.1
In speech and language therapy adult/acquired disorders service mainly based in a community clinic	4	12.9
In speech and language therapy adult/acquired disorders service mainly domiciliary based	15	48.4
In generalist speech and language therapy service mainly based in a hospital	0	0.0
In generalist speech and language therapy service mainly based in a community clinic	0	0.0
In generalist speech and language therapy service mainly domiciliary based	1	3.2
No contact with patients with Parkinson's	0	0.0
Total	31	100.0
No reply	4	—

Of the 33 speech and language therapy services that provided information, 31 (93.9%) specialise in the treatment of patients with neurological conditions and 20 (60.6%) specialise in the treatment of people with Parkinson's.

Availability of speech and language therapy services for people with Parkinson's

Lee Silverman Voice Treatment —

Slightly more than half (18 or 54.5%) of 35 speech and language therapy services responding in the audit reported that Lee Silverman Voice Treatment (LSVT) global prescribed service is offered for people with Parkinson's who meet the inclusion criteria of: louder voice is stimulable, motivated and physically able to cope with intensity. The distribution of speech and language therapy services in relation to offering LSVT is in Table 53.

Table 53. Number of speech and language therapy services for which Lee Silverman Voice Treatment is available for patients with Parkinson's

LSVT service availability	No.	%
LSVT Global® prescribed service offered as required	18	54.5
Not all eligible candidates able to receive full service	3	9.1
Variant(s) of LSVT offered	6	18.2
LSVT not offered because there's no LSVT trained SLT	3	9.1
LSVT not offered because there's no service delivery decision	3	9.1
Total	33	100.0
No reply	2	—

Patient issues with communication irrespective of when in the course of Parkinson's a referral is made —

30 (91.0%) of services participating in the audit have a full service available for all patients with Parkinson's for issues with communication irrespective of when in the course of Parkinson's the referral was made. The distribution of responses to the availability of this service is in Table 54.

Table 54. Number of speech and language therapy services available for patients with Parkinson's for issues with communication irrespective of when in the course of Parkinson's the referral was made

Availability of SLT for issues with communication	No.	%
Full service available, all referrals seen	30	91.0
Not full service, some patients not seen depending on the stage of their Parkinson's	0	0.0
Not full service, restricted by number of hours assigned	1	3.0
Not full service, some patients not seen depending on postcode/area	1	3.0
Not full service, some patients not seen depending on service	1	3.0
Not full service, some patients not seen depending on issue	0	0.0
Not full service, some patients not seen depending on prioritisation in speech and language therapy Parkinson's service	0	0.0
Not full service, some patients not seen depending on prioritisation in overall speech and language therapy service	0	0.0
No service	0	0.0
Total	33	100.0
No reply	2	—

Patient issues with eating/ swallowing/drooling irrespective of when in the course of Parkinson's a referral or re-referral is made —

30 (88.2%) of the services participating in the audit have a full service available for all patients with Parkinson's for issues with eating, swallowing or drooling irrespective of when in the course of Parkinson's the referral or re-referral was made. The distribution of responses to the availability of this service is in Table 55.

Table 55. Number of speech and language services available for all patients with Parkinson's for issues with eating, swallowing or drooling irrespective of when in the course of Parkinson's the referral or re-referral was made

Availability of SLT for issues with eating, swallowing or drooling	No.	%
Full service available, all referrals seen	30	88.2
Not full service, some patients not seen depending on the stage of their Parkinson's	0	0.0
Not full service, restricted by number of hours assigned	1	2.9
Not full service, some patients not seen depending on postcode/area	1	2.9
Not full service, some patients not seen depending on service	1	2.9
Not full service, some patients not seen depending on issue	1	2.9
Not full service, some patients not seen depending on prioritisation in speech and language therapy Parkinson's service	0	0.0
Not full service, some patients not seen depending on prioritisation in overall speech and language therapy service	0	0.0
No service	0	0.0
Total	35	99.8

Patient self-referral or re-referral to speech and language service —

33 (94.3%) of the speech and language therapy services participating in the audit accept patients with Parkinson's who self-refer or re-refer to the speech and language service for communication issues.

25 (71.4%) of speech and language services participating in the audit accept patients with Parkinson's who self-refer or re-refer to the speech and language service for swallowing issues.

Referral for further instrumental swallowing assessment (video fluoroscopy or FEES) as indicated

Video fluoroscopy referrals are possible for all speech and language therapy services responding to the question in the audit, either on site (18 or 54.4%) or via another service (15 or 45.5%).

The situation is different for fibreoptic endoscopic evaluation of swallowing (FEES) as the service is not available for 17 (51.5%) of the 33 speech and language therapy services that responded to this question in the audit.

For patients who require assistive technology (AAC), only 22 (66.6%) of the speech and language therapy services that responded to this question in the audit had timely, appropriate equipment available to support the patients to live independently.

The full distribution of availability of video fluoroscopy, FEES and AAC is in Table 56.

Table 56. Number of speech and language therapy services for which video fluoroscopy, FEES and assistive technology (AAC) are available for patients with Parkinson's when indicated

Possibility of referral for video fluoroscopy or FEES and availability of assistive technology (AAC)	Video fluoroscopy		FEES		Assistive technology (AAC)	
	No.	%	No.	%	No.	%
Yes, referral possible on site/AAC is part of the service	18	54.5	7	21.2	8	24.2
Yes, referral possible via other service/AAC full access via other AAC service	15	45.5	9	27.3	14	42.4
Restricted access/service due to financial restrictions	0	0.0	0	0.0	9	27.3
Restricted access due to postcode	0	0.0	0	0.0	—	—
Restricted AAC service due to equipment range	—	—	—	—	2	6.1
No service available	0	0.0	17	51.5	0	0.0
Total	33	100.0	33	100.0	33	100.0
No reply	2	—	2	—	2	—

Proportion of patients seen with Parkinson's and number of referrals of people with Parkinson's

Of the 33 speech and language therapy services responding in the audit, for 20 (60.6%), the percentage of patients with the diagnosis of Parkinson's that are seen by a speech and language therapist ranges from zero to 19%.

Table 57. Percentage of patients with Parkinson's seen by a speech and language therapist

% of patients	No.	%
0–19%	20	60.6
20–39%	9	27.3
40–59%	1	3.0
60–79%	2	6.1
80–100%	1	3.0
Total	33	100.0
No reply	2	—

The most frequent (mode), middle (median), average (mean) and range number of referrals made to the speech and language therapy services participating in the audit of patients with Parkinson's is in Table 58. The average number of full time equivalent speech and language therapists working with people with Parkinson's also is in the table.

Table 58. Mode, median, mean and range number of referrals of people with Parkinson's to speech and language therapy services and of number of therapists working with patients with Parkinson's

Numbers	Mode	Median	Mean	Range
Referrals made of patients with Parkinson's to speech and language therapy per year	220.0	50.0	88.5	0–304
Full time equivalent speech and language therapists working with patients with Parkinson's in the service	2.0	2.0	2.7	0.1–12.9

Job and grade of speech and language therapist

The job roles of the speech and language therapists who responded in the audit are in Table 59. The majority of the therapists who participated in the audit described their roles as specialist speech and language therapists who see patients with Parkinson's.

Table 59. Job roles of speech and language therapists participating in the audit		
Job role	**No.**	**%**
Overall speech and language therapy service manager	6	18.2
Parkinson's specialist (speech and language therapy)	1	3.0
Specialist speech and language therapist who sees patients with Parkinson's	23	69.7
Generalist speech and language therapist who sees patients with Parkinson's	3	9.1
Total	33	100.0
No reply	2	—

The most frequently occurring job bandings of the speech and language therapists that participated in the audit were band 7 (16 therapists or 48.5% of the therapists who responded in the audit) and band 8a (11 or 33.3% of the therapists). The distribution of bandings of speech and language therapists in the audit is in Table 60. As the majority of speech and language therapist adult neurology posts are at band 6, the group of speech and language therapists that participated in the audit may be a biased sample and not reflect the national picture of speech and language therapy Parkinson's intervention.

Table 60. Grade of speech and language therapist who responded in the audit		
Grade	**No.**	**%**
Band 5	0	0.0
Band 6	4	12.1
Band 7	16	48.5
Band 8a	11	33.3
Band 8b	2	6.1
Band 8c	0	0.0
Total	33	100.0
No reply	2	—

Training and support for speech and language therapists working with patients with Parkinson's

Most speech and language therapy services that participated in the audit have access to continuing professional development related to the management of people with Parkinson's at least yearly, as shown in Table 61. Documented induction and support strategies for new speech and language therapists working with patients with Parkinson's tend to be available as part of general competences, as shown in Table 62.

Table 61. Number of speech and language therapy services with access at least yearly to continuing professional development (CPD) related to the management of people with Parkinson's		
Access to CPD	**No.**	**%**
Yes	30	90.9
No	3	9.1
Total	33	100.0
No reply	2	—

Table 62. Number of speech and language therapy services with availability of documented induction and support strategies for new therapists working with patients with Parkinson's		
Availability of induction and support strategies	**No.**	**%**
Yes, specifically in relation to patients with Parkinson's	1	3.1
Yes, as part of more general competencies	22	68.8
No	9	28.1
Total	32	100.0
No reply	3	—

Speech and language therapists identified the best level of support in relation to Parkinson's that individual speech and language therapists can receive in their services. Only eight (24.2%) speech and language therapists were members of Parkinson's specialist multidisciplinary teams and another seven (21.2%) were members of general neurology or elderly care specialist services. Several (14 or 42.4%) speech and language therapists participating in the audit said they don't work in specialist clinics but can access a Parkinson's multidisciplinary team or a Parkinson's nurse specialist.

Table 63 shows the best level of support available for speech and language therapists in relation to Parkinson's.

Table 63. Number of speech and language therapy services with best level of support available for individual speech and language therapists working with people with Parkinson's

Best level of support	No.	%
Member of Parkinson's specialist multidisciplinary team (MDT)	8	24.2
Member of general neurology/ elderly care specialist service	7	21.2
Do not work in specialist clinics but can readily access Parkinson's specialist MDT/Parkinson's nurse specialist	14	42.4
Do not work in specialist clinics but can readily access specialist neurology or elderly care MDT	2	6.1
Access to motor speech disorder specialist colleagues in LST team	2	6.1
No access to more specialised advice	0	0.0
Work alone	0	0.0
Total	33	100.0
No reply	2	—

Availability of speech and language therapy assistants

Many speech and language therapy services have speech and language therapy assistants involved in the delivery of care to patients with Parkinson's, as shown in Table 64.

Table 64. Number of speech and language therapy services with a speech and language therapy assistant in the delivery of care to patients with Parkinson's

Availability of SLT assistants	No.	%
Always	1	3.0
Sometimes	24	72.7
Never	8	24.2
Total	33	99.9
No reply	2	—

Measures included at initial assessment and each review

Approaches to initial assessment and each review of patients with Parkinson's varies among speech and language services in terms of assessing communication and swallowing function and needs, as shown in Tables 65 and 66.

Table 65. Number of speech and language therapy services using measures of communication function at initial assessment and at each review of patients with Parkinson's

Measures	No.	%
Standardised assessments of all speech/voice and language variables	8	24.2
Selective range of speech-voice and/or language formal assessments	9	27.3
Assessments are restricted to non-standardised informal assessments	4	12.1
No assessments stipulated	12	36.4
Total	33	100.0
No reply	2	—

Table 66. Number of speech and language therapy services using measures of swallowing function at initial assessment and at each review of patients with Parkinson's

Measures carried out	No.	%
Standardised assessments of swallowing	3	9.1
Selective range of formal assessments	8	24.2
Assessments are restricted to non-standardised informal assessments	13	39.4
No assessments stipulated	9	27.3
Total	33	100.0
No reply	2	—

Use of evidence base to inform clinical practice

32 (97.0%) of the speech and language services that replied to the question in the audit said that the choice of speech and language therapy assessments is informed by the evidence base for current best practice.

The range of evidence speech and language therapists may use in the management of people with Parkinson's and the percentage of speech and language therapy services using that evidence to inform clinical practice are in Table 67.

Table 67. Number of speech and language therapy services using sources of evidence to inform clinical practice for people with Parkinson's

Source of evidence	No.	%
Own clinical experience	33	94.3
Advice from colleague	32	91.4
RCSLT Clinical Guidelines	31	88.6
RCSLT Communicating Quality 3 (CQ3)	31	88.6
NICE guidelines	32	91.4
National Service Framework for Long Term Conditions (NSFLTC) guidelines	29	82.9
Published evidence in a peer reviewed journal	20	57.1
Other	8	22.9
None	0	0.0

Speech and language therapy management audit

Objectives

The objectives of the speech and language therapy management audit are to:

- determine the proportion of people with Parkinson's who have an appropriate referral to speech and language therapy
- determine the proportion of people with Parkinson's who have appropriate, timely and effective speech and language therapy assessment
- determine the proportion of people with Parkinson's who have appropriate speech and language therapy interventions that comply with national guidelines

Findings

Overall compliance with the speech and language therapy standards for the care of people with Parkinson's is summarised in Table 68. The percentages are based on 35 speech and language therapy services and 391 patients included in the audit. There were small numbers of no replies for standards 1 to 3; 132 no replies for the parts of standard 4, and 33 and 57 no replies for standard 9.

Table 68. Compliance with speech and language therapy standards for people with Parkinson's

Standard	No.	%
1. 100% of people with Parkinson's are reviewed by a speech and language therapist at six–12 monthly intervals *(Parkinson's NICE CG35 R12, R77 and the NSF LTC QR2)*	4 services	12.1 of services
2. 100% of Parkinson's patients have audio or video recordings made by speech and language therapists of spontaneous speech *(Dutch Guidelines R9a and the RCSLT Guidelines)*	48 patients for audio	12.4 of patients for audio
3. 100% of speech and language therapy notes expressly note a person with Parkinson's 'on/off' periods during treatment *(Dutch Guidelines R6, R19b)*	56 patients	14.4 of patients
4. 100% of people with Parkinson's have a full profile of communication skills carried out to include at a minimum: *(RCSLT Guidelines)* • strengths and needs • usage in current and likely environments • partner's own skills and usage • impact of environment on communication • identification of helpful or disadvantageous factors in environment	337 patients at first referral; 234 patients at each review; 197 patients had strengths and needs in current and likely environments	92.6 of patients at first referral; 90.3 of patients at each review; 52.3 of patients had strengths and needs in current and likely environments
(Number and percentage includes patients for whom reasons for it being not appropriate to		

Table 68. Compliance with speech and language therapy standards for people with Parkinson's		
Standard	**No.**	**%**
do the assessment were documented)		
5. Consideration is given to review and management of 100% of Parkinson's patients to support the safety and efficiency of swallowing and to minimise the risk of aspiration: *(RCSLT Guidelines)* • There is early referral to speech and language therapy for assessment, swallowing advice and where indicated further instrumental assessment. • Problems associated with eating and swallowing are managed on a case-by-case basis. • Problems are anticipated and supportive measures are employed to prevent complications where possible.	*See text for details*	
6. A perceptual assessment is made for 100% of people with Parkinson's, including respiration, phonation, resonance, articulation, prosody and intelligibility, to acquire an accurate profile for analysis *(RCST Clinical Guidelines)*	*296 for respiration; 278 for loudness only; 311 for intelligibility	75.7 for respiration; 71.1 for loudness only; 85.2% for intelligibility
7. 100% of people with Parkinson's are asked explicitly about difficulties with word finding and conversations *(Dutch Guidelines R11)*	—**	—**
8. Speech and language therapists give particular attention to improvement of vocal loudness, pitch range and intelligibility for 100% of people with Parkinson's *(NICE CG R81)*	251 for loudness; 96 for pitch range; 229 for intelligibility	64.2 for loudness; 24.6 for pitch; 58.6 for intelligibility
9. Speech and language therapists report back to the referrer at the conclusion of an intervention period with 100% of people with Parkinson's. 100% of reports detail intervention, duration, frequency, effects and expected prognosis *(Dutch Guidelines R2b)*	303 had reports; 221 reports had required contents	84.6 for reports; 66.2 reports had required contents

* The numbers and percentages are the highest for an aspect of speech assessed; for intelligibility, the number and percentage includes the number of patients for whom there was no assessment but a justification was documented.

** Explicit data were not collected for this standard.

Time between diagnosis and first referral to speech and language therapy in years

The audit involved capturing data on the date of first referral to the speech and language service responding to the audit as well as the date of first referral to any speech and language service. There is considerable variation concerning the length of time between the diagnosis of Parkinson's and the first referral to a speech and language therapist, whether the first referral to the speech and language therapy service responding to the audit or the very first referral to any speech and language therapy service which could be the speech and language therapy service responding to the audit or another speech and language therapy service, as shown in Table 69.

Table 69. Mode, median, mean and range in years between diagnosis and first referral for speech and language therapy for the service responding to the audit and for any speech and language service				
Length of time in years	**Mode**	**Median**	**Mean**	**Range**
Between diagnosis and first referral to this SLT service	0.0	2.0	5.0	0–33
Between diagnosis and first referral to any SLT service	0.0	2.0	4.0	0–24

The mode wait is zero years (patients are referred in the first year), the median wait is two years after diagnosis, and the mean wait to first referral is four or five years.
The wide variation in first referral times to speech and language therapy suggests that some people with Parkinson's are referred to speech and language therapy services sooner than others. Some consultants may refer patients with Parkinson's immediately for assessment about potential communication and swallowing problems and education on how to handle them. Others may wait until patients actually experience communication or swallowing problems and then refer patients at the time actual symptoms appear. It is not possible to draw firm conclusions about the explanations for the referral patterns from the data collected.

Stage of diagnosis at the time of referral to speech and language therapy

Most Parkinson's patients referred to speech and language therapy were in the maintenance phase of Parkinson's, whether determined at the time of referral for the speech and language service responding in the audit or for referral to any speech and language therapy service, as shown in Table 70.

Table 70. Stage of Parkinson's for patients referred for the first time to speech and language therapy				
Stage of Parkinson's	**Referral to present SLT service**		**Referral to any SLT service**	
	No.	**%**	**No.**	**%**
Diagnosis	55	14.3	56	16.8
Maintenance	238	62.0	184	55.1
Complex	85	22.1	37	11.1
Palliative	6	1.6	1	0.3
Not known	—	—	56	16.8
Total	384	100.0	334	100.1
No reply	7	—	57	—

Compliance with target times for speech and language therapy services

84.1% (327) of patients referred to speech and language therapy were seen in accordance with the target time from referral to first speech and language therapy appointment. 9.3% (36) patients were not seen in accordance with the target time and no reason was documented for why.

For 89.4% (336) of patients, the target time from speech and language therapy intention to treat decision to first appointment was met. For 24 (6.4%) patients, the target time was not met and no reason was documented for why. Performance in relation to target times is in Table 71.

Table 71. Compliance with target times for appointments with speech and language therapy services for people with Parkinson's

Compliance	Target time met from referral to appointment		Target time met from intention to treat decision to first appointment	
	No.	%	No.	%
Target time met	327	84.1	336	89.4
No, but reason documented	25	6.4	16	4.3
No, and no reason documented for why	36	9.3	24	6.4
Unknown	1	0.3	0	0.0
Total	389	100.1	376	100.1
No reply	2	—	15	—

Source and nature of referral to speech and language therapy

Referrals to speech and language therapy services for people with Parkinson's who were included in the audit were made by a wide variety of sources, as described in Table 72.

Table 72. Number of patients for each source of referral to speech and language therapy for people with Parkinson's

Referral source	No.	%
Elderly care clinic	47	12.1
General neurology clinic	47	12.1
Parkinson's nurse specialist	138	35.7
Allied health professions colleagues (PT, OT)	52	13.4
SLT colleague	16	4.1
Self/relative	15	3.9
Other	71	18.3
Unknown	1	0.3
Total	387	99.9
No reply	4	—

Two-thirds of the referrals reported in the audit had been as a result of a medical or nurse review, as shown in Table 73.

