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Parkinson's Audit
2010 report

Executive summary

- We audited 1880 patients with a suspected diagnosis of Parkinson's from 53 trusts or equivalent organisations from all over the UK.

- Our Parkinson's audit showed that a review for Parkinson's patients by multidisciplinary team (MDT) is still not the norm. A high percentage of trusts reported no provision of multidisciplinary Parkinson's clinics.

- The six weeks referral target to see a movement disorders specialist is not always met – one third of the suspected Parkinson's patients had to wait for longer than six weeks to see a specialist. The data indicates an ongoing lottery regarding timely access to a specialist in order to get an accurate diagnosis.

- The assessment of activities of daily living (ADL) and non-motor symptoms have a significant impact on the quality of life of people living with Parkinson's. However only two thirds of patients had their ADL assessed and documented. It appears that the availability of ADL tools or checklists remain low, more so for neurology clinics. Non-motor symptoms are often under reported in a clinical setting without a specific documented enquiry. 54% neurology and 28% of elderly care services do not use any written prompts to assess non-motor issues.

- There's still low understanding of the importance of non-drug therapies as only about half of the newly diagnosed Parkinson's patients are assessed for therapy they might need. The documented physiotherapy need is not being matched by a subsequent referral in two thirds of participating trusts.

- One fifth of patients were not offered Parkinson's nurse contact details, even though the service was available. And more than one third of the patients included in the audit were not offered written information about Parkinson's. This information is essential to allow for self-care of the condition.

- Our Parkinson's Audit provides some preliminary data on the ethnic make-up of people accessing Parkinson's service in the UK. A large number of sites recorded no patients from black and ethnic minority groups (BME). There are large conurbations recording no BME patients e.g. Salford, Leeds, Sandwell, Dudley, where there are large BME communities.

Contents

Background

Around 120,000 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. Management is particularly challenging due to the complex mix of problems relating to speech and swallowing, memory and mood, sleep, pain and continence, which compound the movement symptoms of the disorder. An integrated medical, nursing therapy model of care is essential – but far from the norm based on data from 13,000 patients surveyed by the Parkinson’s UK in 2007. The All Party Parliamentary Group Enquiry into Parkinson’s services (2009) also highlights a concerning postcode variation in quality of care. The Parkinson’s NICE Guideline published in 2006 predated the current arrangement for all new NICE Guidelines to be accompanied by an audit tool. To fill this gap, a multi-professional steering group was established under the Chairmanship of Steve Ford, Chief Executive of Parkinson’s UK to facilitate local audit against national standards of good practice by providing audit tools and the facility for central benchmarking.

Aims

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

Objectives

Patient Audit

To examine if the assessment/management of new patients referred with the query “does he/she have Parkinson’s” complies with the NICE and National Service Framework for Long Term Neurological Conditions (NSF-LTNC) guidelines. The Audit relates to the patient’s first clinic visit.

Service Audit

1. To establish, by trust or equivalent organisation, if people with Parkinson’s can access services and treatments recommended by NICE and NSF-LTNC including:
    - Specialist medical assessment
    - Parkinson’s nurse support

- Therapy services (physiotherapy, occupational therapy, speech and language therapy)
- NICE approved medication
- DaTSCAN imaging
- Neurosurgery.

2. To explore the likely quality of Parkinson's therapy services by collecting information on access to different specialists and if delivered via an integrated multidisciplinary team.

Standards

Standards for the Parkinson's Service and Patient Audits are mainly derived from the Parkinson's NICE Guideline audit criteria which link to the NICE key priorities for implementation (Appendix A). They also reflect quality standards contained within the National Service Framework for Long Term Neurological Conditions. Additional standards were added to reflect process of care aspects which would promote compliance with the key priorities.

