Foreword

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

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

And audit is central to driving up service quality.

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

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

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

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

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

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

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

Steve Ford, Chief Executive
Executive Summary

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

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

Key Findings

• 39% of newly diagnosed patients with Parkinson’s are not provided with written information about Parkinson’s

• A third of newly diagnosed patients are waiting longer than six weeks to see a specialist

• Patients on dopamine agonists are not being monitored for impulsive and compulsive behaviour and 40% of patients on long term ergot dopamine agonist therapy are not monitored

• Approximately a third of occupational therapists, physiotherapists and speech and language therapists working in specialised neurological services are not receiving updated training on the management of Parkinson’s.

• Approximately a third of occupational therapists, physiotherapists and speech and language therapists do not use recommended standardised assessments

• 9% of occupational therapy referrals did not include a reason for referral nor details about the patient’s Parkinson’s history or medication

• Only 1.4% of the total audited patients represented black and ethnic minority (BME groups), this is a similar pattern to the previous audits

Key Recommendations

• Clinicians should provide written information about Parkinson’s via signposting to Parkinson’s UK (website or local information support worker)

• 100% of patients with newly diagnosed Parkinson’s should be seen within six weeks
• All patients must be advised and monitored for the risk of impulsive and compulsive behaviour when starting on a dopamine agonist and have ongoing monitoring if on long term ergot dopamine agonist therapy

• All healthcare professionals working for services specialising in neurological conditions and the treatment of people with Parkinson’s to receive appropriate updates in the management of Parkinson’s

• The use of standardised assessments as recommended in guidelines should be encouraged

• Clinical professionals referring patients to therapies need to provide essential information about the patient with the referral

• There is a need for more engagement with black and ethnic minority groups with Parkinson’s.
Recommendations

This section summarises all the recommendations made throughout the National Parkinson’s audit report 2011 for each audit.

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

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

All recommendations

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

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

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

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

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

- Physiotherapy audit: 9% of services did not meet RTT targets
- Speech and language audit: 19% of services did not have RTT targets
Patient management in neurology and elderly care recommendations

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

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

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

- Only 69% of patients were seen within six weeks

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

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

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

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

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

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

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

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

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

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

**PM8:** End of life care requirements should be encouraged throughout the stages of Parkinson’s.
• Approximately 40% of palliative patients are considered for end of life care requirements

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

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

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

**Occupational therapy recommendations**

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

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

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

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

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

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

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

• 28% of services did not use any of the recommended standardised assessments

• Only 13% of services used the recommended standardised assessments

OT5: The time between diagnosis and referral to occupational therapy should be reduced.
• The audit found that occupational therapists see people who have had Parkinson’s for an average of six years.

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

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

**Physiotherapy recommendations**

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

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

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

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

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

**Speech and language therapy recommendations**

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

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

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

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

**SLT3**: All patients with Parkinson’s attending speech and language therapy services should be able to self-refer and/or re-refer themselves for communication and swallowing assessments.
• Only 54% of services allow patients with Parkinson’s to self refer and/or re-refer themselves for problems with swallowing

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

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

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

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