Table 73. Number of patients for each circumstance of referrals to speech and language therapy services for people with Parkinson's

Circumstances of referrals	No.	%
Initial medical appointment	34	8.8
Medical/nurse review appointment	256	66.1
Other	97	25.1
Total	387	100.0
No reply	4	–

Reasons for referrals to speech and language therapy for patients with Parkinson's

For over two-thirds of people with Parkinson's, the original reason for referral to a speech and language therapist was for a specific assessment opinion (see Table 74).

Table 74. Number of patients for the original reason for referral to speech and language therapy for people with Parkinson's

Original reason for referral	No.	%
General assessment opinion	58	14.9
Special assessment opinion	262	67.4
Treatment: no specific stipulation	9	2.3
Treatment: specific stipulation	58	14.9
Unknown	2	0.5
Total	389	100.0
No reply	2	–

Nature of episode of speech and language therapy care for patients with Parkinson's

For 64.9% (240) of patients in the audit, the episode of care reported in the audit was the first episode of speech and language therapy care for the patient.

Table 75. Number of Parkinson's patients for whom this was the first episode of speech and language therapy care

First episode of speech and language therapy for patients with Parkinson's	No.	%
Yes	240	64.9
No	130	35.1
Total	370	100.0
No reply	21	–

The breakdown of the nature of the current episode of speech and language therapy care for Parkinson's patients in the audit is in Table 76.

Table 76. Number of patients for the nature of the current episode of speech and language therapy for patients with Parkinson's

Nature of current episode	No.	%
Review appointment only	80	20.8
Group treatment only	24	6.2
Individual treatment only	226	58.7
Group and individual treatment	55	14.3
Total	385	100.0
No reply	6	—

Regular speech and language therapy review of people with Parkinson's

Differences in review practices of patients with Parkinson's by local speech and language therapy services are shown in Table 77.

Table 77. Number of patients for which speech and language therapy services review patients with Parkinson's

Practice of review of patients Parkinson's	No.	%
All patients in SLT service routinely reviewed within six–12 months	4	12.1
Some patients reviewed at request of wider multidisciplinary team/Parkinson's nurse specialist	11	33.3
Some patients reviewed according to local prioritisation	1	3.0
Patients are not automatically reviewed	11	33.3
No fixed time set for review	6	18.2
Total	33	99.9
No reply	2	—

Speech and language therapy assessments carried out at first referral and reviews for patients with Parkinson's

For patients having a first referral, a full assessment of communication and swallowing functions was documented or a reason the assessment would be inappropriate at the time was documented for 337 (92.6%) of patients for communication assessment and for 325 (90.8%) of patients for swallowing assessment.

For patients having a review, a full assessment of communication and of swallowing functions was documented or a reason the assessment would be inappropriate at the time was documented for 234 (90.4%) of patients for communication assessment and 219 (88.0%) for swallowing assessment.

However, there were large numbers of no replies for these questions in the audit, particularly related to assessments during reviews, as shown in Table 78.

Table 78. Number of patients having a full speech and language assessment at first referral and at each review								
Full speech and language therapy assessment	**At first referral**				**At each review**			
	Communication		**Swallowing**		**Communication**		**Swallowing**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Yes	306	84.1	237	66.2	205	79.2	161	64.7
No, but reasons for not appropriate to assess documented	31	8.5	88	24.6	29	11.2	58	23.3
No reference to assessments documented	27	7.4	33	9.2	25	9.7	30	12.0
Total	364	100.0	358	100.0	259	100.1	249	100.0
No reply	27	—	33	—	132	—	142	—

Assessment of strengths and needs for communication

For 197 (52.3%) of patients, all test scores and interpretation and implications for strengths and needs for communication in current and likely environments were documented. Table 79 shows the distribution of information documented about communication assessments.

Table 79. Number of patients for whom strengths and needs for communication are documented in current and likely environments by speech and language therapists		
Strengths and needs for communication documented	**No.**	**%**
All test scores and interpretation/implications documented	197	52.3
Limited information documented	134	35.5
No information documented	46	12.2
Total	377	100.0
No reply	14	—

Availability of audio recording from initial assessment and follow up of patients with Parkinson's assessed by speech and language therapy services

An audio recording was made at initial assessment and follow-up referrals and is available for only 48 (12.4%) of patients with Parkinson's assessed by a speech and language therapist, as shown in Table 80.

Table 80. Number of patients for whom audio recording made by a speech and language therapist at initial assessment and follow-up referrals are available		
Availability of audio recording	**No.**	**%**
Yes and available	48	12.4
Yes but not available	19	4.9
No	321	82.7
Total	388	100.0
No reply	3	—

Notation of drug cycles of patients with Parkinson's

For 67 (17.4%) of patients with Parkinson's being assessed by a speech and language therapist, notes recorded when in the drug cycle assessments were carried out. For only 56 (14.4%) of patients, notes recorded whether assessments were in off or on state.

Table 81. Number of patients for whom the drug cycle state is recorded in a speech and language therapist's assessment

Recording of drug cycle state in assessment	When in drug cycle state		In off or on state	
	No.	%	No.	%
Yes	67	17.4	56	14.4
No	317	82.6	332	85.6
Total	384	100.0	388	100.0
No reply	7	—	3	—

Assessment results for all speech subsystems for initial and review assessments

Speech and language therapist assessment results were not available for all speech subsystems for initial assessments and all review appointments for all patients with Parkinson's. Table 82 describes the findings relating to availability of results of all speech subsystems.

When the justification was documented for having a restricted range of subsystems and/or conditions assessed or no assessments documented is included, the number of patients whose assessments are compliant with the question increases to 256 (70.2%).

Table 82. Number of patients for whom assessment results for all speech subsystems for initial assessments and all review appointments were available

Availability of assessment results for all speech subsystems	No.	%
Yes, subsystems assessed in both stimulated and unstimulated conditions	84	23.0
Restricted range of subsystems and/or conditions assessed, justification documented	124	34.0
Restricted range of subsystems and/or conditions assessed, justification not documented	107	29.3
No assessments documented, but with justification noted	48	13.2
No assessments and no justification documented	2	0.5
Total	365	100.0
No reply	26	—

The specific tasks, parameters and needs assessed are described in Table 83. The table shows the variations in speech and language therapists assessments, in tasks included, aspects of voice-respiration and prosody, and intelligibility.

The dominant approach to assessment of participation in communication and the impact on partners or carers of patients with Parkinson's is predominantly informal. The alternative approaches to assessment are described in Table 84.

Table 84. Number of patients with Parkinson's having assessment of communication participation

Nature of assessment	Communication participation		Impact of Parkinson's on communication		Impact of communication changes to partner/carer	
	No.	%	No.	%	No.	%
Formal assessment of participation carried out	48	13.0	47	13.0	37	10.6
Informal assessment of participation carried out	247	66.8	235	65.1	171	49.1
Not carried out, but justification documented	23	6.2	24	6.6	21	6.0
Not carried out and no justification documented	52	14.1	55	15.2	75	21.6
No carer	—	—	—	—	44	12.6
Total	370	100.1	361	99.9	348	100.0
No reply	21	—	30	—	43	—

Table 83. Number of patients for whom aspects of speech were assessed		
Tasks/contexts covered	**No.**	**%**
Speaking	331	84.7
Reading	101	25.8
Writing	44	11.3
One to one context	276	70.6
Group context	81	20.7
Voice-respiration parameters assessed	**No.**	**%**
Loudness/amplitude	296	75.7
Pitch and pitch range	208	53.2
Voice quality	258	66.0
Prosody parameters assessed	**No.**	**%**
Rate	215	55.0
Loudness (variation)	278	71.1
Pitch (variation)	190	48.6
Intelligibility assessed	**No.**	**%**
Standardised diagnostic intelligibility test completed and score given	60	16.4
Informal assessment, non-standardised tool/subsection of other test completed and score given	110	30.1
Informal assessment completed	110	30.1
No assessment/results documented but justification given	31	8.5
No assessment documented and no justification given	54	14.8
Total	365	99.9
No reply	26	—
Identified AAC need addressed	**No.**	**%**
Yes, fully	30	7.8
Yes, partially, awaiting action from outside AAC service	2	0.5
Yes, partially, limited range of AAC devices available	6	1.6
Not addressed as not indicated	332	86.0
Indicated but no action documented	16	4.1
Total	386	100.0
No reply	5	—

Communication of information following assessment by speech and language therapists

An explanation of factors tailored to the patient and carer was documented for 331 (85.1%) of patients and for a further 12 (3.1%) patients, there was a justification given when no explanation was documented. Intervention specially including education and advice on self-management was documented for 314 (81.3%) patients, and for another 23 (6.0%) patients, there was a justification for no explanation. Of the 118 patients for whom recommended onward referrals were appropriate, all onward referrals were documented for 109 (92.4%).

Tables 85, 86 and 87 contain additional information on speech and language therapy practices relating to communicating information following assessment of patients with Parkinson's.

Table 85. Number of patients for whom results and rationale for actions were explained to patients and carers		
Documentation of explanation to patients	**No.**	**%**
Explanation of causal/maintaining factors aimed to patient and carer documented	331	85.1
No explanation made/documented but justification documented	12	3.1
No explanation made/documented and no justification documented	46	11.8
Total	389	100.0
No reply	2	—

Table 86. Number of patients for whom information was supplied to make informed decisions about care and treatment		
Patients given information to make informed decisions	**No.**	**%**
Intervention specifically includes education and advice on self-management and is documented	314	81.3
No explanation made/documented but justification documented	23	6.0
No explanation made/documented and no justification documented	49	12.7
Total	386	100.0
No reply	5	—

Table 87. Number of patients for whom recommended onward referrals were made		
Onward referrals made	**No.**	**%**
Yes, all	109	29.1
Yes, some	3	0.8
None and reasons given	2	0.5
None and reasons not documented	4	1.1
No onward referrals recommended	256	68.4
Total	374	99.9
No reply	17	—

Management plan based on assessment results

For 331 (90.4%) of patients, there was a clear plan of management based on the results of assessment, as shown in Table 88.

Table 88. Number of patients for whom a management plan was documented based on assessment		
Management plan	**No.**	**%**
All plans detailed in notes	331	90.4
Some restricted plans documented	32	8.7
No plan documented	3	0.8
Total	366	99.9
No reply	25	—

Nature of speech and language therapy interventions for patients with Parkinson's

For 304 (80.2%) of patients, speech and language therapy interventions included education and planning for upcoming issues, that is, prophylactic and anticipative interventions, not just symptomatic, as shown in Table 89.

Table 89. Number of patients with each type of speech and language therapy intervention		
Nature of SLT interventions	**No.**	**%**
Yes, education/planning for upcoming issues included	304	80.2
No, no prophylactic component	75	19.8
Total	379	100.0
No reply	12	—

Of 361 patients for whom data were provided, 117 were in later stages of Parkinson's. Of the 117 patients in later stages, 61 (52.1%) were not referred to a speech and language therapy service in early stages. Of the remaining 56 patients, 30 had speech and language therapy input documented at all stages of Parkinson's. The breakdown of responses to the relevant question in the audit is in Table 90.

Table 90. Number of patients having speech and language therapy input at all stages of Parkinson's for patients in later stages		
SLT intervention	**No.**	**%**
Input documented at all stages	30	8.3
Input documented at certain stages only	13	3.6
Not referred in early stages	61	16.9
No input documented	13	3.6
Patient not in later stages	244	67.6
Total	361	100.0
No reply	30	—

Speech and language therapy interventions for patients with Parkinson's focused on several aspects of improving speech and communication, as shown in Table 91.

Table 91. Number of patients for whom aspects of communication were targeted by speech and language interventions		
Aspects of communication targeted by SLT intervention	**No.**	**%**
Pitch (range)	96	24.6
Prosody	94	24.0
Improvement of vocal loudness	251	64.2
Strategies to optimise intelligibility	229	58.6

Speech and language therapists used a full range of other interventions for patients with Parkinson's and their carers, as shown in Table 92.

Table 92. Number of patients for whom interventions were targeted by speech and language therapists other than direct speech or voice work

SLT interventions other than speech or voice work	No.	%
Patient education/advice	295	75.4
Managing patient participation	168	43.0
Managing patient impact	135	34.5
Managing generalisation outside clinic	163	41.7
Carer education/advice	148	37.9
Managing career impact	21	5.4
Other	18	4.5

Reports of speech and language therapy interventions

Reports by speech and language therapists were made back to the referrer or other key people at the conclusion of an intervention period (or interim reports when treatment lasts a longer time) for 303 (84.6%) of patients with Parkinson's. For 221 (66.2%) of patients for whom data were provided, reports detailed the intervention, duration, frequency, effects and expected prognosis and provided results from assessments or reassessments.

Referral letters to other agencies varied in the level of content provided. Details about reports being provided are in Tables 93 and 94.

Table 93. Number of patients for whom reports were provided on speech and language therapy interventions

Reports on SLT interventions	Provided		Included required contents	
	No.	%	No.	%
Yes	303	84.6	221	66.2
No	55	15.4	113	33.8
Total	358	100.0	334	100.0
No reply	33	—	57	—

Table 94. Number of patients for whom referral letters to other agencies contained specified information

Contents of SLT referral letters to other agencies	No.	%
Relevant history	124	31.7
Question(s) that the referrer wishes to have answered	108	27.6
Type of referral requested	101	25.8

Good practice involving speech and language therapy demonstrated by the audit

The national audit has demonstrated good practice for patients with Parkinson's being cared for by speech and language therapists in the 35 services that participated in the audit. The aspects of speech and language therapy-related services that represent good practice include the following:

- 91.0% of speech and language therapy services in the audit provide a full speech and language therapy service for people with Parkinson's for issues with communication.
- 94.3% of speech and language therapy services in the audit accept patients with Parkinson's who self-refer or re-refer to the service for communication issues.
- Video fluoroscopy services are accessible for all speech and language therapy services in the audit, either on site or via another service.
- In 90.9% of speech and language therapy services, speech and

language therapists have access to continuing development related to the management of people with Parkinson's at least yearly.

- For 90.5% of patients with Parkinson's referred to speech and language therapy services, the target time between referral to appointment was met (or a reason for the delay was documented), and for 93.7% of Parkinson's patients referred, the target time from intention to treat decision to first appointment was met (or a reason for the delay was documented).

- 92.6% of patients have a full profile of communication skills carried out at first referral to a speech and language therapy service (or a reason given for why the assessment would be inappropriate) and 90.4% of patients have a full profile of communication skills carried out at each review (or a reason given for why the profile is not done).

- 97.0% of speech and language therapy services in the audit said the choice of speech and language therapy assessments are informed by the evidence base and speech and language therapy services access a very wide range of evidence to inform clinical practice or guide intervention for people with Parkinson's.

- For 90.4% of patients, there was documentation of a management plan based on assessment detailed in the patient's notes.

- Of the patients with Parkinson's for whom an onward referral was appropriate, referrals were documented for 92.4% of the patients.

Shortcomings in speech and language therapy for people with Parkinson's

The findings of the audit identify some areas of practice that represent shortcomings in speech and language therapy care in relation to national guidance for the care of people with Parkinson's.

Lack of working in an integrated approach

The most prevalent setting in which speech and language therapists see people with Parkinson's is in an acquired disorders service that is mainly domiciliary based.

Only eight (24.2%) speech and language therapists were members of Parkinson's specialist multidisciplinary teams – another seven (21.2%) speech and language therapists were members of general neurology or elderly care specialist services. 14 (42.4%) of speech and language therapy services said they don't work in specialist clinics but can access a Parkinson's multidisciplinary team or a Parkinson's nurse specialist.

Lack of availability of speech and language services for people with Parkinson's

There are limitations in the availability of speech and language therapy services for people with Parkinson's. For example, only 18 (54.5%) of speech and language therapy services are able to offer Lee Silverman Voice Treatment (LSVT) as required, although six services offer a variant of LSVT, which brings the total to 24 services (72.7%) offering LSVT or a variant. Assistive technology (AAC) is restricted in 11 (33.3%) of speech and language therapy services.

Lack of use of standardised speech and language therapy assessments of people with Parkinson's

Overall, few (eight, 24.2%) speech and language therapy services regularly use standardised assessments of speech, voice and language variables with people with Parkinson's and fewer (three, 9.1%) regularly use standardised assessments of swallowing.

Timing of reviews by speech and language therapy services of people with Parkinson's

Only four (12.1%) speech and language therapy services routinely review people with Parkinson's within six–12 months. For one-third of speech and language therapy services, patients are reviewed on request of a multidisciplinary team or a Parkinson's nurse specialist, and for another third of speech and language therapy services, patients are not automatically reviewed.

Lack of audio recordings and assessments of people with Parkinson's

For only 48 (12.4%) of people with Parkinson's were audio recordings available of initial assessment and follow-up.

For only 67 (17.4%) of Parkinson's patients, did the speech and language therapy assessment include documentation of the patient's drug cycle state. For only 56 (14.4%) patients, the documentation included reference to the off or on state.

Initial assessments and review assessments included all subsystems in both stimulated and unstimulated conditions for only 84 (23.0%) of Parkinson's patients.

Lack of reports by speech and language services

For 55 (15.4%) of patients with Parkinson's, speech and language therapists did not provide a report. Reports did not routinely include the required contents of speech and language therapy reports.

Actions indicated by audit findings for speech and language therapy for people with Parkinson's

Closer integration of speech and language therapy services for patients with Parkinson's

In view of the audit evidence about how speech and language therapy services are being delivered for people with Parkinson's, speech and language therapy services and commissioners of such services could consider the specialisation of speech and language therapists in assessing and providing interventions for people with Parkinson's. Such specialisation might enable more appropriate and early interventions provided more uniformly for people with Parkinson's.

Availability of speech and language therapy services for patients with Parkinson's

Limitations in the availability of speech and language therapy services for people with Parkinson's should be addressed so that all speech and language therapy services are able to offer Lee Silverman Voice Treatment (LSVT) and assistive technology (AAC) to patients with Parkinson's when these services are indicated. As video fluoroscopy services are accessible for all speech and language therapy services in the audit, either on site or via another service, the need for specialist fibre optic endoscopic evaluation of swallowing (FEES) to patients with Parkinson's is mitigated.

Speech and language therapy services' practices for patients with Parkinson's

Speech and language therapists need to review current professional practices for patients with Parkinson's, specifically the timing of reviews, assessments and their documentation, management plans and their documentation, interventions and their documentation, and reports. Improvements are indicated in aspects of speech and language therapy practices relating to patients with Parkinson's.

A shift is needed from reliance on informal assessments when standardised, more objective assessments are indicated and available. The persistent use of informal assessments undermines the accuracy and comparability of outcome/change measurement and threatens the validity of evidence that patients with Parkinson's benefit from speech and language therapy interventions.

Actions indicated by the Parkinson's national audit findings

Integration of services needed by people living with Parkinson's

Elderly care and neurology services, and commissioners of these services, need to consider how medical, specialist Parkinson's nursing, occupational therapy, physiotherapy and speech and language therapy services can be organised to support an integrated multiprofessional approach to service delivery for people with Parkinson's.

Such an approach supports the continuous recognition that Parkinson's is a complex disease with many varied symptoms of the condition and complications of the treatment. An integrated approach to care of these patients may be more likely to facilitate and support the provision of a full range of continuous assessments and therapies, including those relating to the psychological and psychiatric issues patients may face, needed to provide the best possible care for these patients. The approach also can facilitate the continuous expert development of the full range of healthcare professionals to focus on the clinical and therapeutic needs of people with Parkinson's.

Professionals providing care to people with Parkinson's should arrange to meet with local managers and commissioners, presenting the evidence of good practice concerning an integrated model of service delivery and the findings of this audit, considering any barriers to changing the service delivery model for people with Parkinson's and overcoming any local barriers to an integrated service delivery approach.