Findings – Patient Audit

The Audit data was submitted for 1880 patients with a suspected diagnosis of Parkinson's from 53 trusts or equivalent organisations from all over the UK. In 18 of the trusts data was returned as requested for both neurology and elderly care services, in 22 for only elderly care and in 13 for neurology services only (Appendix B). The range of data returned for the Patient Audit was quite wide, with some trusts returning figures for just one patient, whilst others returned figures for up to 81 patients, with a median of 18. Eleven trusts had a sample of less than 10 suspected Parkinson's patients, and in fourteen trusts less than five patients in their sample received a diagnosis of Idiopathic Parkinson's. These organisations received results of their performance but were not included in the benchmarking analysis because of the potential to disproportionally influence the total data. Benchmarking analysis was limited to 42 trusts for standards 1-2 and 39 for standards 3-9.

The majority of the patients were male (57%) of white origin (95%) with an average age of 74 (SD=9.7) years.

The Audit results give initial insight into the ethnic profiling of UK Parkinson's clinics. A large number of sites recorded no patients from black and ethnic minority groups (Figure1). For many sites, this would be expected in terms of local demography e.g. Cornwall and Devon, while for others, an alternative explanation is required. There are large conurbations recording no BME patients e.g. Salford, Leeds, Sandwell, Dudley, where large numbers of BME residents are known to live. Furthermore, unexpected variations were found in the proportions of BME patients attending certain clinics. King's College in South London, covers a large African-Caribbean