Improvement of clinic processes to support the care of people with Parkinson's by elderly care and neurology services

Elderly care and neurology services that provide care for people with Parkinson's should consider how to improve a number of processes that support the care of people with Parkinson's, including:

booking and communication, including with patients' GPs, to facilitate the review by a specialist of every patient with Parkinson's at least every year

the provision of suitable written information on Parkinson's in all clinics in which people with Parkinson's are seen, and information especially on adverse effects of new medications prescribed for people with the condition

provision of advice on the impact of driving for all patients experiencing daytime sleepiness and monitoring for impulse control disorders for all patients on dopamine agonists

monitoring of patients on ergot-derived dopamine agents for all patients on these medications

the role of the specialist in supporting patients with Parkinson's with advanced care planning

Review of use of standardised assessments and evidence-based practice

Professionals involved in the assessment and management of people with Parkinson's need to consider the availability of standardised tools relevant to the assessment of people with Parkinson's. Professionals should consider the regular use of such tools to support the provision of a full range of care and services to people with Parkinson's.

Occupational therapists and physiotherapists need to access evidence of best practice relevant to the assessment and treatment of people with Parkinson's, particularly guidelines published by professional bodies and Parkinson's UK.

Training and continuing professional development for therapists assessing and treating people with Parkinson's

Medical, nursing and therapy services caring for people with Parkinson's need to consider how the on-going training and development of all professionals caring for people with Parkinson's can be maintained.

Availability of speech and language therapy services for patients with Parkinson's

Limitations in the availability of speech and language therapy services for people with Parkinson's should be addressed so that all speech and language therapy services are able to offer Lee Silverman Voice Treatment (LSVT) and assistive technology (AAC) to patients with Parkinson's when these services are indicated.

Improvements in professional practices

All professional groups participating in the audit should review the audit findings in detail and act to improve professional practices shown as not being provided to every patient with Parkinson's.

The role of Parkinson's UK in acting on the audit findings

Working with relevant professional groups, Parkinson's UK and the Parkinson's National Audit Governance Group should consider:

creating a professional forum in which the examples of information for people with Parkinson's and assessment tools and checklists can be shared among the professions involved in the care of people with Parkinson's

providing and promoting standardised validated information on Parkinson's medications that specialist services can refer to and use for Parkinson's

patients when they are prescribed new Parkinson's medications

the provision of current evidence-based advice on the use of assessment tools

the role of the specialist doctor and Parkinson's nurse specialist in supporting the patient with Parkinson's in end-of-life care and the provision of advice for specialist teams on these roles

amending the data collection directions and tool for future national Parkinson's audits for the areas for which data provided could not be collated because of the lack of consistency in reporting

recruiting the participation of care homes in the National Parkinson's Audit, given the number of people living with Parkinson's who are cared for in care homes

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Appendix 1: List of organisations participating in the national clinical audit

Elderly care

No.	Employing Trust (Medical)	Employing Trust (Nurse Specialist)	Geographical area covered
1	Airedale NHS Foundation Trust	Limited Parkinson's nurse specialist coverage only	Parts of West Yorkshire
2	Royal United Hospital NHS Trust	Sirona Care and Health	Bath and North East Somerset and Mendip
3	Berkshire Healthcare Foundation Trust	Berkshire Healthcare Foundation Trust	Berkshire East part of BHFT and six contracted GP surgeries in South Bucks
4	Brighton and Sussex University Hospitals NHS Trust	Brighton and Hove PCT, Brighton and Sussex University Hospitals NHS Trust	East and West Sussex as far north as Lewes
5	Central Manchester University Hospitals NHS Foundation Trust	Trafford PCT	Trafford area
6	Central Manchester University Hospitals NHS Foundation Trust	No Parkinson's nurse specialist	Central Manchester
7	City Hospitals Sunderland NHS Foundation Trust	City Hospitals Sunderland NHS Foundation Trust	Sunderland
8	County Durham and Darlington NHS Foundation Trust	County Durham and Darlington NHS Foundation Trust	County Durham and Darlington
9	Cwm Taf University Health Board	Cwm Taf University Health Board	Rhondda, Cynon, Taff Ely and Merthyr
10	Derby Hospitals NHS Foundation Trust	Derby Hospitals NHS Foundation Trust	Southern Derbyshire
11	Dorset County Hospital NHS Foundation Trust	Dorset County Hospital NHS Foundation Trust	West Dorset
12	The Dudley Group of NHS Foundation Trust	Dudley PCT	Dudley and includes some Wolverhampton and Sandwell areas
13	East and North Hertfordshire NHS Trust	Hertfordshire PCT	Hertfordshire
14	East Kent Hospitals University NHS Foundation Trust	East Kent Hospitals University NHS Foundation Trust	Eastern and Coastal Kent
15	East Kent Hospitals University NHS Foundation Trust	East Kent Hospitals University NHS Foundation Trust	Eastern and Coastal Kent
16	East Kent Hospitals University NHS Foundation Trust	East Kent Hospitals University NHS Foundation Trust	Eastern and Coastal Kent
17	Epsom and St Helier	No information provided	Surrey

	University Hospitals NHS Trust		
18	Frimley Park Hospital NHS Foundation Trust	Surrey PCT	Surrey, Hampshire and Berkshire
19	Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire PCT	Gloucestershire and boundaries
20	Great Western Hospital Foundation Trust	Great Western Hospital Foundation Trust	Swindon and Wiltshire
21	Guys and St Thomas' NHS Foundation Trust	Guys and St Thomas' NHS Foundation Trust	London boroughs including Southwark and Lambeth (principle) and parts of Westminster and Lewisham
22	Hinchingbrooke Health Care NHS Trust	Cambridge Community Services	Huntingdon area of Cambs and part of Fenland
23	Hull and East Yorkshire NHS Trust	No Parkinson's nurse specialist	Hull and East Yorkshire
24	Maidstone and Tunbridge Wells NHS Trust	Kent Community Health NHS Trust	Tunbridge Wells and surrounding area
25	Maidstone and Tunbridge Wells NHS Trust	King's College Hospital NHS Foundation Trust	Maidstone and surrounding rural areas
26	NHS Ayrshire and Arran	NHS Ayrshire and Arran	East Ayrshire
27	North Bristol NHS Trust	South Gloucestershire Community Health	Bristol, South Gloucestershire, North Somerset
28	North Cumbria University Hospital Trust	North Cumbria University Hospital Trust	East Cumbria
29	Greater Glasgow and Clyde NHS Trust	Greater Glasgow and Clyde NHS Trust	North East Glasgow
30	North Tees and Hartlepool NHS Foundation Trust	North Tees and Hartlepool NHS Foundation Trust	North Tees PCT, Hartlepool PCT, Peterlee and Sedgefield (Durham PCT)
31	Northampton General Hospital NHS Trust	Northamptonshire Healthcare Foundation Trust	South Northamptonshire
32	Northumbria Healthcare NHS Foundation Trust	Northumbria Healthcare NHS Foundation Trust	North Tyneside and Northumberland
33	Pennine Acute Hospitals NHS Trust	Pennine Care NHS Foundation Trust	Heywood, Middleton and Rochdale
34	Pennine Acute Hospitals NHS Trust	Pennine Acute Hospitals NHS Trust	Bury
35	Pennine Acute Hospitals NHS Trust	Pennine Care NHS Foundation Trust	Pennine Care Parkinson's nurse specialist covers Oldham Community patients but also works alongside the main consultant in the Parkinson's clinic in acute care once weekly. The audit is based on joint notes from patients seen in the consultants clinic and also patients who are seen in Oldham community
36	Poole Hospital NHS Foundation Trust	Poole Hospital NHS Foundation Trust	Poole, Purbecks and East Dorset

37	Royal Free London NHS Trust	No Parkinson's nurse specialist	Camden and Barnet
38	Salford Royal NHS Foundation Trust	Salford Royal NHS Foundation Trust	Salford in Greater Manchester, although some patients come from other localities and further afield
39	York Teaching Hospitals NHS Foundation Trust	York Teaching Hospitals NHS Foundation Trust	Whitby, Scarborough, Bridlington, Driffield, Malton & Pickering
40	South Warwickshire NHS Foundation Trust	South Warwickshire NHS Foundation Trust	South Warwickshire
41	Southern Health NHS Foundation Trust	Southern Health NHS Foundation Trust	New Forest, Hampshire
42	Southport and Ormskirk Hospital NHS Trust	No Parkinson's nurse specialist	West Lancashire, Southport and Formby, Sefton
43	Surrey and Sussex Healthcare NHS Trust	First Community Care	East Surrey and West Sussex
44	The Rotherham NHS Foundation Trust	The Rotherham NHS Foundation Trust	Rotherham
45	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	East Dorset
46	United Lincolnshire Hospitals NHS Trust	United Lincolnshire Hospitals NHS Trust	East Lindsey, Lincolnshire
47	University Hospitals of Leicester NHS Trust	University Hospitals of Leicester NHS Trust	Leicestershire and Rutland
48	Cumbria Partnership NHS Foundation Trust	University Hospitals of Morecambe Bay NHS Foundation Trust	North West Cumbria and Lakes. Part of North Cumbria
49	University Hospitals of Morecambe Bay NHS Foundation Trust	University Hospitals of Morecambe Bay NHS Foundation Trust	Langdale in North, Grange over sands in West, Lancashire border South, East as far as Sedbergh
50	Ashford and St Peter's Hospitals NHS Foundation Trust	Virgin Care Community Services, Surrey	North West Surrey
51	Western Health and Social Care Trust	Western Health and Social Care Trust	Omagh and Fermanagh
52	Western Health and Social Care Trust	Western Health and Social Care Trust	Londonderry, Dungiven, Strabane, Limavady
53	Royal United Hospital NHS Trust	Great Western Hospitals NHS Foundation Trust	North and West Wiltshire
54	Wirral University Teaching Hospital NHS Foundation Trust	Wirral PCT	Wirral
55	Wye Valley NHS Trust	Wye Valley NHS Trust	Herefordshire
56	Yeovil District Hospital NHS Foundation Trust	Yeovil District Hospital NHS Foundation Trust	East Somerset and part of North Dorset
57	Kettering General Hospital NHS Foundation Trust	Northamptonshire Healthcare NHS Foundation Trust	North Northamptonshire – Kettering, Corby, Rushden, Wellingborough
58	University Hospitals of Morecambe Bay NHS Foundation Trust	University Hospitals of Morecambe Bay NHS Foundation Trust	North – border with Cumbria, East as far as Ingleton/Bentham in Yorkshire, South as far as

			Garstang
59	Central London Community Healthcare NHS Trust	Central London Community Healthcare NHS Trust	Barnet, Brent, Harrow, West Herts, Enfield, Camden

Neurology

No.	Employing Trust (Medical)	Employing Trust (Nurse Specialist)	Geographical area covered
1	Airedale NHS Foundation Trust	Limited Parkinson's nurse specialist coverage only	Parts of West Yorkshire
2	Royal United Hospital NHS Trust	Sirona Health and Care Bath	Bath and North East Somerset, Mendip district of Somerset
3	Royal United Hospital NHS Trust	Great Western Hospital NHS Foundation Trust	North and West Wiltshire
4	Barking Havering and Redbridge University Hospitals NHS Trust	Barking Havering and Redbridge University Hospitals NHS Trust	Redbridge and Ilford
5	Bradford Teaching Hospitals NHS Foundation Trust	Bradford Teaching Hospitals NHS Foundation Trust	Bradford, Keighley and Airedale
6	Buckinghamshire Healthcare NHS Trust	Buckinghamshire Healthcare NHS Trust	Aylesbury, Beaconsfield, Buckingham, Gerard's Cross, High Wycombe, Leighton Buzzard, Marlow and Thame
7	Calderdale and Huddersfield NHS Foundation Trust	Calderdale and Huddersfield NHS Foundation Trust	Huddersfield, West Yorkshire
8	Cambridge University Hospitals NHS Foundation Trust	Cambridge University Hospitals NHS Foundation Trust	Cambridge, South and East Cambridgeshire, Hunts
9	*Data transferred to Elderly Care Audit*		
10	Dorset County Hospital NHS Foundation Trust	Dorset County Hospital NHS Foundation Trust	West Dorset
11	Dudley Group of Hospitals NHS Trust	Dudley PCT	Dudley and includes some Wolverhampton and Sandwell areas
12	East and North Hertfordshire NHS Trust	Hertfordshire PCT	Hertfordshire
13	East Sussex Healthcare NHS Trust	East Sussex Healthcare NHS Trust	East Sussex
14	No data provided	East Sussex Healthcare NHS Trust	East Sussex
15	Frimley Park Hospital NHS Foundation Trust	Surrey Community Health	Parts of Surrey, Hampshire
16	Guys and St Thomas' NHS Foundation Trust	Guys and St Thomas' NHS Foundation Trust	Lambeth, Southwark, Lewisham and parts of Westminster. Patients travel from Tenby, Kent and Sussex
17	Harrogate and District NHS Foundation Trust	Harrogate and District NHS Foundation Trust	Harrogate and District NHS Foundation Trust catchment area
18	Heatherwood and Wexham Park Hospitals NHS Foundation Trust	Heatherwood and Wexham Park Hospitals NHS Foundation Trust	Berkshire East
19	Imperial College Healthcare NHS Trust	Imperial College Healthcare NHS Trust	North West London and, as a tertiary service, any other area that wishes to refer

			patients here
20	King's College Hospital NHS Trust	King's College Hospital NHS Trust	Lambeth and Southwark and tertiary covering the UK
21	Leeds Teaching Hospitals NHS Trust	Leeds Teaching Hospitals NHS Trust	The whole of Leeds with some referrals from local towns
22	Lewisham Healthcare NHS Trust	Lewisham Healthcare NHS Trust	Lewisham, Greenwich, Dartford, Bromley and Sidcup
23	Maidstone and Tunbridge Wells NHS Trust	Kent Community Health NHS Trust	Tunbridge Wells surrounding area and East Sussex
24	Maidstone and Tunbridge Wells NHS Trust	King's College Hospital NHS Trust	West Kent
25	Mid Essex Hospital Services NHS Trust	Mid Essex Hospital Services NHS Trust	No data provided
26	Mid Yorkshire Hospitals NHS Trust	Mid Yorkshire Hospitals NHS Trust	Wakefield, Pontefract and Kirklees patients under Mid Yorks consultant
27	Basildon and Thurrock University Hospitals NHS Trust	North East London Foundation Trust	South West Essex
28	No consultant input	Norfolk Community Health and Care NHS Trust	North Norfolk, South Norfolk
29	Northampton General Hospital NHS Trust	Northamptonshire PCT	Northamptonshire
30	Northern Health and Social Care Trust	Northern Health and Social Care Trust	North East of Northern Ireland
31	Northwest London Hospitals NHS trust	No Parkinson's nurse specialist	Brent, Harrow, Ealing
32	Oxford University Hospitals NHS Trust	Oxford University Hospitals NHS Trust	Oxfordshire (Thames Valley)
33	Poole Hospital NHS Foundation Trust	Poole Hospital NHS Foundation Trust	Poole, Purbecks and East Dorset
34	Nottingham University Hospitals NHS Trust	Royal Derby Hospitals NHS Trust	Southern Derbyshire but International centre of excellence so extensive outside referral
35	Royal Free London NHS Foundation Trust	Royal Free London NHS Foundation Trust	North London and Herts
36	South London Healthcare NHS Trust	South London Healthcare NHS Trust	Greenwich and Bexley
37	University Hospital of South Manchester NHS Foundation Trust	No data provided	No data provided
38	South Tees Hospitals NHS Foundation Trust	South Tees Hospitals NHS Foundation Trust	Teesside includes North and South Tees, Hambleton and Richmondshire, South Durham, North Yorkshire
39	Southern Health and Social Care Trust	No data provided	Including districts of Craigavon, Banbridge, Armagh, Dungannon, South Tyrone
40	No consultant input	North East London Foundation Trust	Havering and Barking and Dagenham
41	UHB Queen Elizabeth	No data provided	No data provided

	Hospital		
42	University College London Hospitals NHS Foundation Trust	University College London Hospitals NHS Foundation Trust	National
43	University Hospitals Coventry and Warwickshire NHS Trust	University Hospitals Coventry and Warwickshire NHS Trust	Coventry & Warwickshire, occasional patients from surrounding counties (Worcestershire, Leicestershire, Birmingham, Northamptonshire etc.)
44	No data provided	Virgin Care, Community Services Surrey	South West Surrey - Surrey Heath, Farnham, Guildford and Waverley
45	Western Health and Social Care Trust	Western Health and Social Care Trust	Omagh and Fermanagh
46	Western Health and Social Care Trust	Western Health and Social Care Trust	Londonderry, Dungiven, Strabane, Limavady
47	Salisbury NHS Foundation Trust	Great Western Hospitals NHS Foundation Trust	South Wiltshire, North Dorset, New Forest Hants, parts of North Wiltshire
48	Taunton and Somerset NHS Foundation Trust	Yeovil District Hospital NHS Foundation Trust	East Somerset and part of North Dorset. Any patient that comes to Yeovil District Hospital to see a consultant
49	Lancashire Teaching Hospitals NHS Foundation Trust	Lancashire Teaching Hospitals NHS Foundation Trust	Lancashire and parts of South Cumbria
50	The Princess Alexandra Hospital NHS Trust	South Essex Partnership University NHS Foundation Trust (SEPT)	West Essex – Harlow, Epping and Uttlesford
51	Southend University Hospital NHS Foundation Trust	Southend University Hospital NHS Foundation Trust	South East Essex
52	Cambridge University Hospitals NHS Foundation Trust	South Essex Partnership University NHS Foundation Trust (SEPT)	Bedfordshire – North and Mid. South – clinics only

Occupational therapy

No.	Trust	Hospital/Service
1	Airedale NHS Foundation Trust	Inpatient and Community services
2	Calderdale and Huddersfield NHS Foundation Trust	
3	Central London Community Healthcare NHS Trust	Adults 1
4	Central London Community Healthcare NHS Trust	Hammersmith and Fulham
5	Central London Community Healthcare NHS Trust	Kensington and Chelsea
6	Central Manchester Foundation Trust	Manchester Royal Infirmary
7	Cheshire and Wirral Partnership Trust	Community Rehabilitation Therapy Services
8	CLCH NHS Community Trust	Edgware Community Hospital – Parkinson's Unit
9	CNWL	Camden Provider Service – Stroke and Neurology Team
10	County Durham and Darlington NHS Foundation Trust	Bishop Auckland and Darlington Service
11	County Durham and Darlington NHS Foundation Trust	Darlington Memorial Hospital
12	County Durham and Darlington NHS Foundation Trust	Durham and Chester-le-Street
13	Cumbria Partnership Trust	West Cumberland Hospital
14	Derby Hospitals NHS Foundation Trust	London Road Community Hospital – Specialist Assessment and Rehabilitation Centre (SpARC)
15	Dorset Healthcare University Foundation Trust	St Leonard's Community Hospital
16	East Lancashire Hospitals NHS Trust	
17	Fife Acute Hospitals NHS Trust	Queen Margaret Hospital – Whitefield Day Hospital
18	Hinchingbrooke Healthcare NHS Trust	Hinchingbrooke Hospital
19	Hull and East Yorkshire NHS Trust	Hull Royal Infirmary
20	Leeds Teaching Hospitals Trust	
21	Liverpool Community Health NHS Trust	
22	Maidstone and Tunbridge Wells NHS Trust	Maidstone Hospital
23	North East London Foundation Trust	
24	Norfolk Community Health and Care NHS Trust	
25	North East London Community Services	St George's Hospital, Hornchurch
26	Pennine Care NHS Foundation Trust	Heywood, Middleton and

		Rochdale Community Services
27	Pennine Care NHS Foundation Trust	Bury Community Services
28	Pennine Care NHS Foundation Trust	Oldham Community Services
29	SEQOL	Community Intermediate Care Team
30	Sheffield Health and Social Care NHS Foundation Trust	Fulwood House
31	Solent NHS Trust	St James Hospital – Community Neurological Service
32	South Tyneside NHS Foundation Trust	Queen Elizabeth Hospital
33	Southport and Ormskirk Hospital NHS Trust	Southport District General Hospital
34	St George's Healthcare NHS Trust	St George's Hospital
35	Surrey Community Health – Virgin Care	
36	The Rotherham NHS Foundation Trust	Rotherham Hospital
37	The Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust	Christchurch Hospital
38	Western Health and Social Care Trust	Woodview
39	Sirona Health and Care	
40	Warrington and Halton Hospitals NHS Foundation Trust	
41	Barnet NHS Primary Care Trust	
42	Harrogate and District NHS Foundation Trust	
43	South East Essex Partnership Trust	

Physiotherapy

No.	Trust	Hospital
1	North Tees and Hartlepool NHS Foundation Trust	University Hospital of North Tees and University Hospital of Hartlepool
2	The Rotherham NHS Foundation Trust	Rotherham Hospital
3	Norfolk Community Health and Care NHS Trust	
4	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Christchurch Hospital
5	Virgin Care	Community Health Surrey
6	North East London Community Services	St George's Hospital, Hornchurch
7	Solent NHS Trust	Amulree Day Hospital – St Mary's Hospital
8	Solent NHS Trust	Turner Centre – St James' Hospital
9	Berkshire Healthcare NHS Foundation Trust	Upton Community Health Clinic
10	Pennine Care NHS Foundation Trust	Heywood, Middleton and Rochdale Community Healthcare
11	Bristol Primary Care Trust	Knowle Clinic
12	Central London Community Healthcare NHS Trust (CLCH)	Hammersmith and Fulham
13	Central and North West London NHS Foundation Trust	St Pancras Hospital
14	County Durham and Darlington NHS Foundation Trust	Bishop Auckland Hospital and Darlington Memorial Hospital
15	Sirona Care and Health	St. Martin's Hospital
16	Kingston Hospital NHS Trust	Kingston Hospital NHS Trust
17		Northampton General Hospital
18		Heartlands Hospital
19	Cambridgeshire Community Services NHS Trust	Hinchingbrooke Hospital
20	Heatherwood and Wexham Park Hospitals NHS Foundation Trust	Heatherwood Hospital
21	Cwm Taf University Health Board	Parkinson's Rehab Unit
22	NHS Fife	Whitefield Day Hospital – Queen Margaret Hospital
23	Central Manchester University Hospitals NHS Foundation Trust	
24	Stockport NHS Foundation Trust	
25	Cumbria Partnership NHS Foundation Trust	West Cumberland Hospital
26	Betsi Cadwaladr University Local Health Board	
27	Calderdale and Huddersfield NHS Foundation Trust	Huddersfield

28	South Tees NHS Trust	James Cook University Hospital Middlesbrough
29	Derby NHS Foundation Trust	London Road Community Hospital
30	SEQOL	Community Intermediate Care Team
31	University Hospitals Bristol NHS Foundation Trust	South Bristol Community Hospital
32	East Lancashire Hospitals NHS Trust	Royal Blackburn Hospital
33	Guy's and St Thomas' NHS Foundation Trust	St Thomas' Hospital
34	Central London Community Healthcare NHS Trust	Kensington and Chelsea Community Neurorehabilitation Service
35	Central London Community Healthcare NHS Trust (CLCH)	Adults 1
36	Southport and Ormskirk Hospital NHS Trust	
37	Hull and East Yorkshire Hospitals NHS Trust	Neurology Outreach Physiotherapy Service
38	Cheshire and Wirral Partnership 1	Community Rehab
39	Bradford Teaching Hospitals NHS Foundation Trust	
40	ONEL Community Services	
41	Barnet	
42	East Sussex Healthcare	
43	Airedale NHS Foundation Trust	Airedale General Hospital
44	Leeds Teaching Hospitals	
45	St Georges Healthcare NHS Trust	
46	Sheffield health and social care NHS foundation trust	Neurological Enablement Service (NES)
47	Warrington and Halton Hospitals NHS Foundation Trust	
48	County Durham and Darlington NHS Foundation Trust	Chester-le-Street Hospital
49	Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	Scunthorpe General Hospital
50	North West London Hospitals NHS Trust	
51	Harrogate and District NHS Foundation Trust	
52	County Durham and Darlington NHS Foundation Trust	Derwentside

Speech and language therapy

No.	Trust	Hospital/Service
1	North Tees and Hartlepool NHS Foundation Trust	University Hospital of North Tees and University Hospital of Hartlepool
2	Norfolk Community Health and Care NHS Trust	
3	North East London Community Services	St George's Hospital, Hornchurch
4	SEQOL	Community Intermediate Care Team
5	University Hospitals Bristol NHS Foundation Trust	Bristol Royal Infirmary
6	Sussex Community NHS Trust	Horsham Hospital
7	East Sussex Healthcare NHS Trust	Integrated Care Division (Therapies)
8	Leeds Community Healthcare NHS Trust	St James' Hospital
9	Central Manchester University Hospitals NHS Foundation Trust	
10	Southport and Ormskirk Hospital NHS Trust	
11	Oxfordshire Health	John Radcliffe Hospital, Dept of Neurorehabilitation
12	NHS Greater Glasgow and Clyde	Victoria Infirmary
13	NHS East Lancashire	Burnley General Hospital
14	Gloucestershire Healthcare Community Trust	Gloucestershire Royal Hospital
15	Central London Community Healthcare NHS Trust	Kensington and Chelsea Community Neuro Rehabilitation Service
16	Central London Community Healthcare NHS Trust	Hammersmith and Fulham
17	Camden –- Central North West London Foundation Trust	
18	Cwm Taf Local Health Board	
19	Goole Primary Care Trust	Goole
20	Pennine Care NHS Foundation Trust	Heywood, Middleton and Rochdale Community Services
21	Pennine Care NHS Foundation Trust	Bury Community Services
22	Pennine Care NHS Foundation Trust	Oldham Community Services
23	Sheffield Health and Social Care NHS Foundation Trust	
24	The Rotherham NHS Foundation Trust	Rotherham Hospital
25	North West London NHS Foundation Trust	
26	County Durham and Darlington NHS Foundation Trust	
27	Central London Community Health Care Trust	Adults One
28	NHS Greater Glasgow and Clyde	Southern General Hospital

29	NHS Greater Glasgow and Clyde	Drumchapel Hospital, Glasgow
30	NHS Greater Glasgow and Clyde	Stobhill Hospital, Glasgow
31	NHS Greater Glasgow and Clyde	Lightburn Hospital, Glasgow
32	Harrogate District and Foundation Trust	
33	SEPT CHS Bedfordshire	
34	NHS West Essex	
35	South East Essex Partnership Trust	

Appendix 2: National Parkinson's Audit Patient Management 2012 Standards and Guidance

National Parkinson's Audit Patient Management 2012

Standards and guidance

National Parkinson's Audit
Patient Management 2012

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

Background

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

The Parkinson's NICE Guideline was published in 2006 but predated the current arrangement for new NICE Guidelines to be accompanied by an audit tool. A multi-professional steering group[3] was established in 2007 under the chairmanship of Steve Ford, Chief Executive of Parkinson's UK to develop national Parkinson's audit tools with the facility for central benchmarking. Standards are derived from the NICE Guideline but incorporate other national guidance relevant to Parkinson's care, in particular the National Service Framework for Long Term Neurological Conditions (NSF LTNC) and the SIGN Guidelines[4]. In 2009 and 2010 the patient audit focused on standards relating to new patients referred with the query "does he/she have Parkinson's?" This year we will be auditing patients with an established Parkinson's diagnosis, to capture how they have been managed over the previous year.

Aim

The aim of the audit includes the early treatment, maintenance, complex care and palliative care phases of the pathway of care for people with Parkinson's disease. The aim excludes people newly referred to the service for purposes of diagnosis. The aim incorporates: monitoring the physical status and current needs for support, and,

[1] Published June 2006 and available on line at www.nice.org.uk/CG035

[2] Published March 2005 and available on line at www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Long-termNeurologicalConditionsNSF/index.htm

[3] College of Occupational Therapists Specialist Section for Neurological Practice, Royal College of Speech and Language Therapists, Chartered Society of Physiotherapy, Parkinson's Disease Nurse Specialist Association, British Geriatric Society Movement Disorder Section, The British and Irish Neurologists Movement Disorder Section.

[4] Published January 2010 and available on line at www.sign.ac.uk/guidelines/fulltext/113/index.html

as appropriate, making referrals and providing treatment, education and support and coordination of services among care providers and the patient and carer. The audit focuses on care provided by consultants who specialise in movement disorders in geriatric medicine and in neurology and Parkinson's nurse specialists

1. To encourage clinicians to audit compliance of their local Parkinson's service against Parkinson's guidelines by providing a simple peer reviewed audit tool with the facility for central data analysis to allow benchmarking with other services.
2. To highlight areas of good and poor practice to inform local discussions leading to 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.

Objective

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

The Parkinson's patient management audit also intends to increase the proportion of people who have a diagnosis of Parkinson's and have been receiving care for their condition for whom the processes of care, management and support are consistent with national guidelines.

Methodology

It is recognized that it is not always necessary, or practical to undertake a full assessment of activities of daily living (ADL) function, social care, motor and non-motor problems at every visit. For example, when there has been a recent in-depth assessment and the patient is attending for brief review of a medication change. For this reason, our Parkinson's patient management audit is designed to examine how the patient has been managed/assessed over the previous year rather than on a single visit. Although this complicates data collection it will be more representative of actual patient care. For most patients, this will capture 2-3 assessments over a year, if the service complies with NICE Guideline requirement for at least 6 – 12 monthly review.

Definition of an audit site

We are aware there is considerable variation in how Parkinson's services are organized and delivered throughout the country, which is a challenge for conducting a national Parkinson's Audit. There is, in addition an ongoing reconfiguration of services and how they are commissioned.

An audit site is roughly defined as a service provided by consultants with (or without) a Parkinson's nurse to a geographical area, regardless of who commissions the constituent

parts. Clinicians are best placed to decide what constitutes, for them a discrete service. To facilitate benchmarking, each patient management audit spreadsheet will include a brief service description to clarify:

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

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

The following rules will allow meaningful benchmarking:

1. **Neurology and elderly care will be analyzed as separate services.** Conduct separate audits and return data on separate spreadsheets, even if patients share the same Parkinson's nurse input and cover the same geographical area.

2. Discrete services should be logged as separate audit sites and data returned on separate spreadsheets.

3. Parkinson's nurses should conduct the audit in collaboration with their patients' consultant service(s) – and vice versa.

4. The audit can be completed purely from the medical input received only in services without Parkinson's nurse cover.

5. Clinicians working across more than one discrete service, e.g. a consultant working with different Parkinson's nurses in different commissioning/geographical areas, should return separate audits for each service or opt which to audit this year.

Patient sample

The minimum audit sample size is 20 consecutive Parkinson's patients seen during the audit data collection period which runs from 1 August 2012 to 11 January 2013. Take account of the need to capture a minimum sample of 20 patients when deciding locally on your start date for collecting the consecutive patient sample. The patient management audit spreadsheet will have the capacity to capture 50 patients if clinicians wish to audit a larger sample.

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

Patients should only be included if the service is responsible for the persons ongoing management i.e. not if seen as tertiary referral for advice.

Data collection and entry

For audit sites without a Parkinson's nurse, audit data from medical notes can be entered directly onto the spreadsheet (or use paper version of the tool) either at the end of the clinic, or in batches at a later date when convenient.

Audit sites with Parkinson's nurse provision using integrated medical/Parkinson's nurse notes can enter audit data from integrated notes as above. Services with separate medical and Parkinson's nurse notes can either:

- Collect list of patient names and enter audit data at later date when both sets of notes are available
- Or use paper version of the tool to answer what they can from one set of the notes and mark questions still to be completed from other notes.

Enter data onto spreadsheet when missing information is completed from other notes.
Enter patient with Parkinson's data onto our spreadsheet which you can save on your computer and add to at your convenience. Complete a separate column for every patient with Parkinson's. Remember to save the data each time you add new information. When completed, send it to pdaudit@parkinsons.org.uk by **11th January 2013**. We will **NOT** accept any submissions after **Friday 11 January (12:00am**).
Don't forget to complete the service description on the spreadsheet and remove patient identification details prior to submission. See Diagram 1 for more structured process of the audit.

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

Confidentiality

Patients
Patients' confidentiality needs to be protected. Please ensure that any information you submit for the audit is anonymised, and does not include any personally identifiable information about your patients. 'Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it. (HPC 2007 p7)[5]'.

[5] Health Professionals Council (2008) 'Confidentiality – guidance for registrants': Health Professionals Council: London. Available at:- http://www.hpc-uk.org/assets/documents/100023F1Guidanceonconfidentiality FINAL.pdf accessed 26.1.2011

When you complete the patient audit section, you will see that there is space for a patient identifier. It is suggested that you write code letters or a number here to help you keep track (for example, patient's initials, hospital number), **but you must delete this before submitting your information to Parkinson's UK.** It will help if you keep a list of the code words or number securely yourself, so that if there is any query about the information you have submitted, you can track back to the original client.

Employers

In order to comply with HQIP Principles of national Clinical Audit guidelines, the report on the audit findings will list all participating organisations, along with their individual audit data. This means that your employer's confidentiality will not be protected. **This is a change from the 2011 audit, and it is therefore vital that your employer is aware of, and agrees to, your participation in the audit, and to the submission of your final data.**

Participants

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

Data security

You will receive a password-protected spreadsheet for data collection, allowing no one else but eligible participant to enter and make changes to the spreadsheet. Please make sure that the password is well protected and can't be used by other people. To ensure the security of your dataset, we also advise you to save and use your spreadsheet on a secure computer at work and not at your personal computer at home. We advise you to comply with your Trust Data Protection guidelines at all times.

After the dataset has been sent to Parkinson's UK it will be stored in encrypted password-protected files at Parkinson's UK in accordance with NHS requirements. Within Parkinson's UK, access to the raw data set is restricted to Mary Sinnathamby, Clinical Audit Manager, members of the Steering Group and staff working directly on analysis. Raw data will not be accessible in the public domain.

How the audit results will be communicated

Findings will be presented in the form of one main report and a summary (preliminary) report.

Services will receive an initial summary of results, in the form of charts, providing data from their centre compared with the national average. This will allow audit sites to start to work on local action plans.

The final audit report will contain more detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. This full audit report will also include a list of names of all participating services and their individual audit data.

This is a change that has taken place this year to comply with the HQIP Principles of National Clinical Audit guidelines. The report will be sent to all audit participants, Trust Audit leads and Strategic health authority/ health board audit leads. The Report will also be in the public domain via the Parkinson's UK website.

Data collected during the audit will be used to generate a national picture of service delivery and to compare this with the expectations detailed in national guidance such as the Parkinson's NICE Guideline and the NSF LTNC. Therefore, this data will provide valuable information about priority areas within the existing health care provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's, e.g. the Fair Care campaign for better quality services, which has been launched in 2009 by Parkinson's UK.

Thank you for your participation in the National Parkinson's Audit 2012.

Log participation with your Trust's Audit Departments and managers

Plan an audit meeting

- Agree start date for acquiring patient sample
- Agree target sample size (minimum 20 patients)

Log names and case record numbers of consecutive patients from your agreed start date

We strongly encourage collecting 50% of the audit sample from consecutive patients seen by medical staff and 50% seen by Parkinson's nurse to avoid bias.

Patient data entry

Enter patient data directly onto spreadsheet or use paper version of the tool with subsequent data entry onto the spreadsheet (do not return any paper forms to Parkinson's UK). See page 4 for data entry tips, and make sure you save changes before closing the spreadsheet.

Data validation

Please refer to the Data validation document for help in validating your service's data.

Complete service description on the spreadsheet and delete patient identifiable data

Send patient management audit spreadsheet to Parkinson's UK by 11th January 2013

Diagram 1. Audit process flow chart

Patient Management Standards

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

No.	Question	Data items/ Answer options	Help notes
Service Description			
	General information		
1	Did this service take part in the Parkinson's audit 2011? If yes, what was your Trust code?	• Yes • No	
2	Who commissions this service? Geographical area covered by this Parkinson's service	• Free text • Free text	Please provide the name of the commissioning board
3	What is the most common model of service provision for the medical input to this service?	• Doctor alone • Joint/parallel doctor and nurse specialists clinics • Integrated clinics (doctor/nurse specialist/therapy in same venue)	By integrated multidisciplinary clinics we mean neurologist or care of the elderly specialist, Parkinson's nurse and therapist, for example, occupational therapist and/or physiotherapist and/or speech and language therapist, seeing patients within the same clinic venue.

4	Are clinic patients seen within specific Parkinson's/ Movement Disorder clinics?	• All patients • Most patients (>75%) • Some patients (25-74%) • Few patients (<25%) • None	A specialist service would be expected to have a) an identified lead clinician for training, service development and specialist opinion. **AND** b) The provision of specific Parkinson's/Movement Disorder clinics.
5	Is written information regarding Parkinson's routinely available when patients attend clinic venues?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	Routinely available means accessible to patients such as on tables or in racks and/or accessible to staff to distribute to patients.
	Assessments		
6	Is a formal Activities of Daily Living assessment tool or check list **used** when Parkinson's patients are reviewed in this service?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	Clinicians are often the gatekeepers for referral to other disciplines. The use of a formal Activities of Daily Living (ADL) assessment tool is essential to ensure awareness of practical difficulties in daily life to prompt referral for therapy input.
7	Is the Parkinson's non-motor symptoms questionnaire or other form of checklist **used** to screen for non-motor	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	

	symptoms when Parkinson's patients are assessed?		
8	Is a standardised assessment tool routinely **available** in clinic venues to assess and monitor cognitive function?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	The 10 point Abbreviated Mental Test Score is not be sufficient to meet this standard. This question relates to whether the paperwork is available in clinics for this to be done.
9	Is a standardised assessment tool routinely **available** in clinic venues to assess mood?	• All clinics • Most clinics (>75%) • Some clinics • Not routinely available	This question relates to whether the paperwork is available in clinics for this to be done.
Consultants and Parkinson's nurse specialists			
	Consultants		
10	Consultant Details	• Lead Consultant Name • Specialty • Employing Trust • Contact tel no and email	
11	How many consultants routinely provide medical input for this service?	• Please provide the number of consultants	Routinely means a regular clinic commitment. **Include:** Any consultant who sees Parkinson's patients for diagnosis and ongoing management. Non specialist consultants should be

			included if they keep Parkinson's patients under their care.
12	What percentage of consultants providing medical input to this service have attended Movement Disorder specific external CME during the 2011/2012 CME cycle?	• Please provide the percentage	The question refers to **external** CME i.e. regional, national or international education updates relevant to Parkinson's. Use the number of consultants (headcount) and not the whole-time equivalents they represent.
13	Did all Consultants working in this service participate in this audit?	• Yes, please go to Q15 • No, please go to Q14	
14	If no, how many consultants participated?	Please provide the number of consultants	
	Parkinson's Nurse Specialists		
15	Can patients in this service access a	• Yes • No, omit Q16, Q17 and Q18 • No service, omit Q16, Q17 and Q18	

	Parkinson's Nurse Specialist?		
16	Parkinson's Nurse Specialist details	• Name • Employing Trust • Contact tel no and email	
17	Have all Parkinson's Nurse Specialists associated with this service attended Parkinson specific external CME in the 2011/2012 cycle?	• Yes • No	The question refers to **external** CME i.e. regional, national or international education updates relevant to Parkinson's. Use the number of nurses (head count) and not the whole-time equivalents they represent.
18	What is the main arrangement for contact between Consultants and Parkinson's Nurse Specialists?	• Regular contact in Multidisciplinary meeting, joint or parallel clinic • Regular face to face contact outside clinic • Regular telephone/email contact with occasional face to face contact • Telephone/email contact only • No or rare contact	Omit this question if there is no Parkinson's nurse service for neurology patients. This information is collected as surrogate marker of integrated care. Regular is defined as at least twice a month Use the number of consultants and not the whole-time equivalents they represent.
	Comments (e.g. tertiary referral centre etc)	• Free text	Please provide any other comments you would like us to know about your service

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

No.	Question	Data items/Answer options	Help notes
1. Descriptive data			
1.1	Patient identifier	This can be used to identify audited patients	You must remove any patient identification before submitting the audit tool to Parkinson's UK
1.2	Gender	• Male • Female	
1.3	Ethnicity	• White British • Any Other White Background • Black/Black British • Asian/Asian British • Mixed Race • Chinese • Not stated • Other Ethnic Group	
1.4	Date of birth (dd/mm/yyyy)	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of birth in the following format e.g. July 2007 will be 01/07/2007. If only the year known, please provide in the following format, e.g. 2012 as 01/01/2012. If not known at all, please leave blank. Please do not write 00/00/0000
1.5	Date of Parkinson's diagnosis (dd/mm/yyyy)	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of diagnosis in the following format e.g. July 2007 will be 01/07/2007. If only the year known, please provide in the following format, e.g. 2012 as 01/01/2012. If not known at all, please leave blank.