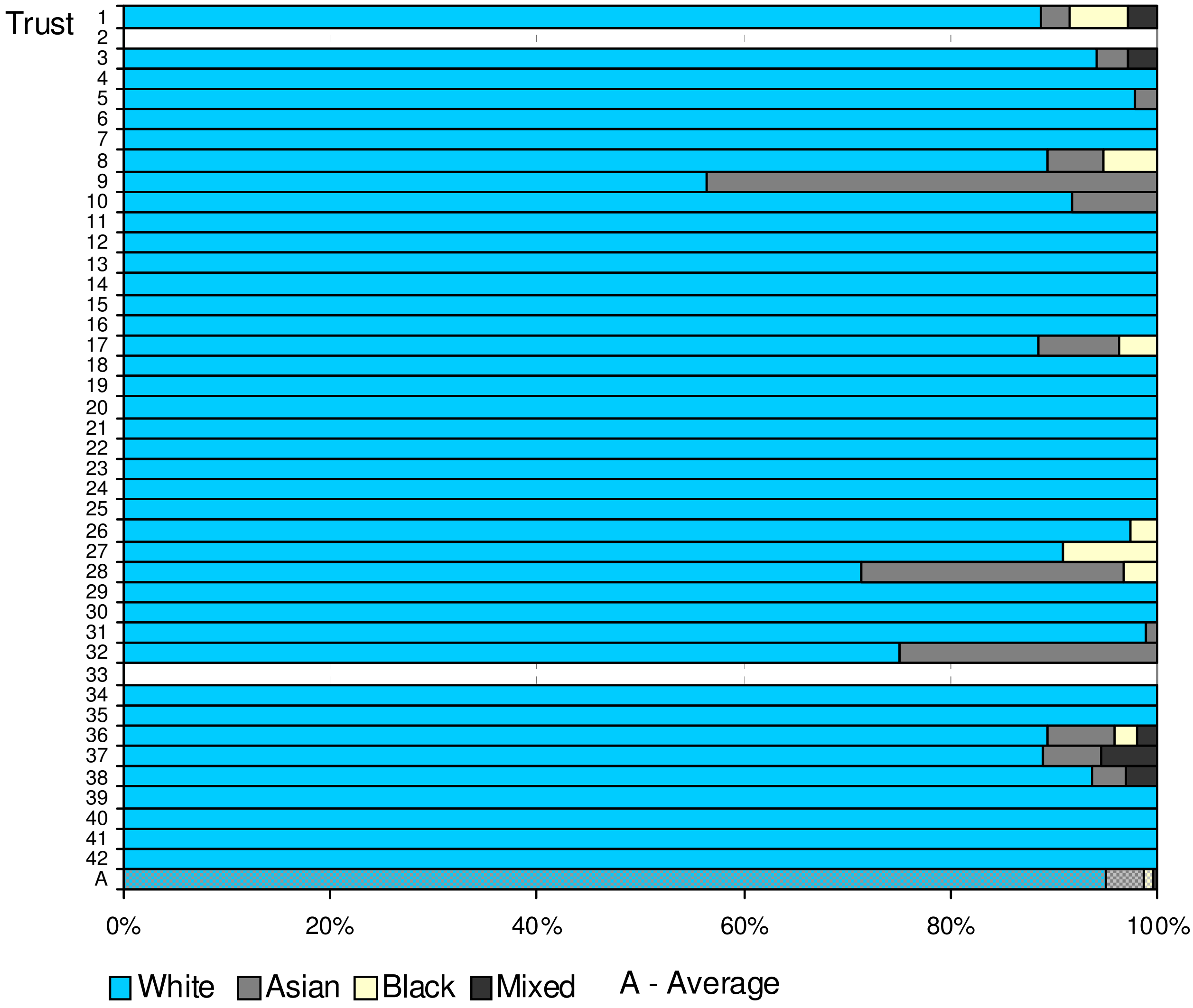

Figure 1. Ethnicity of suspected Parkinson's patients

resident population, but recorded no patients from this ethnic group during this audit, although Asian patients were well represented (25%).

The discrepancies may have a variety of explanations including sample bias, small sample size, limited study duration and different age banding between BME and white residents. The Audit provides initial data on the ethnic make-up of people accessing Parkinson's service in the UK and should pave the way to more rigorous studies of ethnicity and its effect on involvement with secondary care services.

Two thirds (65%) of the audit patients were referred for their diagnosis to elderly care consultants reflecting the larger number of elderly care consultants taking part in the Audit (40 trusts compared to 31 trusts that audited neurology patients). The majority (84%) of patients were referred by their general practitioner (GP) and 13% by a consultant without a specialisation in movement disorders.

Standard 1

Patients with suspected Parkinson’s should be seen by a movement disorders specialist within 6 weeks.

Parkinson’s NICE Guideline recommendations R9; R11 (Table 3.1 Key NICE Audit priority) NSF LTN QR2.1.

Two thirds (66%) of patients were seen within the NICE Guideline target time of 6 weeks from initial referral. The median delay for those who were not seen within 6 weeks was 19 calendar days. Less than 3% of the delays were patient related.

Compliance with this standard shows a wide variation. Eight (19%) out of the 42 benchmarked trusts achieved 100% compliance with the 6 weeks target (Figure 2). Half of the trusts saw two thirds or more of their patients within this time frame, whilst four (10%) trusts met the standard in less than a third of patients. The average delay beyond 6 weeks between trusts varied from 8 to 100 calendar days.