			Please do not write 00/00/0000
1.6	Parkinson's Phase	• Diagnosis • Maintenance • Complex • Palliative	**Definitions of phases** **Diagnosis** • From first recognition of symptoms/sign/problem • Diagnosis not established or accepted. **Maintenance** • Established diagnosis of Parkinson's • Reconciled to diagnosis • No drugs or single drug 4 or less doses/day • Or 2 drugs but stable medication for >3/12 • Absence of postural instability. **Complex** • 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** • Inability to tolerate adequate dopaminergic therapy • Unsuitable for surgery

			• Advanced co-morbidity (life threatening or disabling).
1.7	Living Alone	• Yes • No, • No, at residential home • No, at nursing home	
1.8	Current Medication (Please tick all that apply)	• Levodopa/PDI • COMT inhibitor • Dopamine agonist • MAOB inhibitor • Amantadine • Anticholinergic • Other e.g. research trial drug	
2. Specialist Review			
Standard 1: 100% of people with Parkinson's must be reviewed at 6-12 monthly intervals. (Parkinson's NICE:R12, R77; NSF LTC:QR2)			
2.1	Has the patient been reviewed by a specialist within the last year? (can be doctor or nurse specialist)	• Yes • No	
2.2	Time since most recent medical review	• Less than 6 months • 6-12 months • More than 1 year • More than 2 years • Never	Time interval since the index review when the patient was captured for audit sample

2.3	Time since most recent Parkinson's nurse assessment	• Less than 6 months • 6-12 months • More than 1 year • More than 2 years • Never • No service	
3. New / Recent Parkinson's medication			
Standard 2: 100 % of people on medications for Parkinson's are prescribed drugs in accordance with national guideline options for initial and later pharmacological therapy (Parkinson's NICE Table 7.1, Table 7.4, SIGN Guideline 2.2.1, 2.2.2) **Standard 3: 100% of people with Parkinson's should be provided with both oral and written communication throughout the course of the disease, which should be individually tailored and reinforced as necessary.** (Parkinson's NICE R3)			
3.1	Was Parkinson's medication initiated for the first time during the last year? (including current visit)	• Yes • No, skip to Q3.4	First line refers to the initial PD medication following diagnosis
3.2	What was started?	• Levodopa/PDI • MAOB inhibitor • Dopamine agonist • Levodopa/PDI/COMT inhibitor • Anticholinergic • Amantadine	Only answer this question for patients started on PD medication for the first time during the previous year

	Please specify if Other	• Other e.g. research drug trial	
3.3	Did the choice of first line Rx comply with national prescribing guidelines for initial therapy	• Yes • No	**Early disease first line options** Levodopa/PDI, or Dopamine agonists or MAOB inhibitor or Research drug in context of clinical trial Anticholinergics, amantadine, COMT inhibitors, and controlled release levodopa/PDI should not be the initial treatment (CR levodopa only allowed for nocturnal symptoms). An ergot dopamine agonist should not be the first choice
3.4	For patients already on Parkinson's medication, was a new class of PD drugs started in the last year?	• Yes • No, skip to Section 4	
3.5	If yes, which medications? (Tick all that apply)	• Levodopa/PDI • COMT inhibitor • Dopamine agonist • MAOB inhibitor • Amantadine • Anticholinergic • Other e.g. research trial drug	

	Please specify if Other		
3.6	Did medication changes comply with PD NICE guidelines for prescribing in early and later disease?	• Yes • No • No but research drug in clinical trial	Levodopa/PDI, dopamine agonists and MAOB inhibitors allowed at all stages of the illness COMT inhibitors only as adjunct in later disease, Tolcapone second line to Entacapone Anticholinergics only as second line in young people with early Parkinson's and severe tremor Amantadine can be used for dyskinesia
3.7	Is there evidence that the patient/carer was provided with written information regarding potential adverse effects for any new medications	• Yes • No	The audit examines the provision of written information. This can include a copy of clinic letter if adverse effects are listed. To meet the standard, diarrhoea must be discussed if started on a COMT inhibitor and compulsive behaviour risk discussed for dopamine agonists
4. Specific adverse effect monitoring (omit this section if the patient is not yet on Parkinson's medication)			
Standard 4: 100% of people with Parkinson's who have sudden onset of sleep should be advised not to drive and to consider any occupational hazards (Parkinson's NICE R72) **Standard 5: 100% of patients on dopamine are monitored for dopamine dysregulation syndrome** (Parkinson's NICE R 54) **Standard 6: If an ergot-derived dopamine agonist is used, 100% of patients should have a minimum of renal function tests, erythrocyte sedimentation rate (ESR)and chest radiograph (CXR) performed before starting treatment, and annually thereafter** (Parkinson's NICE R30 and 40)			
4.1	Evidence of enquiry re	• Yes	

	daytime sleepiness	• No	
4.2	If daytime sleepiness is documented as present, was the impact on driving discussed and advice given?	• Yes • No • No but, doesn't drive	Omit Question 4.2 if it is documented that the patient does not have daytime sleepiness
4.3	Evidence patients taking dopamine agonists are monitored re compulsive behaviour	• Yes • No • No, but not on dopamine agonist	Evidence means documentation that the patient was specifically asked about the presence of compulsive behaviour symptoms during the previous year…
4.4	Evidence of patients taking ergot dopamine agonists are having the required monitoring for fibrosis related adverse effects	• Yes • No • No but, not on ergot dopamine agonists	If initiated during the previous year * Echocardiogram and * Erythrocyte sedimentation rate or other inflammatory markers, lung function/chest x-ray and renal function If on long-term treatment * Echocardiogram at least yearly * Additional investigations e.g. CXR, CT scan, ESR,renal function if symptoms suggest pleuro-pulmonary disease, cardiac failure, renal failure Evidence means documentation that these tests have been arranged by the PD Service directly or letter sent asking GP to arrange…Evidence means documentation that these tests have been arranged by the PD Service directly or letter sent asking GP to arrange…
5. Advanced Care Planning			

Standard 7: For 100% of people with Parkinson's end of life care requirements should be considered throughout all phases of the disease. Parkinson's NICE R82 (please refer to help note 5.1) **Standard 8: 100% of people with Parkinson's and their carers should be given the opportunity to discuss end-of-life issues with appropriate healthcare professionals.** (Parkinson's NICE R 83)			
5.1	Are there markers of advanced disease e.g. dementia, increasing frailty, impaired swallowing, nursing home level of care required?	• Yes • No, skip to Section 6	A diagnosis of Parkinson's dementia or significant problems with swallow should be regarded as markers of the need to consider end of life issues. The Parkinson's NICE Guideline recommends that end of life care requirements should be considered throughout the illness. This audit only examines this standard in relation to patients with markers of advanced disease as many discussions early in the illness are poorly documented and the timing of when the patient is ready to discuss these matters is individual If no markers of advanced disease, go to Section 6
5.2	Are there any documented discussions regarding end of life care issues?	• Yes • No	
5.3	Is there evidence the patient/carer has been offered information about, or has set up a Lasting Power of Attorney?	• Yes • No	

5.4	Is there evidence the patient/carer has been offered information about, or has established an End of Life Care Plan?	• Yes • No	

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

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

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

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

Total process score: 34

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

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

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

Domain 1: Non-motor assessments during the previous year (Maximum score = 12)			
1	Blood pressure documented lying (or	• Yes • No	

	sitting) and standing	• No but, doesn't stand	
2	Evidence of enquiry/assessment re cognitive status	• Yes • No	
3	Evidence of enquiry re hallucinations/psychosis	• Yes • No	
4	Evidence of enquiry re mood	• Yes • No	
5	Evidence of enquiry re communication difficulties	• Yes • No	
6	Evidence of enquiry re problems with swallowing function	• Yes • No	
7	Evidence of screening for malnutrition (weight checked at least yearly)	• Yes • No	
8	Evidence of enquiry re problems with saliva	• Yes • No	
9	Evidence of enquiry re bowel function	• Yes • No	
10	Evidence of enquiry re	• Yes • No	

	bladder function		
11	Evidence of enquiry re pain	• Yes • No	
12	Evidence of enquiry re sleep quality	• Yes • No	
Domain 2: Motor and ADL assessment during the previous year (12)			
1	Evidence of enquiry re “On/Off” fluctuations	• Yes • No • No but, not yet on treatment • No but, less than 3 years from starting medication	
2	Evidence of enquiry/assessment re problems with gait including freezing	• Yes • No • No but, doesn't walk	
3	Evidence of enquiry re falls and balance	• Yes • No • No but, assisted for transfers and doesn't walk	
4	Evidence fracture risk/osteoporosis considered	• Yes • No • No but, notes document not falling and no concern re balance	
5	Evidence of enquiry re problems with bed	• Yes • No	

	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)	• Yes • No • No but, but early/mild disease, active lifestyle	
7	Evidence of enquiry/assessment of tremor	• Yes • No • No but, no tremor	
8	Evidence of enquiry re problems with dressing	• Yes • No • No but, in care home	
9	Evidence of enquiry re problems with hygiene (e.g. ashing/bathing/hair /nails)	• Yes • No • No but, in nursing home	
10	Evidence of enquiry re difficulty eating and drinking (i.e. cutlery/ managing drinks etc. not swallowing)	• Yes • No • No but, PEG fed	
11	Evidence of enquiry re domestic activities (cooking/cleaning/shoppi	• Yes • No • No but, in care home	

	ng)		
12	Evidence of enquiry re problems with function at work	• Yes • No • No but, retired or doesn't work	
Domain 3: Education and multi-disciplinary involvement during the previous year (10)			
1	Evidence of referral/input from Parkinson's nurse	• Yes • No • No but, declined	
2	Evidence of physiotherapy referral/assessment/input	• Yes, for therapy/assessment • No but, declined • No but, clear documentation no therapy need • No but, no achievable physiotherapy goals	The option "No but clear documentation no therapy need" should only be used if there is clear documentation of relevant enquiries/assessments re physiotherapy related problems (gait / balance/ posture/transfers Use **"No but, no achievable physiotherapy goals"** option only if no change and extensive prior physiotherapy input
3	Evidence of occupational therapy referral/input	• Yes, for therapy/assessment • No but, declined • No but, clear documentation no therapy need • No but, no achievable occupational therapy goals	The option "No but clear documentation no therapy need" can only be used if there is clear documentation of assessment/enquiry re problems with activities of daily living and/or difficulties at work if working Use **"No but, no achievable occupational therapy goals"** option only if no change and extensive prior occupational therapy input
4	Evidence of speech and language therapy	• Yes, for therapy/assessment • No but, declined • No but, clear documentation no	The option "No but clear documentation no therapy need" can only be used if there is clear documentation of

	referral/input **for communication**	therapy need • No but, no achievable SLT goals	assessment/enquiry re communication Use **"No but, no achievable SLT goals"** option only if no change, extensive prior SLT input and alternative communication means already explored
5	Evidence of speech and language therapy referral/input **for swallowing**	• Yes • No • No but, declined • No but, swallow documented normal • No but, PEG fed or adequate care plan in place	
6	Evidence of social work referral/input	• Yes • No • No but declined • No but documented as self funding and referred to other sources of support and information re care • No but social work input not required, as social care needs are being met.	Use **"No but social work input not required, as social care needs are being met"** option only if there is evidence that current care arrangements are working well or that the person is independent in mobility and personal care.
7	Evidence that patient's and carer's entitlement to financial benefits has been considered and advice given	• Yes • No • No but, independent in mobility and personal care	
8	Evidence that patient and/or carer has been signposted to Parkinson's UK	• Yes • No	

9	Evidence that patient and/or carer has been signposted to Information Support Worker	• Yes • No • No but, declined	
10	Evidence of communication with carers about their entitlement to carer assessment and support services	• Yes • No • No but, in care home • No but, patient not in complex or palliative stage • No but, no carer	

Appendix 3: National Parkinson's Audit Occupational Therapy 2012 Standards and Guidance

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

College of Occupational Therapists

National Parkinson's Audit Occupational therapy 2012

Standards and guidance

National Parkinson's Audit 2012
Occupational therapy audit

Audit of national standards relating to Parkinson's care, incorporating NICE Parkinson's disease Guideline and National Service Framework for Long Term Neurological Conditions (NSF-LTNC) quality standards

Background

This occupational therapy audit is part of the Parkinson's UK national audit, which has been extended to include occupational therapy, physiotherapy and speech and language therapy since 2011. This is the second year in which occupational therapists will be able to take part, along with physiotherapists and speech and language therapists. The occupational therapy audit has received research governance approval by the College of Occupational Therapists.

Previous reports have found that whilst 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.

From 2009, the Parkinson's national audit has been completed by neurologists and geriatricians, and has comprised a service audit (i.e. what services are available to clients compared with what is recommended by the guidelines), and a 'new patient audit' (again, comparing what interventions newly diagnosed patients receive compared with guideline recommendations).

The occupational therapy audit has been structured according to 'Occupational therapy for people with Parkinson's: Best Practice Guidelines'[6] (referred to as OT Best Practice Guidelines in Appendices), and the National Service Framework for Long Term Conditions[7]. It has also been structured according to principles of occupational therapy for Parkinson's, as outlined by NICE Guidelines[8].

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[6] Aragon, A., Kings, J., (2010) *Occupational therapy for people with Parkinson's: Best Practice Guidelines* College of Occupational Therapists: London. In Partnership with Parkinson's UK and College of Occupational Therapists Specialist Section Neurological Practice. Available at http://www.cot.org.uk/MainWebSite/Resources/Document/OTPeopleParkinsons.pdf Accessed 21.7.2010

[7] National Service Framework for Long Term Neurological Conditions. Published March 2005 and available on line at http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Long-termNeurologicalConditionsNSF/index.htm

[8] Parkinson's disease: diagnosis and management in primary and secondary care clinical guidelines 35. Published June 2006 and available on line at http://www.nice.org.uk/guidance/CG35/NICEGuidance

The principles of occupation therapy for Parkinson's include:

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

NICE Guidelines state that occupational therapy should be available for people with Parkinson's, and that particular consideration should be given to:

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

(Source: NICE 2006 p14)

Aim

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

Objectives

It is anticipated that the audit will establish:

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 Guideline and NSF-LTNC
2. Which clients with Parkinson's are referred for occupational therapy. This will include information on number of referrals, stage of the disease process, 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.

Methodology

A small scale pilot of the audit tool took place in November 2010, with the assistance of the College of Occupational Therapists Specialist Section Neurological Practice Long Term Conditions Forum. Feedback from the pilot and the 2011 audit has been used to update the current audit tool.

Most of the questions in the audit are based on audit statements. For example, question 12:- 'What goals amenable to occupational therapy intervention were identified and by whom?' is based on occupational therapy guidelines for specific areas of intervention, such as mobility, falls prevention, fatigue management etc. In some instances however, a question has been asked for which there is no supporting audit statement, for example, question 1:- 'Who made the referral to occupational therapy?', or question 11:- 'As an occupational therapist, do you feel that the client was referred at an appropriate time?. These types of 'survey' questions have been included because although there is no comparable audit statement, the information will still be valuable.

For information, the full list of questions and audit statements, together with information to be gained from each question is given in Appendix 1 (Client audit) and 2 (Service audit)**.**

Data source and data collection

The audit tool is composed of 3 sections:- a 'client' section, which allows you to enter data for up to 20 clients, a 'service' section which consists of some general questions about your service (which just needs to be filled in once), and 'summary tables', which will be completed automatically as you enter your data.

Participating occupational therapists should complete the audit for the first 10 Parkinson's clients that finish an episode of occupational therapy intervention between 1 August and 11 January 2013. Although we ask for data for 10 clients, it will be helpful to collect more data if possible. Therefore, if more than 10 clients finish an episode of intervention within the audit time, please also submit the data for these additional clients, up to a maximum of 20 clients.

Enter your clients' data onto our spreadsheet. Please note that when inputting data, a number of questions have drop down menus which become visible when you click on a data entry box. You may wish to click on the boxes before inputting data, so you can see if options are provided, and what these options are.

Please send in the completed spreadsheet to pdaudit@parkinsons.org.uk by **11 January 2013**. We will **NOT** accept any submissions after **Friday 11 January (12:00am**). Don't forget to remove all information relating to named clients from the spreadsheet prior to submission. If you need to see how questions refer to audit statements, please refer to Appendix 1 and 2.

Confidentiality

Clients

Clients' confidentiality needs to be protected. Please ensure that any information you submit for the audit is anonymised, and does not include any personally identifiable information about your clients. 'Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it. (HPC 2007 p7)[9]'.

When you complete the client section of the audit, you will see that there is space for a code number. It is suggested that you write code letters or a number here to help you keep track (for example, client's initials, hospital number), **but you must delete this before submitting your information to Parkinson's UK.** It will help if you keep a list of the code words or number securely yourself, so that if there is any query about the information you have submitted, you can track back to the original client.

Employers

In order to comply with Healthcare Quality Improvement Partnership (HQIP) Principles of national Clinical Audit guidelines, the report on the audit findings will list all participating organisations, along with their individual audit data. This means that your employer's confidentiality will not be protected. **This is a change from the 2011 audit, and it is therefore vital that your employer is aware of, and agrees to, your participation in the audit, and to the submission of your final data.**

Participants

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

Data security

You will receive a password-protected spreadsheet for data collection, allowing no one else but the eligible participant to enter and make changes to the spreadsheet. Please make sure that the password (that has been sent to you in a separate e-mail), is well protected and can't be used by other people. To ensure the security of your dataset, we also advise you to save and use your spreadsheet on a secure computer at work rather than personal computer at home.

After the dataset has been sent to **pdaudit@parkinsons.org.uk** it will be stored in encrypted password-protected files at Parkinson's UK in accordance with NHS requirements. Access to the raw data set is restricted to Mary Sinnathamby, Clinical

[9] Health Professionals Council (2008) 'Confidentiality – guidance for registrants': Health Professionals Council: London. Available at:- http://www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf accessed 26.1.2011

Audit Manager and Dr Kieran Breen, Director of Research and Development at Parkinson's UK.

Consent

Please note that by returning the completed audit to Parkinson's UK, your consent to participate in the audit is implied. **Please check that your service manager is happy for you to be involved in this work, before you submit any information.**

How the audit results will be communicated

Participating services will receive an initial summary of results providing data from their service compared with the national average. This will allow audit sites to start to work on local action plans. The full audit report will contain more detailed analysis and comments on the data along with Key Recommendations for commissioners and clinicians. The full report will include in an Appendix, a list of all participating organisations and their individual audit data (in percentages). This is a change that has taken place this year to comply with the HQIP Principles of National Clinical Audit guidelines. The report will be sent to all audit participants, Trust Audit leads and Strategic health authority/ health board audit leads. The Report will also be in the public domain via the Parkinson' UK website.

Data collected during the Audit will be used to generate a national picture of service delivery and compare this with the expectations detailed in national guidance such as the Parkinson's disease NICE Guidance and the NSF-LTNC. Therefore, this data will provide valuable information about priority areas within the existing health care provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's, e.g. the Fair Care campaign for better quality services, which has been launched in 2009 by Parkinson's UK.

Thank you for assisting us by taking part in this audit.

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Client audit: Audit standards, questions and supporting information

	Question	Audit statement or justification	Information gained from question	Comments
	Demographics			
1	Gender		Whether the client is male or female	Enables to identify the proportion of males and females
2	Ethnicity		Identifies the ethnicity of the client	
3	Date of birth **(dd/mm/yyyy)**		Identifies the age of the client	
	Referral **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)			
4	Who made the referral to OT?		Which health care professionals refer to OT	Identifies which health care professionals might need information on role of OT and when to refer
5	Date of Parkinson's diagnosis (dd/mm/yyyy)		Date of diagnosis	
6	Date of referral letter to this episode (dd/mm/yyyy)			Type in 'Don't know' if the date is unknown
7	Date of initial OT intervention (dd/mm/yyyy)	'The principles of occupational therapy include: Early intervention to establish rapport, prevent activities and roles being restricted or lost and, where needed, to develop appropriate coping strategies' (OT Best Practice Guidelines 2010 p16)	Time between diagnosis and OT intervention	Early intervention recommended. Type in 'Don't know' if the date is unknown
8	Has the person received previous OT for Parkinson's?		Whether the person has been seen by occupational therapist working in any setting	
9	If yes, how many episodes of OT has s/he		Whether the client has had repeated episodes of OT	

	received for Parkinson's related problems, prior to this referral?		intervention	
10	Has this referral been triggered as a result of a medical review?	'Regular reviews, at least every six to twelve months, are recommended to help fine-tune medication regimes for as smooth a control of symptoms as possible. The need for referral to other healthcare professionals such as occupational therapy... should also be considered during these regular reviews (OT Best Practice Guidelines 2010 p13, quoting NICE 2006) NSF QR1 Rationale- successful care planning is person centred and recognises that needs will change over time	Extent to which OT referrals correlate with medical review	Regular review is recommended for medication, and to check whether intervention from other professionals is needed, not that clients should be reviewed regularly by OT, SLT, physio etc.
11	What was the reason for referral to OT? (Tick all that apply)			
11a	• Maintenance of work roles	Maintenance of work and family roles, (NICE)		
11b	• Maintenance of family roles	Maintenance of work and family roles, (NICE)		
11c	• Domestic activities of daily living	Home care (NICE)		
11d	• Leisure activities	Leisure activities (NICE)		

11e	• Improvement and maintenance of transfers and mobility	Improvement and maintenance of transfers and mobility (NICE)		
11f	• Improvement of personal self-care activities such as eating, drinking, washing and dressing	Improvement of personal self-care activities such as eating, drinking, washing and dressing (NICE)		
11g	• Environmental issues to improve safety and motor function	Environmental issues to improve safety and motor function (NICE)		
11h	• Mental wellbeing, including cognition, emotional and/or neuro-psychiatric problems.	Guidelines for occupational therapists aiming to assess and promote the mental wellbeing of people with Parkinson's (OT Best Practice Guidelines 2010 p30)		Mental wellbeing includes cognition (as recommended by NICE), but also includes possible emotional and / or psychiatric problems, where OTs also have a role.
11i	• Management of fatigue	Guidelines for occupational therapists aiming to promote self-management of fatigue with people with Parkinson's (OT Best Practice Guidelines 2010 p44-5)		Although not included in NICE guidelines, fatigue management is clearly a role for occupational therapists, described in the OT Guidelines.
11j	• Other (please specify)		Other reasons for referral to occupational therapy.	
12	Was all the information	NSF QR1- An integrated	Whether occupational	If key pieces of referral

	essential for OT assessment and intervention on referral?	approach to assessment of care and support needs, and to the delivery of services is key to improving the quality of life for people with KLTC. The most effective support is provide when local health and socials services team communicate ; have access to up to date case notes and patients held records and work together to provide a co-ordinated service	therapists receive essential referral information	information are regularly missed, this may be useful for education.
13	If 'no', what information was missing?		Identify information which may be regularly missed off referral information.	Identifies occupational therapists' information needs which may be useful for education
14	As an occupational therapist, do you feel that the client was referred at an appropriate time?		OT's/auditor's opinion of whether the client was referred at the right time	Establish whether the OT was proactively able to optimise function with the person and/or carer, or whether s/he was managing a crisis situation. Subjective question.
	Goals Identified **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**			
15	What goals amenable to occupational therapy	'The principles of occupational therapy for Parkinson's include,	Goals which have been identified for occupational	Most goals are linked to OT Best Practice Guidelines

	intervention were identified and by whom? **Optimising activities** • Mobility • Falls prevention • Transfers	Development of goals in collaboration with the individual and carer, with regular review' (OT Best Practice Guidelines 2010 p16). 'Goal setting:- Goals identified by the client, in partnership with the therapist' (Figure 1, Jain et al 2005, reproduced in OT Best Practice Guidelines 2010 p18) 2.1 Mobility guidelines (OT Best Practice Guidelines 2010 p33-4) 2.2 Falls prevention guidelines (OT Best Practice Guidelines 2010 p35) NICE 1.8.3.1 Falls For all people with PD at risk of falling, please refer to 'Falls: assessment and prevention of falls in older people' *NICE clinical guideline* no. 21(available from www.nice.org.uk/CG021) 2.3 Guidelines for transfers (OT Best Practice Guidelines 2010	therapy intervention. Whether the areas of intervention have been identified collaboratively	except:- 'Structuring day', 'managing medication' and 'planning skills and memory'.

	• Bed mobility • Posture and seating, (including wheelchair mobility) • Eating and drinking • Self care routines • Domestic skills • Fatigue management • Handwriting and /or computers • Driving	p36-7) 2.4 Bed mobility guidelines (OT Best Practice Guidelines 2010 p38) 2.5 Posture and seating guidelines (OT Best Practice Guidelines 2010 p40) 2.6 Eating and drinking guidelines (OT Best Practice Guidelines 2010 p41-2) 2.7Guidelines for self care (OT Best Practice Guidelines 2010 p42-3) 2.8 Domestic skills guidelines (OT Best Practice Guidelines 2010 p43-4) 2.9 Fatigue management guidelines (OT Best Practice Guidelines 2010 p44-5) 2.10 Handwriting guidelines (OT Best Practice Guidelines 2010 p45-6)		

	• Managing medications • Structuring day	3.5 Driving guidelines (OT Best Practice Guidelines 2010 p52) G 2.2.5: timing of dyskinetic episodes in relation to the use of medication should be recorded, and movements, tasks or positions that help to relieve, or exacerbate, involuntary movement identified.' (OT Best Practice Guidelines 2010 p35). This relates to prevention of falls. G 2.7.1: the timing of the first dose of anti- Parkinson's medication is established, because this has important bearing on function. If it is usually taken after washing and dressing, liaise with the medication prescriber to see if the first dose may be taken before the individual gets washed and dressed.(OT Best Practice Guidelines 2010 p42) This relates to self care G 2.9.2 A diary to record specific tasks that increase fatigue and specific times of the day when fatigue is more of a problem		

	Supporting participation • Self efficacy (maintaining a sense of control) • Roles and relationships • Work	(should be considered) (OT Best Practice Guidelines 2010 p45) (This relates to fatigue) 3.1 Self efficacy guidelines (OT Best Practice Guidelines 2010 p48) 3.2 guidelines for roles and relationships (OT Best Practice Guidelines 2010 p49) 3.3 Guidelines for work related issues (OT Best Practice Guidelines 2010 p49-50) Also QR 6:- 'People with long term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities.' (NSF LtC 2005 p39) 3.4 Guidelines to promote social, recreational and leisure activities		

	• Social, recreational and leisure activities • Driving • Community living skills and outdoor mobility **End of Life Care** (if appropriate)	(OT Best Practice Guidelines 2010 p51) 3.5 Guidelines related to driving (OT Best Practice Guidelines 2010 p52) 3.6 Guidelines to promote participation in community life and outdoor mobility (OT Best Practice Guidelines 2010 p53) 4.1Guidelines to address palliative and end of life care needs (OT Best Practice Guidelines 2010 p55) 4.2 Guidelines for manual handling and minimising risk (OT Best Practice Guidelines 2010 p56) 4.3 Guidelines to address alternative living arrangements (OT Best Practice Guidelines 2010 p57)		

	• 24 hour approach to posture, positioning and pressure care • Manual handling and minimising risk • Alternative living arrangements	NICE 1.10 Palliative care in Parkinson's disease 1.10.1.1 Palliative care requirements of people with Parkinson's Disease should be considered throughout all phases of the disease. D(GPP) 1.10.1.2 People with PD and their carers should be given the opportunity to discuss end-of-life issues with appropriate healthcare professionals. D(GPP) QR9- People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.		
	Intervention strategies used			

16	What treatment strategies and techniques were used?	'3a Skill level intervention to enhance performance' 3b Knowledge level intervention to support performance 3c Attitude level intervention to change performance' (Figure 1, Jain et al 2005, reproduced in OT Best Practice Guidelines 2010 p18) QR 5: Community rehabilitation and support People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.	Identifies whether specific treatment strategies are applicable and used, applicable but not used or not applicable for each client	
a	<u>Initiating and maintaining movement</u> Promoting functional abilities through trial of	1.1.1 Guideline on internal cueing techniques (OT Best Practice Guidelines 2010 p24)		

	intrinsic cueing techniques (for example, repeating silently 'Big Steps', if shuffling gait is a problem, imagining the action to be carried out in detail before starting the movement			
b	Promoting functional abilities through trial of extrinsic cueing techniques, (for example, stepping over a line on the floor, use of a metronome etc)	1.2.1, 1.2.2 Guidelines on extrinsic cueing techniques (OT Best Practice Guidelines 2010 p26)		
c	Promoting functional ability throughout a typical day, taking into account timing of medication	G 2.2.5: timing of dyskinetic episodes in relation to the use of medication should be recorded, and movements, tasks or positions that help to relieve, or exacerbate, involuntary movement identified.' (OT guidelines 2010 p35). This relates to prevention of falls. G 2.7.1: the timing of the first dose of anti- Parkinson's medication is established,		

		because this has important bearing on function. If it is usually taken after washing and dressing, liaise with the medication prescriber to see if the first dose may be taken before the individual gets washed and dressed.(OT Best Practice guidelines 2010 p42) This relates to self care		
d	Promoting functional ability throughout a typical day, taking into account fatigue	G 2.9.2 A diary to record specific tasks that increase fatigue and specific times of the day when fatigue is more of a problem. (OT Best Practice Guidelines 2010 p45) (This relates to fatigue)		
e	None of the above treatment strategies applicable			
	<u>Engagement, motivation, learning and carryover</u>			
a	Promoting mental well-being (for example, intervention to address	1.3.1 – 1.3.6 Guidelines on promoting mental wellbeing (OT Best Practice Guidelines 2010		

	emotional, cognitive and/or neuropsychiatric impairment)	p30)		
b	Promoting new learning (for example, ensuring full conscious attention, demonstration of movement, 'backward chaining' etc)	1.3.7 Guideline on promoting new learning (OT Best Practice Guidelines 2010 p31) Cognitive issues NICE 1.1.1.3 Because people with PD may develop impaired cognitive ability, a communication deficit and/or depression, they should be provided with both oral and written communication throughout the course of the disease, which should be individually tailored and reinforced as necessary		
c	None of the above treatment strategies applicable			
	<u>Environmental adaptations/assistive technology did</u>	NSF LtC Q R7: Providing equipment and accommodation. People with long term	The OT role in environmental adaptation and assistive technology for people with	Although the overall question links to NSF LtC, the specific questions relate to

	<u>intervention include assessment for</u>:-	neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life. (DH 2005 p43)	Parkinson's	occupational therapy role
a	Small aids and adaptations (e.g. grab rails, perching stool, adapted cutlery)			
b	Wheelchair and seating			
c	Major adaptations			
d	Assistive technology (e.g. telecare)			
e	None of the above treatment strategies applicable			
	<u>Ensuring community rehabilitation and social support:- were referrals made to:-</u>	NSF LtC QR 5: Community rehabilitation and support People with long term neurological conditions living at	Onward referral information for occupational therapists for people with Parkinson's	Although the overall question links to NSF LtC, the specific questions relate to the occupational therapy role.

a b c d e f g h	Social services OT Social worker /carers Other allied health professions Respite care Voluntary services Access to work Other (please state) None of the above treatment strategies applicable	home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish. '2(b) Access to other services:- Therapist identifies and educates clients regarding contribution of other team members. Consent for 'referral' gained and timely 'referral on' undertaken. (Figure 1, Jain et al 2005, reproduced in OT Best Practice Guidelines 2010 p18)		
	<u>Providing information to increase client's knowledge</u>	Referral onto PT and SLT Nice Guideline Recommendation R78 (Table 3.1 Key NICE Audit Priority) NSF LTN QR4.1; 4.2;	Information provision by occupational therapists for people with Parkinson's	

a b c d e	Work advice and resources Specific ADL techniques Cognitive strategies Fatigue management Relaxation / stress management	5.1; 5.2; 10.1; 10.2 NSF LtC QR 1: A person centred service People with long term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves. QR 6: Vocational rehabilitation People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access oth1.8.2.2 QR 8: Providing personal care and support Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve		

		maximum choice about living independently at home		
f	None of the above treatment strategies applicable			
	<u>Providing information and support for family and carers</u>	NSF LtC QR 10: Supporting family and carers Carers of people with long term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own		
a	Optimising function			
b	Safe moving and handling			
c	Support services			
d	Managing changes in mood, cognition or behaviour.			
e	None of the above treatment strategies applicable			
	<u>Providing support to facilitate change in attitude:-</u>	'3c Attitude level intervention to change performance' (Figure 1, Jain et al 2005, reproduced in OT Best Practice	OT role in supporting change in attitude where applicable	'Positive attitude/emotional set appears in guidelines (p23). The other questions are survey-based.

a b c d e	Positive attitude/emotional set Developing self awareness/adjustment to limitations Increasing confidence Explore new occupations None of the above treatment strategies applicable	Guidelines 2010 p18)		.
	If any specific treatment strategies identified above (in 'Intervention strategies used') were applicable but not used, what were the reasons for this? Options:- Lack of training in the technique Lack of experience in the technique Lack of time/not a priority Lack of resources (e.g.	This question is asked after every intervention/treatment strategies e.g. Initiating and maintaining movement and Engagement, motivation, learning and carryover.	Identifies possible reasons why applicable treatment strategies may not be being used by occupational therapists.	

	equipment, assessment tools etc) Other (please state)			

Service audit: Audit standards, questions and supporting information

	Question	Information gained from question	Comments
	Service Description		
1	Describe the setting in which you work • Integrated medical and therapy Parkinson's clinic • In-patient acute service • In-patient rehabilitation service • Community rehabilitation service • Social services • Other (please specify)	The setting in which the occupational therapist works	Settings include integrated medical and therapy Parkinson's clinic, in-patient acute service, in-patient rehabilitation service, community rehabilitation service, social services, other
2	Does your service specialise in the treatment of clients with neurological conditions? • Yes • No	Degree of specialisation	
3	Does your service specialise in the treatment of clients with Parkinson's? • Yes • No	Degree of specialisation	
	Clients with Parkinson's		

4	Approximately what percentage of the clients that you see have a diagnosis of Parkinson's Disease? • 19% • 20-39%40-59% • 60-79% • 80-100%	Degree of specialisation	
5	Approximately how many referrals of clients with Parkinson's are made to your service per year?	Number of referral per year	
	Occupational therapy Professionals		
6	Approximately how many therapists work with clients with Parkinson's in your service?		
7	What is your NHS banding/social service grade?	Grade	
8	Can you access Parkinson's related continuing professional development (at least yearly)? • Yes • No	Access to continuing professional development (CPD)	Occupational therapists need to be able to participate in relevant CPD in order to deliver effective services for people with Parkinson's
9	Are there any documented induction and support strategies for new occupational therapists working with clients with Parkinson's? • Yes, specifically in relation to clients with Parkinson's		

	• Yes, as part of more general competencies • No		
10	What is the best level of support in relation to Parkinson's that individual OTs can receive in the service? • Member of Parkinson's specialist MDT • Member of general neurology/elderly care specialist service • Do not work in specialist clinics but can readily access Parkinson's specialist MDT/Parkinson's Nurse Specialist • Do not work in specialist clinics but can readily access specialist neurology or elderly care MDT • No access to more specialised advice • Work alone		
	Clinical Practice		
11	How does your service approach assessment of a person with Parkinson's? • Single occupational therapy assessment • MDT assessment • Interview with clients and carer • Assessment during group work • Functional Assessment • Other (please specify)	Approach to assessment	'Assessment during group work' and 'Functional Assessment' are included in the 2012 audit as they were identified as a frequent approach to occupational therapy assessment in the 2011 audit.
12	How do you usually see your clients with Parkinson's?	Extent of group intervention	Some OTs may find the audit difficult to complete if they see

	• Individually • In a group setting • Both individually and in groups		clients in group setting only.
12a	If your intervention includes group work, what needs are addressed in these groups? 1. Maintenance of work roles 2. Maintenance of family roles 3. Domestic activities of daily living 4. Leisure activities 5. Improvement and maintenance of transfers and mobility 6. Improvement of personal self care activities such as eating, drinking, washing and dressing 7. Environmental issues to improve safety and motor function 8. Mental wellbeing, including cognition, emotional and/or neuro-psychiatric problems 9. Management of fatigue 10. Education 11. Social interaction/social support 12. Other (please specify)	How clients' needs are addressed during group activities	Options 1-7 – supported by NICE Guidelines Options 8-9 – supported by Occupational therapy for people with Parkinson's: Best Practice Guidelines Options 10-11 – survey question
13	Please list the standardised assessments that you use:- 1. Assessment of Motor and Process Skills 2. Canadian Occupational Performance Measure (Law et al 2005) 3. Nottingham Extended Activities of Daily Living Assessment (NEADL) (Nouri and Lincoln 1987) 4. Fatigue Impact Scale (FIS) (Whitehead 2009) 5. Unified Parkinson's Disease Rating Scale (UPDRS)	Approach to assessment	Assessment/measurement tools 1-4 are considered appropriate for use by occupational therapists for people with Parkinson's (See OT Guidelines 2010 p16)

	6. Model of Human Occupation Screening Tool (MOHOST) 7. Non-motor Questionnaire 8. Other (please specify)		Assessment 5 (UPDRS) is designed for use by a person with Parkinson's or his/her carer, but can be reviewed by the investigator. Assessment tools 5-7 were frequently used by occupational therapists in the 2011 audit; information from this question may be useful to consider when updating future Guidelines.
14	What is used to inform clinical practice or guide intervention in this area? • Clinical experience • Advice from colleague or supervisor • Recommendations given in OT Best Practice Guidelines? (Parkinson's UK 2010) • Information from Parkinson's UK website • National Service Framework for Long term Conditions (2005) • NICE Guidelines (2006} • Published evidence in a peer reviewed journal • None • Other (please specify)	Evidence base for intervention	

Appendix 4: National Parkinson's Audit Physiotherapy 2012 Standards and Guidance

National Parkinson's Audit Physiotherapy 2012

Standards and guidance

National Parkinson's Audit Physiotherapy 2012

An audit of national standards relating to physiotherapy for people with Parkinson's incorporating NICE Guideline and quality standards from the National Service Framework for Long Term Neurological Conditions

Background

The Parkinson's diagnosis and management in primary and secondary care clinical guidelines 35[10] published by the National Institute of Health and Clinical Excellence (NICE, 2006) state that physiotherapy should be available for all people with Parkinson's, and that particular consideration should be given to:

- Re-educating gait (improving balance and flexibility)
- Enhancing aerobic capacity
- Improving movement initiation
- Improving functional independence (including mobility and activities of daily living)
- Providing advice about safety at home.

Throughout this document these guidelines will be referred to as NICE CG35.

The National Service Framework for Long Term Neurological Conditions[11] (NSF LTNC, 2005) is a key tool for delivering the government's strategy to support people with long term conditions such as Parkinson's. In particular, aspects of the quality requirements 1, 4, 5 and 7 have been highlighted as important when considering the needs of people with long term conditions.