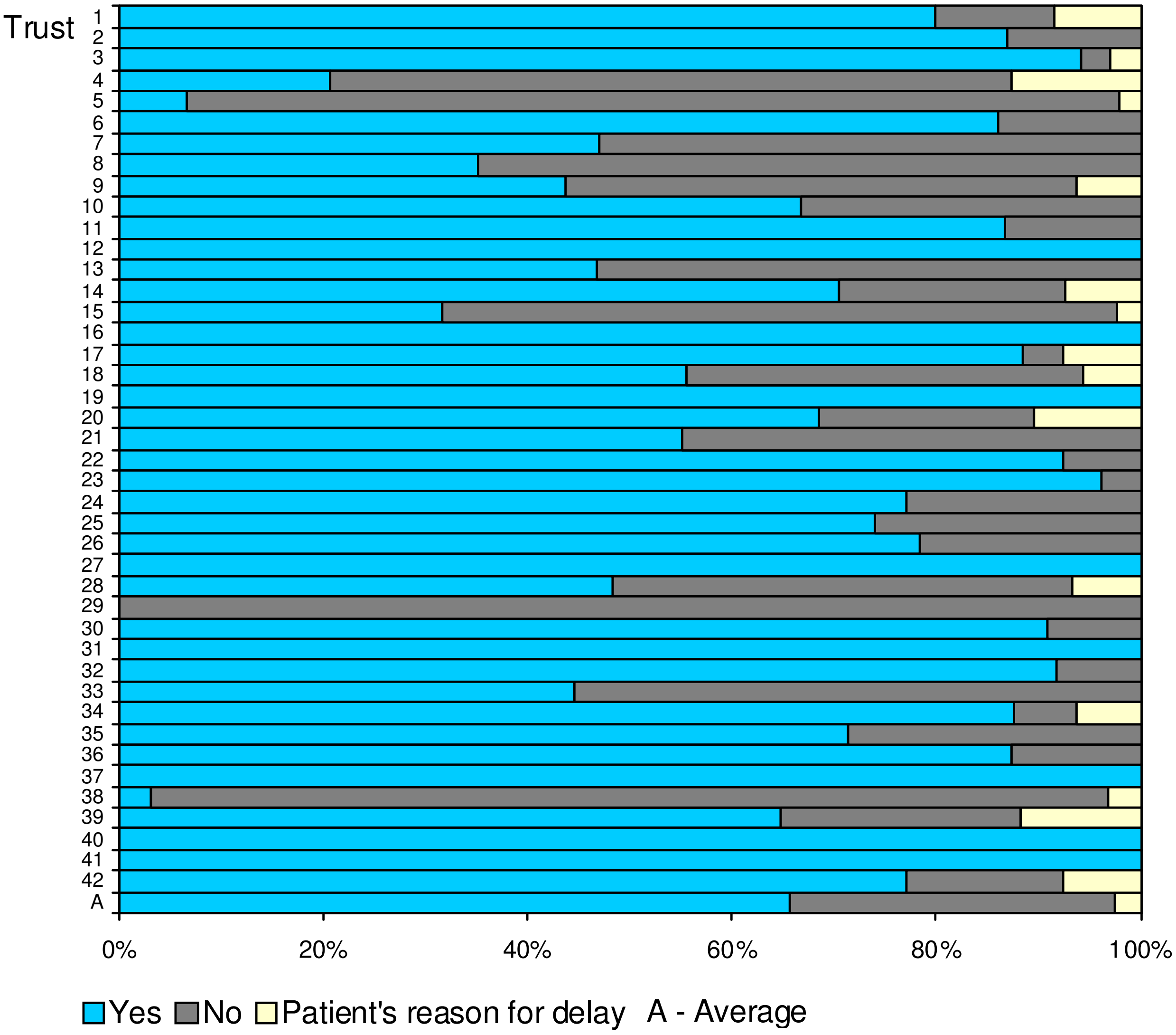

Figure 2. Suspected Parkinson’s patients seen in 6 weeks from referral

Elderly care consultants were slightly more likely to see referred patients within the recommended 6 weeks compared to neurologists (Table 1, p=.000). In trusts not meeting the target, the mean delay waiting to see a neurologist was 26 days, two days longer than waiting to see an elderly care consultant (p=.314). The data indicates an ongoing lottery regarding timely access to diagnosis. Compared with the 2009 Audit results, there is no change overall in the proportion of patients seen within 6 weeks (63% in 2009 and 66% in 2010) but elderly care clinics are faring better (66% in 2009 and 77% in 2010) and neurology figures have worsened (58% in 2009 and 50% in 2010). All trusts except one met the 18 weeks general outpatient target.

Table 1. Patients seen by elderly care and neurology consultants for differential diagnosis

Seen within 6 weeks	Elderly care		Neurology	
	n	%	n	%
Yes	568	77	204	50
No	148	20	198	48
Patient's reason for delay	23	3	8	2
Total	**739**	**100.0**	**410**	**100**

Standard 2
Patients with suspected Parkinson's should be referred untreated.

Parkinson's NICE Guideline recommendation R11 (Table 3.1 Key NICE Audit priority).

The majority (86%) of patients were referred untreated. Most trusts (91%) met the standard in two thirds or more of their patients. There was no difference in the delay from referral when comparing treated and untreated patients (mean=25, p=0.878), Of the 14% treated patients, 78% had been started on Levodopa (Table 2), 4% on combined Levodopa and Entacapone (not licensed in this situation) and 2% had been prescribed an anticholinergic drug, although this is not recommended as a first line treatment.

NICE recommends that patients are referred untreated to allow specialist input into the choice of medication, but also to ensure that the diagnosis is correct. This view is supported by the relatively low number of patients (47%) who had their suspected Parkinson's diagnosis confirmed at the clinic visit. The most common alternative diagnoses were vascular parkinsonism and drug induced parkinsonism (Table 3). The "other" diagnosis category (31%) mainly includes other tremor conditions e.g. Essential Tremor.

The diagnosis of Parkinson's was more likely to be confirmed in the subgroup of patients whose referrer had felt confident enough to initiate treatment, but the diagnosis was still incorrect in a third (32%) of these patients.

Table 2. Drugs that were used to treat patients before referring them to consultant to confirm Parkinson's diagnosis

Drug	n	%
Levodopa	122	78
Dopamine agonist	22	14
MAOB inhibitor	3	2
Anticholinergic	4	2
Combination of Levodopa and Entacapone	6	4
Total	**157**	**100**

Table 3. Initial working diagnosis following specialist's assessment

Diagnosis	n	%
Idiopathic Parkinson's disease	561	47
Vascular parkinsonism	130	11
Progressive Supranuclear Palsy	19	2
Multiple System Atrophy	10	1
Dementia with Lewy bodies	19	2
Drug induced parkinsonism	67	6
Other diagnosis	371	31
Total	**1177**	**100**

Nearly 6% of patients were referred despite being prescribed medication known to cause drug induced parkinsonism – a similar proportion to the 2009 Audit. Explicit guidance as part of the referral pathway might help to improve awareness and reduce these referrals.

Standards 3 – 9
The data was collected only in the subgroup of 537 patients who received a working diagnosis of Parkinson's at the clinic visit. The conclusions are limited by the small sample size (range 2 – 29) although 39 of the 42 trusts that were benchmarked provided information on 5 and more patients.

Standard 3

The assessment should include documentation of difficulties with activities of living, including speech and swallowing.

NSF LTN QR1.1; 5.1.

The 2009 Parkinson's Audit report listed the documentation of problems relating to ADL function as an area for improvement. Although a lower proportion of patients were assessed for ADL problems in the current Audit (67% compared to 78% in 2009) the quality of assessment may have improved as clinicians were encouraged to use a simple ADL tool or to use this as a guide to the level of detail expected. In the 2009 Audit only 15% of patients were screened using a formal ADL tool or checklist. In contrast, data from the current Service Audit indicates that 38% of the elderly care services and 11% of neurology services are routinely using an ADL checklist in >75% of their clinics.

Four trusts had no record of ADL assessment for any of their patients, whilst eleven met the standard in 100% (Figure 3). Elderly care consultants were more likely to document an assessment of ADL compared to neurology consultants (35% and 26% respectively, p=.000), possibly because the paperwork was more readily available in clinic.