A group of key clinical, academic and research physiotherapists undertook work to adapt the Dutch Guidelines for physical therapy in Parkinson's disease Quick Reference Cards[12], principally in relation to the use of outcome measures, for use by physiotherapists working with people with Parkinson's in the UK[13]. In addition, this

[10] Parkinson's disease: diagnosis and management in primary and secondary care clinical guidelines 35. Published June 2006 and available online at http://www.nice.org.uk/guidance/CG35/NICEGuidance

[11] National Service Framework for Long Term Neurological Conditions. Published March 2005 and available online at http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Long-termNeurologicalConditionsNSF/index.htm

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

[13] Ramaswamy B et al. Quick Reference Cards (UK) and guidance notes for physiotherapists working with people with Parkinson's disease. Published in 2009 and available online at

group has worked together to provide standards for service delivery.

This second Parkinson's physiotherapy audit is part of the national Parkinson's Audit coordinated by Parkinson's UK and led by a steering group of professionals. Occupational therapy and speech therapy audits are also being conducted simultaneously.

Aim

The aim of the physiotherapy audit is to address the pathway of care for people with Parkinson's disease incorporating assessment of the status and current needs for support from physiotherapy for people referred with Parkinson's. The audit also focuses on the services provided by physiotherapists.

Objective

The objectives of the physiotherapy audit are, as follows:

1. To evaluate if physiotherapy services are currently providing assessment and interventions appropriate to the needs of people with Parkinson's, taking into account recommendations made in the NICE CG35 and the NSF LTNC.

2. To increase the proportion of people with Parkinson's who have an appropriate referral to physiotherapy; an appropriate, timely and effective assessment; and appropriate interventions that comply with national guidelines.

It is key for physiotherapy services to record:

1. How long after diagnosis people with Parkinson's are referred for physiotherapy
2. Evidence that recommendations for physiotherapists from the NICE CG35, the NSF LTNC and the Quick Reference Cards have been implemented.

With this audit we want to answer the following questions:

- Are those physiotherapists assessing and treating people with Parkinson's aware of the UK Quick Reference Cards for Physiotherapy and are they using them? 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
- Is there a match between 'reason for referral' and 'areas identified for physiotherapy intervention' at the point of initial assessment?

Methodology

Following the development of physiotherapy audit tool, a pilot audit was carried out in May 2011. The pilot audit tool was distributed to members of the Chartered Society of Physiotherapy (CSP) clinical interest group for physiotherapists working with older

http://www.parkinsons.org.uk/default.aspx?page=10827

people (AGILE) asking them to participate in this project. Feedback from the pilot enabled adjustments to be made to the tool before the official launch of the first physiotherapy audit in July 2011. Feedback from the 2011 audit enabled further adjustments for the 2012 audit tool.

Parkinson's physiotherapy audit tool consists of two parts – service audit and patient audit. Please ensure both sections are completed before returning it to Parkinson's UK.

Service audit
This section should be completed by only one person. This may be the service manager or the lead for this audit in your service. It asks some general questions about your Parkinson's service and only needs to be completed once.

In question 8, by 'training', we mean either in-service training within the trust/PCT, or external courses and conferences.

Audit of people with Parkinson's
Participating physiotherapy clinicians should complete a separate column for every person with Parkinson's (minimum of 10) seen in their service between 1 August 2012 and 11 January 2013. These include both newly seen people with Parkinson's and follow ups, but each person should only be documented once, even if they attend more than once during this period. Audit questions refer to information regarding to person with Parkinson's from the time of referral to initial assessment and goal setting.

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

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

It is good practice for the auditor to keep the physiotherapy notes separate from the 'medical' notes. If possible, both sets of notes should be used to complete the audit. It will be useful for us to know if all clinicians have access to these.

Enter your people with Parkinson's data onto our spreadsheet which you can save onto your computer and add to at your convenience. Remember to save the data each time you add new information. When completed, send it to pdaudit@parkinsons.org.uk by **11 January 2013**. We will **NOT** accept any submissions after **Friday 11 January (12:00am).** Don't forget to remove all information relating to named people with Parkinson's from the spreadsheet prior to submission. Please find standards and help notes to the audit questions in Table 1.

Confidentiality

Patients
Patients' confidentiality needs to be protected. Please ensure that any information you submit for the audit is anonymised, and does not include any personally

identifiable information about your patients. 'Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it. (HPC 2007 p7)[14]'.

When you complete the patient section of the audit, you will see that there is space for a code number. It is suggested that you write code letters or a number here to help you keep track (for example, client's initials, hospital number), **but you must delete this before submitting your information to Parkinson's UK.** It will help if you keep a list of the code words or number securely yourself, so that if there is any query about the information you have submitted, you can track back to the original client.

Employers

In order to comply with HQIP Principles of national Clinical Audit guidelines, the report on the audit findings will list all participating organisations, along with their individual audit data. This means that your employer's confidentiality will not be protected. **This is a change from the 2011 audit, and it is therefore vital that your employer is aware of, and agrees to, your participation in the audit, and to the submission of your final data.**

Participants

Individuals who participate and submit data will not be named in the audit report. Only the Trust/service name will be published in the main report.

Data Security

You will receive a password-protected spreadsheet for data collection, allowing no one else but eligible participant to enter and make changes to the spreadsheet. Please make sure that the password is well protected and can't be used by other people. To ensure the security of your dataset, we also advise you to save and use your spreadsheet on a secure computer at work rather than personal computer at home.

After the dataset has been sent to pdaudit@parkinsons.org.uk it will be stored in encrypted password-protected files at Parkinson's UK in accordance with NHS requirements. Access to the raw data set is restricted to Mary Sinnathamby, Clinical Audit Manager and Dr Kieran Breen, Director of Research and Development at Parkinson's UK.

[14] Health Professionals Council (2008) 'Confidentiality – guidance for registrants': Health Professionals Council: London. Available at:- http://www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf accessed 26.1.2011

Consent

Please note that by returning the completed audit spreadsheet to Parkinson's UK, your consent to participate in the audit is implied. **Please check that your service manager is happy for you to be involved in this work, before you submit any information.**

How the audit results will be communicated

Participating services will receive an initial summary of results providing data from their service compared with the national average. This will allow audit sites to start to work on local action plans. The full audit report will contain more detailed analysis and comments on the data along with Key Recommendations for commissioners and clinicians. The full report will include in an Appendix, a list of all participating organisations and their individual audit data (in percentages). This is a change that has taken place this year to comply with the HQIP Principles of National Clinical Audit guidelines. The report will be sent to all audit participants, Trust Audit leads and Strategic health authority/ health board audit leads. The Report will also be in the public domain via the Parkinson' UK website.

Data collected during the Audit will be used to generate a national picture of service delivery and compare this with the expectations detailed in national guidance such as the Parkinson's disease NICE Guidance and the NSF-LTNC. Therefore, this data will provide valuable information about priority areas within the existing health care provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's, e.g. the Fair Care campaign for better quality services, which has been launched in 2009 by Parkinson's UK.

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

Standards and help notes for physiotherapy audit of people with Parkinson's

No.	Question	Answer options	Help notes
1. Demographics			
1.1	Gender	• Male • Female	
1.2	Ethnicity	• White British • Any Other White Background • Black/Black British • Asian/Asian British • Mixed Race • Chinese • Not stated • Other Ethnic Group	
1.3	Date of birth (dd/mm/yyyy)	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of diagnosis in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
2. Referral			
2.1	Date of Parkinson's diagnosis (dd/mm/yyyy)	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of diagnosis in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
2.2	Has the person received previous physiotherapy specifically for Parkinson's?	• Yes, please go to Q 2.3 • No, please skip to Q 3 • Offered but declined • Unknown	This question is related to whether the person with Parkinson's had physiotherapy specifically for Parkinson's before the current referral.

2.3	Date of the first referral letter if known (dd/mm/yyyy)	(dd/mm/yyyy)	We are trying to establish the length of time between diagnosis and first referral to physiotherapy. If the actual date is not known please give the estimated year of that initial referral in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
3. Time from referral to initial assessment			
3.1	Date of referral letter to this episode (dd/mm/yyyy)	(dd/mm/yyyy)	This is the date that the letter was written. If the actual date is not known please give the estimated year of that initial referral in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
3.2	Was the referral routine or urgent?	• Urgent • Routine • Unknown	Urgent or routine may be stated on referral letter or the physiotherapy department/ physiotherapist may have decided whether to treat as urgent of routine according to details in the letter
3.3	What was the reason for referral to physiotherapy? (Tick all that apply)	• 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	The suggested list refers to NICE CG35

		• Education and advice regarding their diagnosis • Unclear • Not stated	
3.4	Date of initial physiotherapy assessment (dd/mm/yyyy)	(dd/mm/yyyy)	If the actual date is not known please give the estimated year of that initial referral in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
3.5	Did it meet your local standard for time from referral to initial assessment for urgent or routine?	• Yes • No • No local standard	The department /physiotherapist may have a local standard of seeing people with Parkinson's within a certain time frame e.g. 4 weeks from receipt of referral
4. About the physiotherapist			
4.1	What band (grade) is the physiotherapist who assessed this person?	• Band 5 • Band 6 • Band 7 • Band 8a • Band 8b • Band 8c • Other	
4.2	Approximately what percentage of people with Parkinson's does the audited physiotherapist see in a year?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown	

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

Nb.	Question	Answer options	Standard	Help notes
5. Implementation of national recommendations				
5.1	Do the physiotherapy notes identify the area(s) of anticipated intervention in the initial assessment?	• Yes • No	100% of physiotherapy notes will identify the area of physiotherapy intervention on which to work at the point of initial assessment	There may be documentation of gait, balance, posture, transfers etc.
	If yes, please tick all that apply	• Gait • Balance • Posture • Transfers • Reaching and Grasping • Physical activity • Positioning • Chest Care • Other		
5.2	Do the initial assessment notes record the treatment strategies and techniques to be used for intervention?	• Yes • No	100% of notes will record the treatment strategies and techniques to be used for intervention	There may be documentation of cueing, movement strategies, exercise etc.
	If yes, please list			There may be documentation of

				cueing, movement strategies, exercise etc.
5.3	Were outcome measures used in this case?	• Yes • No	100% of all assessments will use outcome measures	
	If yes, please tick all that apply	• UPDRS • MDS – UPDRS • Lindop Parkinson's Assessment (LPAS) • Berg • Six minute walk test • 10 meter walk test • Time Up and Go (TUG) • Time UnSupported Stand (TUSS) • Parkinson's activity scale retropulsion test • Tragus to wall • Freezing of Gait Questionnaire • History of Falls Questionnaire • PDQ39 • Phone FITT • General Practice Physical Activity Questionnaire (GPPAQ) • The Falls Efficacy Scale - International (Short FES-I) • EQ-5D tool • Other (please list)		

5. Evidence base				
6.1	Which of the following was the physiotherapist using to inform clinical practice or guide intervention in that area?	• Clinical experience • Advice from colleague or supervisor • Recommendations given in Dutch guidelines • Quick Reference Cards (UK, 2009) • Information from Parkinson's UK website • NSF LTC (2005) • NICE CG35 (2006) • Published evidence in a peer reviewed journal • Other • None		

Appendix 5: National Parkinson's Audit Speech and Language Therapy 2012 Standards and Guidance

National Parkinson's Audit
Speech and language therapy 2012

Standards and guidance

National Parkinson's Audit
Speech and language therapy 2012

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

Background

Continuous monitoring of the organisation and delivery of one's service is a sine qua non of ensuring that what should be happening is happening, and if not to identify where changes can or need to be implemented and what those changes might be. Through this, one is able to improve patient care, financial efficiencies and working practices. Audit and service development is especially enhanced when it can be conducted against explicit, nationally agreed criteria.

Various guidelines published in recent years offer recommendations for speech language therapists in the management of people with Parkinson's. These include in particular '*Parkinson's disease*: diagnosis and management in primary and secondary care, Clinical Guidelines 35 published by the National Institute of Health and Clinical Excellence (NICE)[15] and sections/quality requirements of the National Service Framework for Long Term Neurological Conditions (NSF-LTNC)[16]. The Royal College of Speech and Language Therapists (RCSLT) has also published guidelines pertinent to Parkinson's in their Clinical Guidelines documents[17] and Communicating Quality 3[18]. The Dutch Speech Language Therapy organisation in conjunction with the wider Parkinson Net organisation has also published detailed speech and language therapy (SLT) guidelines for Parkinson's[19].

Parkinson's UK, in partnership with the British Geriatrics Society, Association of British Neurologists, Colleges of Physiotherapists and of Occupational Therapists

[15] Parkinson's disease: diagnosis and management in primary and secondary care clinical guidelines 35. Published June 2006 and available online at http://www.nice.org.uk/guidance/CG35/NICEGuidance

[16] National Service Framework for Long Term Neurological Conditions. Published March 2005 and available online at http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Long-termNeurologicalConditionsNSF/index.htm

[17] Royal College of Speech and Language Therapists Clinical Guidelines (Dysarthria), Royal College of Speech and Language Therapists/Speechmark, 2005 Milton Keynes

[18] Royal College of Speech and Language Therapists Communicating Quality 3, Royal College of Speech and Language Therapists, 2006 London

[19] H Kalf et al, Logopedie bij de ziekte van Parkinson (Speech therapy in Parkinson's), Lemma, 2008 Den Haag

and the RCSLT, as well as representatives from the Parkinson's Nurse Specialist Network set up a committee to develop audit tools to monitor the quality of medical and allied health input to Parkinson's in the light of NICE and NSF-LTNC recommendations. A tool for neurology and elderly care consultants has been in operation since 2009. Tools to audit other channels of care for people with Parkinson's, including physiotherapy and occupational therapy input are being introduced last year (2011).

Presently our Parkinson's SLT audit tool concentrates on communication management, with only general coverage of swallowing and drooling. A document covering audit of dysphagia services will be developed in due course.

Recent national surveys[20, 21] indicate that SLT provision for people with Parkinson's is highly variable across the country, with potential for improvement in many areas. This tool will allow SLT services to conduct self audit in relation to NICE, NSF-LTNC and other key national and international guidelines (e.g. RCSLT Clinical Guidelines, Communicating Quality 3). Via Parkinson's UK it will enable SLT managers to compare their service with the pattern nationally of all responding SLT services. It will permit colleagues to identify strengths and key areas for development in both overall service organisation (service audit) and in individual case management (patient audit). When repeating the audit in subsequent years it will enable you to chart maintenance of your strengths and progress in the implementation of action plans.

Aim

The aim of this audit is to enable evaluation of SLT services in relation to the assessment and interventions they provide appropriate to the needs of people with Parkinson's, judged against recommendations made in the NICE CG35, the NSF-LTNC, RCSLT Clinical Guidelines for Dysarthria and RCSLT Communicating Quality 3 standards for motor speech disorders and progressive neurological conditions.

The audit focuses on the early and maintenance phases of the pathway of care for people with Parkinson's disease and incorporates items around: assessing the status and current needs for support from speech and language therapy for people newly referred to a service with Parkinson's or those identified at a review as needing support, and initiating treatments.

[20] Miller N., Noble E., Jones D., Deane K., Gibb C. Survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: patients' and carers' perspectives. International Journal of Language and Communication Disorders, 46, pp179-188; 2011

[21] Miller N., Deane K., Jones D., Noble E., Gibb C. National survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: therapists' practices. International Journal of Language and Communication Disorders, 46, pp189-201; 2011

Objectives

The ultimate objective is to increase the proportion of people with Parkinson's who have an appropriate referral to speech and language therapy; an appropriate, timely and effective assessment; and appropriate interventions that comply with national guidelines.

Through the audit, SLT managers will be able to identify strengths within their service provision and organisation and possible areas for change. Managers 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 managers 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. For more information on guidelines and criteria used in service and patient audit please see Appendix A.

Methodology
Standards agreed to be pertinent to SLT were transformed into a set of target audit/standards statements and reviewed by the core specialist SLTs. Following amendments on advice from the wider professional team the tool was ready for piloting. It was circulated via SLT managers, individual RCSLT advisors and secretaries of RCSLT special interest groups to forward on to members who could be expected to work with people with Parkinson's. They were asked to complete the audit form for 5 cases and give their feedback. The current tool is based on further modifications after feedback obtained from 11 different services and around 70 individual audit spreadsheets.

Data source and data collection

This audit is open to all SLT services and individual SLTs that work with people with Parkinson's in the United Kingdom. It is divided into two parts:

Service audit

The service part of the audit asks some general questions about your Parkinson's service and only needs to be completed once by a manager or senior colleague familiar with the service set-up and running.

Patient audit

The patient audit may be carried out by a designated colleague (with permission from participating therapists) or individual therapists responsible for their own notes. This part of the audit is completed on the basis of individual patient records. Complete the

audit for a minimum of 10 patients with Parkinson's seen in your service between 1 August 2012 and 11 January 2013.

The inclusion criterion for audited patients is as follows:
a) patients who are currently receiving active intervention (including education/counselling) at the start of the audit period;
b) those who are seen on a review appointment (irrespective of whether they then go to start another episode of active treatment) during the audit period;
c) patients newly referred to your service who undergo full assessment (again irrespective of whether they then proceed to immediate active intervention rather than being placed on review).

If it is unlikely that there will be 20 people with Parkinson's in active treatment/review assessment (for example, you see people with a variety of conditions), simply deliver data on all people with Parkinson's you will see in that time, who are either in active treatment or who undergo a major review in that period.

Enter your patients' and service data onto our spreadsheet and send it to pdaudit@parkinsons.org.uk by **11 January 2013**. We will **NOT** accept any submissions after **Friday 11 January (12:00am**). Don't forget to remove all information relating to named patients from the spreadsheet prior to submission.

Confidentiality

Patients

Patients' confidentiality needs to be protected. Please ensure that any information you submit for the audit is anonymised, and does not include any personally identifiable information about your clients. 'Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it. (HPC 2007 p7)[22]'.

When you complete the patient section of the audit, you will see that there is space for a code number. It is suggested that you write code letters or a number here to help you keep track (for example, client's initials, hospital number), but you must delete this before submitting your information to Parkinson's UK. It will help if you keep a list of the code words or number securely yourself, so that if there is any query about the information you have submitted, you can track back to the original client.

[22] Health Professionals Council (2008) 'Confidentiality – guidance for registrants': Health Professionals Council: London. Available at:- http://www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf accessed 26.1.2011

Employers

In order to comply with HQIP Principles of national Clinical Audit guidelines, the report on the audit findings will list all participating organisations, along with their individual audit data. This means that your employer's confidentiality will not be protected. **This is a change from the 2011 audit, and it is therefore vital that your employer is aware of, and agrees to, your participation in the audit, and to the submission of your final data.**

Participants

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

Data security

You will receive a password-protected spreadsheet for data collection, allowing no one else but eligible participant to enter and make changes to the spreadsheet. Please make sure that the password is well protected and can't be used by other people. To ensure the security of your dataset, we also advise you to save and use your spreadsheet on a secure computer at work rather than personal computer at home.

After the dataset has been sent to pdaudit@parkinsons.org.uk it will be stored in encrypted password-protected files at Parkinson's UK in accordance with NHS requirements. Access to the raw data set is restricted to Mary Sinnathamby, Clinical Audit Manager and Dr Kieran Breen, Director of Research and Development at Parkinson's UK.

Consent

Please note that by returning the completed audit spreadsheet to Parkinson's UK, your consent to participate in the audit is implied. Please check that your service manager is happy for you to be involved in this work, before you submit any information.

How the audit results will be communicated

Participating services will receive an initial summary of results providing data from their service compared with the national average. This will allow audit sites to start to work on local action plans. The full audit report will contain more detailed analysis and comments on the data along with Key Recommendations for commissioners and clinicians. The full report will include in an Appendix, a list of all participating organisations and their individual audit data (in percentages). This is a change that has taken place this year to comply with the HQIP Principles of National Clinical Audit guidelines. The report will be sent to all audit participants, Trust Audit leads and Strategic health authority/ health board audit leads. The Report will also be in the public domain via the Parkinson' UK website.

Data collected during the Audit will be used to generate a national picture of service delivery and compare this with the expectations detailed in national guidance such as the Parkinson's disease NICE Guidance and the NSF-LTNC. Therefore, this data will provide valuable information about priority areas within the existing health care provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's, e.g. the Fair Care campaign for better quality services, which has been launched in 2009 by Parkinson's UK.

Thank you for your participation in the National Parkinson's Audit 2012

Standards and help notes for speech and language therapy audit of people with Parkinson's

No.	Question	Answer options	Help notes
1. Service Description			
1.1	Gender	• Male • Female	
1.2	Ethnicity	• White British • Any Other White Background • Black/Black British • Asian/Asian British • Mixed Race • Chinese • Not stated • Other Ethnic Group	
1.3	Date of birth (dd/mm/yyyy)	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of birth in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
1.4	Date of Parkinson's diagnosis (dd/mm/yyyy)	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of diagnosis in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
2. Referral			
Standard 1: 100% of people with Parkinson's must be reviewed at 6-12 monthly intervals. (Parkinson's NICE:R12, R77; NSF LTC:QR2)			

2.1	Date of first referral to SLT service involved in the current audit (dd/mm/yyyy)	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of diagnosis in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
2.2	At what stage in their Parkinson's was the patient on first referral to this particular service i.e. service involved in the audit?	• Diagnosis • Maintenance • Complex • Palliative	The definitions are taken from: MacMahon and Thomas (19 Practical approach to quality of life in Parkinson's disease: nurse's role. J. Neurol 245(Suppl 1): S19-S22. • **Diagnosis** : Initial Parkinson's disease signs and symptoms are present but the diagnosis may not have been confirmed, or accepted by the individual. • **Maintenance**: The person with Parkinson's disease 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 disease is receiving an increasingly complex regimen of anti-Parkinsonian drugs (at least 2 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. Autonomic problems and significant dysphagia or aspiration may be experienced. • **Palliative**: The person with Parkinson's disease is increasingly disabled by the disease's progression, with likely advanced co-morbidity. Anti-Parkinsonian drugs may have been withdrawn in order to reduce side-effects, particularly confusion.

2.3	Referred by If Other, please specify	• Elderly care clinic • General neurology clinic • Parkinson's nurse specialist • Allied health professions colleague (PT, OT) • SLT colleague • Self/relative • Other	
2.4	Original reason for referral to service involved in the current audit	• General assessment opinion • Specific assessment opinion: breathing; voice; speech; swallowing; drooling; other • Treatment: no specific stipulation • Treatment: specific stipulation: education/counseling; breathing; voice; speech; swallowing; drooling; other • Unknown	
2.5	What was the source of the current SLT referral? If Other, please specify	• Initial medical appointment • Medical/nurse review appointment • Other	
2.6	Is this the first episode of SLT care for this patient in	• Yes • No	

	any SLT service? If no, how many previous episodes of care has patient had?	Free text	Please give the total number of completed episodes
2.7	If date of very first referral to any SLT service known, when was this (dd/mm/yyyy), please specify below if "not known"	(dd/mm/yyyy)	If actual date is not known, please give the estimated year of diagnosis in the following format e.g. July 2007 will be 01/07/2007. If not known at all, please leave blank. Please do not write 00/00/0000
2.8	For the very first referral to any SLT service, at what stage of their Parkinson's was the person referred?	• Diagnosis • Maintenance • Complex • Palliative • Not known	
2.9	Describe current episode	• Review appointment only • Group treatment only • Individual treatment only • Group and individual treatment	
2.10	Was the target time from referral to first SLT appointment met?	• Yes • No, and no reason documented for why • No, but reason documented (e.g. clinician leave)	

2.11	Was SLT intention to treat decision to first appointment wait time target met?	• Yes • No, and no reason documented for why • No, but reason documented (e.g. failed appointment)	

3. Assessments

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

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

Standard 3: A full profile of each individual's communication skills should be carried out to include at a minimum:

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

(RCSLT Guidelines)

Standard 4: Particular consideration should be given to review and management to support the safety and efficiency of swallowing and to minimise the risk of aspiration:

- **There should be early referral to SLT for assessment, swallowing advice and where indicated further instrumental assessment**

- **Problems associated with eating and swallowing should be managed on a case by case basis**

• **Problems should be anticipated and supportive measures employed to prevent complications where possible (RCSLT Guidelines)**			
3.1	Full assessment carried out on a first referral for: • communication? • swallowing?	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented	
3.2	Assessment carried out at each review for: • communication? • swallowing?	• Yes • No reference to assessments documented • No, but reasons for not appropriate to assess documented	
3.3	Was an audio recording made at initial assessment and follow-up referrals to the service being audited and is this available?	• Yes and available • Yes but not available • No	
3.4	Assessment notes record when in the drug cycle the assessment was carried out?	• Yes • No	
3.5	Assessment notes record	• Yes • No	

	whether assessment was in off or on state?		
3.6	Are strengths and needs for communication in current and likely environments documented?	• All test scores and interpretation/implications documented • Limited information documented • No information documented	
3.7	Is there a clear plan of management based on assessment outcomes?	• All plans detailed in notes • Some restricted plans documented • No plans documented	
	Assessment of speech subsystems **Standard 5: A perceptual assessment should be made, including respiration, phonation, resonance, articulation, prosody and intelligibility, to acquire an accurate profile for analysis (RCSLT Clinical Guidelines).**		
3.8	Are assessment results available for all speech subsystems for the initial assessment and all review appointments?	• Yes, subsystems assessed in both stimulated and unstimulated conditions • Restricted range of subsystems and/or conditions assessed, justification documented • Restricted range of subsystems and/or conditions assessed, justification not documented • No assessments documented, but with justification documented • No assessments and with no	

		justification documented	
3.9	What tasks/contexts does assessment cover? (Tick all that apply)	• Speaking • Reading • Writing • One to one context • Group context	
3.10	Which voice-respiration parameters were assessed? (Tick all that apply)	• Loudness/amplitude • Pitch and pitch range • Voice quality	
3.11	Which prosody parameters were assessed? (Tick all that apply)	• Rate • Loudness (variation) • Pitch (variation)	
3.12	Was intelligibility assessed?	• Standardised diagnostic intelligibility test completed and score given • Informal assessment, nonstandardised tool/subsection of other test completed and score given • Informal assessment (e.g. rating scale) completed • No assessment/results documented but justification given • No assessment documented and no justification given	

	Communication **Standard 6: People with Parkinson's should be asked explicitly about difficulties with word finding and conversations (Dutch Guidelines: R11).**		
3.13	Was AAC identified and need addressed?	• Yes, fully • Yes, partially, awaiting action from outside AAC service • Yes, partially, limited range of AAC devices available • Not addressed as not indicated • Indicated but no action documented	
3.14	Does assessment cover: • communication participation? • the impact of Parkinson's on communication? • the impact of communication changes on partner/carer?	• Formal assessment of participation carried out • Informal assessment of participation carried out • Not carried out, but justification documented • Not carried out and no justification documented • No carer	
	Results of assessment		
3.15	Were results and rationale for resulting actions (e.g. review period; intervention	• Explanation of causal/maintaining factors aimed to patient and carer documented • No explanation made/documented but	

	plans) conveyed and explained to patient and carer?	justification documented • No explanation made/documented and no justification documented	
3.16	Was information supplied to make informed decisions about care and treatment?	• Intervention specifically includes education and advice on self management and is documented • No explanation made/documented but justification documented • No explanation made/documented and no justification documented	
3.17	Where notes recommend onward referrals (e.g. ENT, video fluoroscopy), have these been made?	• Yes, some • None and reasons documented • None and reasons not documented • No onward referrals recommended	
4. Interventions			
Standard 7: Speech and language therapists should give particular attention to improvement of vocal loudness, pitch range and intelligibility (NICE: R81). **Standard 8: Speech and language therapists should report back to the referrer at the conclusion of an intervention period. Reports should detail intervention, duration, frequency, effects and expected prognosis (Dutch Guidelines: R2b).**			
4.1	Is intervention prophylactic and anticipative and not just symptomatic?	• Yes, education/planning for upcoming issues included • No, no prophylactic component	
4.2	If a patient is in later	• Input documented at all stages	

	stages, was intervention across the whole time span of Parkinson's	• Input documented at certain stages only • Not referred in early stages • No input documented • Patient not in later stages	
4.3	Which of the following does intervention target:	• Pitch (range) • Prosody • Improvement of vocal loudness • Strategies to optimise intelligibility	
4.4	Does intervention target features outside of direct speech/voice work? (Tick all that apply) Please specify if Other	• Patient education/advice • Managing patient participation • Managing patient impact • Managing generalisation outside clinic • Carer education/advice • Managing career impact • Other • Free text	
4.4	Were reports made back to the referrer/other key people at the conclusion of an intervention period (or when treatment lasts a	• Yes • No	

	longer time there are interim reports)?		
4.5	Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?	• Yes • No	
4.6	Do referral letters to other agencies contain the following? (Tick all that apply)	• Relevant history • Question(s) that the referrer wishes to have answered • Type of referral requested (e.g. single consultation for advice/initiation of treatment)	

Criteria for Parkinson's speech and language therapy audit

Main criteria used in formulating speech and language service and patient audit items were taken from:

- Parkinson's disease**:** diagnosis and management in primary and secondary care, Clinical Guidelines 35 (NICE CG35), National Institute of Health and Clinical Excellence, 2006
- National Service Framework for Long Term Neurological Conditions (NSF-LTNC), Department of Health, 2005
- Royal College of Speech and Language Therapists Guidelines Clinical Guidelines (Dysarthria), Royal College Speech and Language Therapists (RCSLT)/Speech mark, 2005
- Royal College of Speech and Language Therapists Communicating Quality 3 (RCSLT CQ3), Royal College Speech and Language Therapists, 2006
- Logopedie bij de ziekte van Parkinson's (Speech therapy in Parkinson's Dutch Guidelines), H Kalf et al, Lemma, 2008

NICE CG35

For 100% of people with Parkinson's at diagnosis and each regular review SLT is available and appropriate referral is activated (audit criteria p43-4, R78, and Table 3.1; exceptions - not Parkinson's, declined referral).

100% of people with Parkinson's are reviewed at 6-12 month intervals, no exceptions (R12 p35).

General recommendations, p5 (and recommendations 1.1.1; R1-5):

Patient centred care: treatment and care should take into account patients' individual needs and preferences

Patients with Parkinson's should have the opportunity to make informed decisions about their care and treatment

The treatment, care and information provided should be culturally appropriate and in a form accessible to patients who have additional needs such as people with physical, cognitive or sensory disabilities and people who do not speak or read English

Carers and relatives should also be provided with the information and support they need.

NICE 1.9.4/R81. SLT should be available for people with Parkinson's. Particular consideration should be given to:

Improvement of vocal loudness and pitch range, including SLT programmes such as LSVT

Teaching strategies to optimise intelligibility

Ensuring effective means of communication is maintained throughout the course of the condition, including use of assistive technologies.

R76 People with Parkinson's should be treated appropriately for autonomic disturbances, dysphagia, sialorrhoea.

R81/1.9.4.1 Particular consideration should be given to review and management to support the safety and efficiency of swallowing and to minimise the risk of aspiration:

There should be early referral to SLT for assessment, swallowing advice and where indicated further instrumental assessment

Problems associated with eating and swallowing should be managed on a case by case basis

Problems should be anticipated and supportive measures employed to prevent complications where possible.

R 82/ 1.10.1.1. Palliative care requirements should be considered throughout all phases of the disease.

R83/ 1.10.1.2. Patients with Parkinson's and their carers should be given the opportunity to discuss end of life issues with appropriate healthcare professionals.

Relevant excerpts from NSF-LTNC quality requirements (QR's)

People with long terms conditions:

QR 1) are to have the information they need to make informed decisions about their care and treatment and where appropriate to support them to manage their condition themselves

QR 4) who would benefit from rehabilitation are to receive timely, ongoing high quality rehabilitation services in hospital or other specialist settings to meet continuing and changing needs

QR 6) are to have access to appropriate vocational assessment, rehabilitation and ongoing support to find, regain or remain in work

QR 7) are to receive timely, appropriate assistive technology/equipment to support them to live independently

QR 9) in later stages of long term conditions are to receive a comprehensive range of palliative care services to meet their needs for personal, social, psychological and spiritual support

QR 10) Carers of people with long term conditions are to have access to appropriate support and services, both in their role as carer and in their own right.

RCSLT CQ3

Motor speech disorders section: SLTs must be cognisant of both the national and international guidelines on best practice for their area of work.

Education: development of care pathways for SLT involvement are shaped by the evolving underlying medical picture and evolving real and perceived impact of changes on communication.

Progressive neurological conditions section:

- Early intervention is vital
- Flexible and responsive approach
- Forward discussion when person is still able to communicate to prepare for later changes (e.g. AAC)
- Individual self management with or without the support of a carer and friends
- Promotion and maintenance of an acceptable quality of life
- Provision of information and support at the appropriate times
- Provision of equipment to support communication where necessary.

RCSLT Clinical Guidelines (Dysarthria)

Assessment:

- The SLT works as a core member of the MDT
- Assessment findings will be analysed to formulate a differential diagnosis of Dysarthria
- An evaluation of the emotional, psychological and psychosocial impact of the dysarthria should be made for both the individual and the family
- An explanation of the causal and maintaining factors that make up the dysarthria will be discussed.

A perceptual assessment will be made:

- To acquire an accurate profile for analysis (respiration, phonation, resonance, articulation, prosody, intelligibility)
- For establishment of a baseline and a measure of overall severity
- A good quality audio recording is beneficial.

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

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

It is important to gain the perspective of the individual and family regarding how the dysarthria affects all aspects of their lives.

When speech alone is insufficient to meet the individual's communication needs, a variety of augmentive strategies should be used.

Recommendations from the Dutch Guidelines 2008 (not duplicated above)

Recommendation 2b:

The formal caregivers to whom the patient was referred report back to the referrer (and to the Parkinson's nurse) at the conclusion of an intervention period. When the treatment lasts a longer time the person should deliver interim reports at least once a year.

In the report the formal caregiver should at a minimum describe the intervention, the duration of the treatment and its frequency, effects and expected prognosis. If possible the results of treatment are supported with results from assessment instruments used.

Recommendation 5:
It is recommended in clinical dysarthria assessment with people with idiopathic Parkinson's to judge limitations in:
a. spontaneous or unstimulated speech
b. stimulability of the different speech parameters with the help of maximum performance tests.

Recommendation 6:
In interpreting (speech assessment) results it is important to know whether the person was being observed in an 'on' or an 'off' period.

Recommendation 9a:
It is recommended to make audio or video recordings of spontaneous speech.

Recommendation 10:
It is recommended that the SLT should refer somebody with Parkinson's and hypokinetic dysarthria to ENT only if there are suspicions of voice pathology which is not related to the neurological picture.

Recommendation 11:
It is recommended to ask people with Parkinson's explicitly about difficulties with word finding and conversations.

Recommendation 19b: During treatment it is also recommended that the SLT expressly takes note of the individual's 'on'/'off' periods.

Appendix 6: Checking your data before submission

National Parkinson's Audit 2012

Checking your data before submission

Introduction

Everyone involved in the Parkinson's national clinical audit needs to feel confident that the data collected through the audit is accurate and complete. Parkinson's UK staff can check if data are missing in data collection forms submitted to the national clinical audit and can check the accuracy of data in reports based on data submitted from organisations participating in the audit.

However, only staff working in participating organisations can check the accuracy and completeness of data submitted for the audit. For the national clinical audit being carried out in 2012–13, the Clinical Steering Group for the audit is asking participating organisations to check a small sample of the data collected prior to submission.

Checking data is time consuming, so the directions we are providing are intended to make the process of checking as easy as possible, while still providing some assurance that there has been a process in place to check on the reliability of data for the national clinical audit.

Follow these directions for each audit in the national Parkinson's clinical audit in which your organisation is participating. For example, if your organisation is participating in the Parkinson's Patient Management Clinical Audit and the Parkinson's Occupational Therapy Clinical Audit, you should check the quality of the data for each audit independently.

Preparing to check data submitted

However you collect data for the Parkinson's national clinical audit — at the same time patients are seen, for example, as the patient records are available for clinics, or retrospectively after patients are seen and treated — arrange for someone to help with the data checking just after the data have been collected for the audit, in order to minimise the retrieval of records later.

You can share data checking among colleagues who see patients with Parkinson's. For example, if a doctor enters the data for a part of the audit, a nurse specialist could do the checking and vice versa. Therapists can check data for nurses or doctors or for each other. It doesn't matter who does the checking. Another option is to ask a member of your Trust's clinical audit department to help with the data checking.

Although it is not ideal, if it is not practical to have another person do the data checking, you can check your own data collection. If you choose this option, you should be prepared to retrieve patient records at some time in the future and allow

sufficient time to pass to minimise the likelihood that you might recall the data you entered the first time.

How to pick cases for checking data

We are asking participating organisations to check the data for 15% of the cases submitted for each of the audits in which they are participating. This is a small sample. However, in view of the extra time involved in checking data, this is reasonable for this year's audit.

To pick the cases for checking data for each audit in which your organisation is participating, do the following:

1. Get or make a list of the cases for which data have been collected for the audit. You can make the list for an individual clinic session or across sessions. Put the list of cases in chronological order of date and time of appointment. Assign a consecutive number to each case in your list.

2. Find the total number of cases on each list. Determine how many cases comprise a 15% sample. Round up to the next whole number if you need to. This is the number of cases for your sample for checking on data quality.

3. Get a random number table or use a computer-generated list of random numbers to select the actual cases for checking data quality from all the cases in your list.

4. Retrieve the patient records and any other relevant documentation for the cases selected to be in the 15% sample for checking data quality.

5. Retrieve the data collection forms that have been completed already for each case in the sample, to have available for checking later. However, don't allow anyone who will be doing the data quality check to see the data recorded before completing the data collection forms for the data quality check.

Repeat this process for each of the remaining Parkinson's audits in which your organisation is participating. This means that for each audit, you will have a 15% sample of cases for checking on data quality.

How to collect data for the data quality check for each audit

To collect data for the cases in the data quality check for each of the audits, do the following:

1. Be sure that the person doing data collection for the data quality check has been trained to collect data for the clinical audit, that is, knows what key terms mean, where to look for information and how to make decisions in completing the data collection forms.

2. Have the person who is carrying out the data quality check collect and record data from the same records that were used originally, for the cases selected for the 15% data quality sample. The data quality check person does this work independently, does not discuss decisions, and does not have access to the data collected originally.

3. Have the person who is carrying out the data quality check complete the data collection forms for each case for the sample of cases in the data quality check.

How to check the data for each case in the data quality check for each audit

For each of the audits, compare the data collected originally with the data collected by the person doing the data quality check. Look for the following:

- Were the data for each case *complete* in the original data collection form? Was there a response entered in each 'response cell' on the data collection form?

- Were the data for each case *accurate* in the original data collection form? Are the data correctly input without mistakes due to incorrect data entry or incorrect interpretation of information in a patient's record?

- If data are missing or not accurate in the original data collection form, be sure that the complete and accurate data collection form is submitted for the audit.

What to do when you have completed the data checking for each audit

For each audit, when you are confident that data from the sample checked are complete and accurate:

1. Submit your data for all cases for the specific audit to us.

2. Tell us via email how many cases you included in your data checking for that audit.

3. If you have any questions about how to interpret information in patient records and what to enter on a data collection form, contact us directly for help.

If you wish to, you can calculate for each audit what is called the level of inter-rater reliability (data collector consistency) of the data collected by doing the following:

- Comparing the data collected originally for the specific audit with the data collected for the data quality check, count (1) the number of data items for which there was complete agreement and (2) the total number of data items, for all the cases in the data quality check.

- Divide the number of data items for which there was complete agreement across the cases in the data quality check sample by the total number of data items collected across all the cases in the data quality check sample. Multiply by 100 to get a percentage of inter-rater (data collector) agreement.

- International good practice for national clinical audits is that the percentage of agreement is at least 90%. If your level of agreement for a specific audit is lower than 90%, feedback the findings to all those involved in data collection, try to determine what accounts for discrepancies in the data collection and resolve them among the people involved.