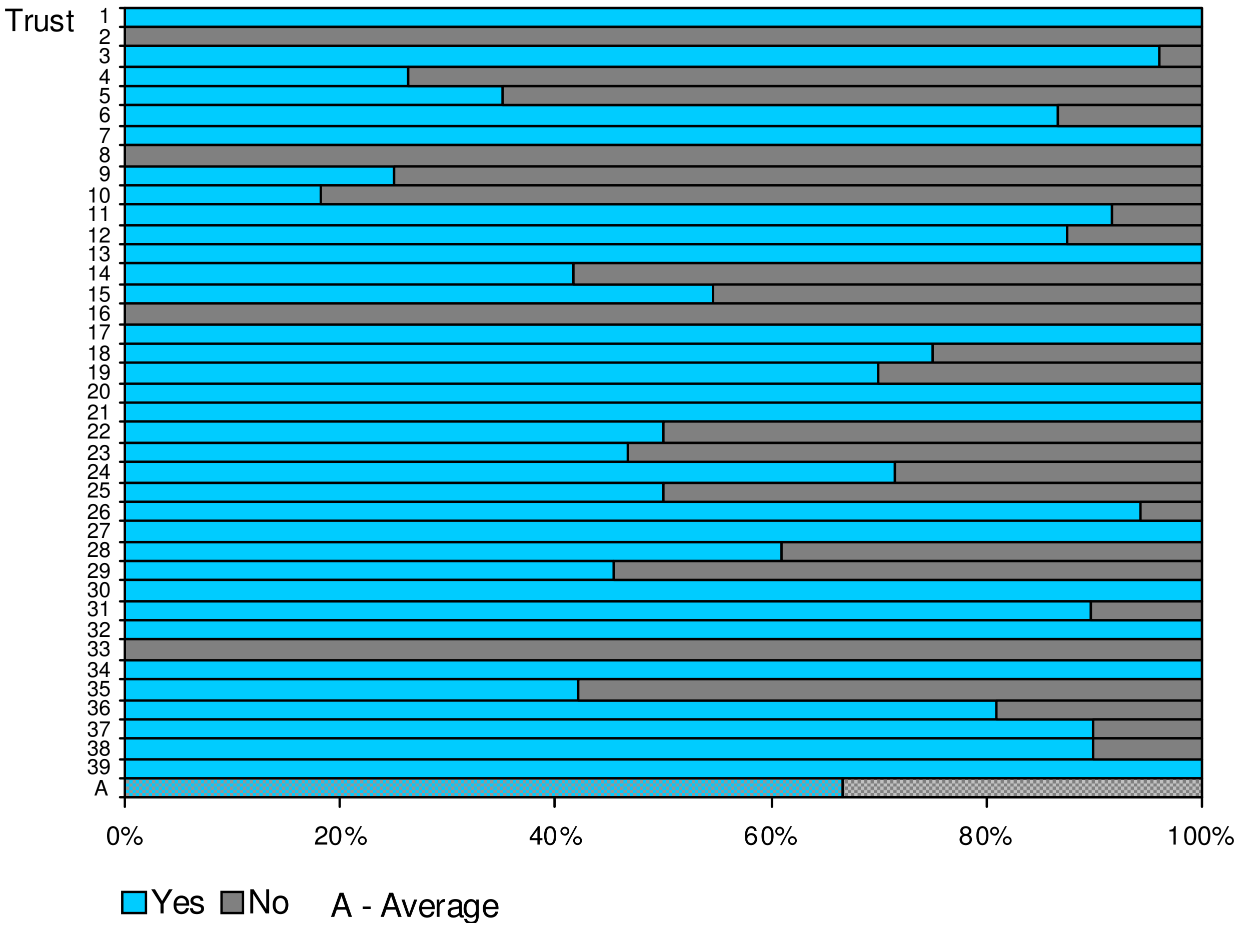

Figure 3. Assessment of activities of daily living documented by trusts

Two thirds (66%) of patients' notes recorded an assessment of communication and 60% commented on swallowing. The level of detail of the assessment (e.g. clinician's own opinion; patients' self report; formal and informal assessment) is unknown. Seven trusts (17%) achieved 100% documentation of communication assessment, but three trusts had no documentation at all (Figure 4).

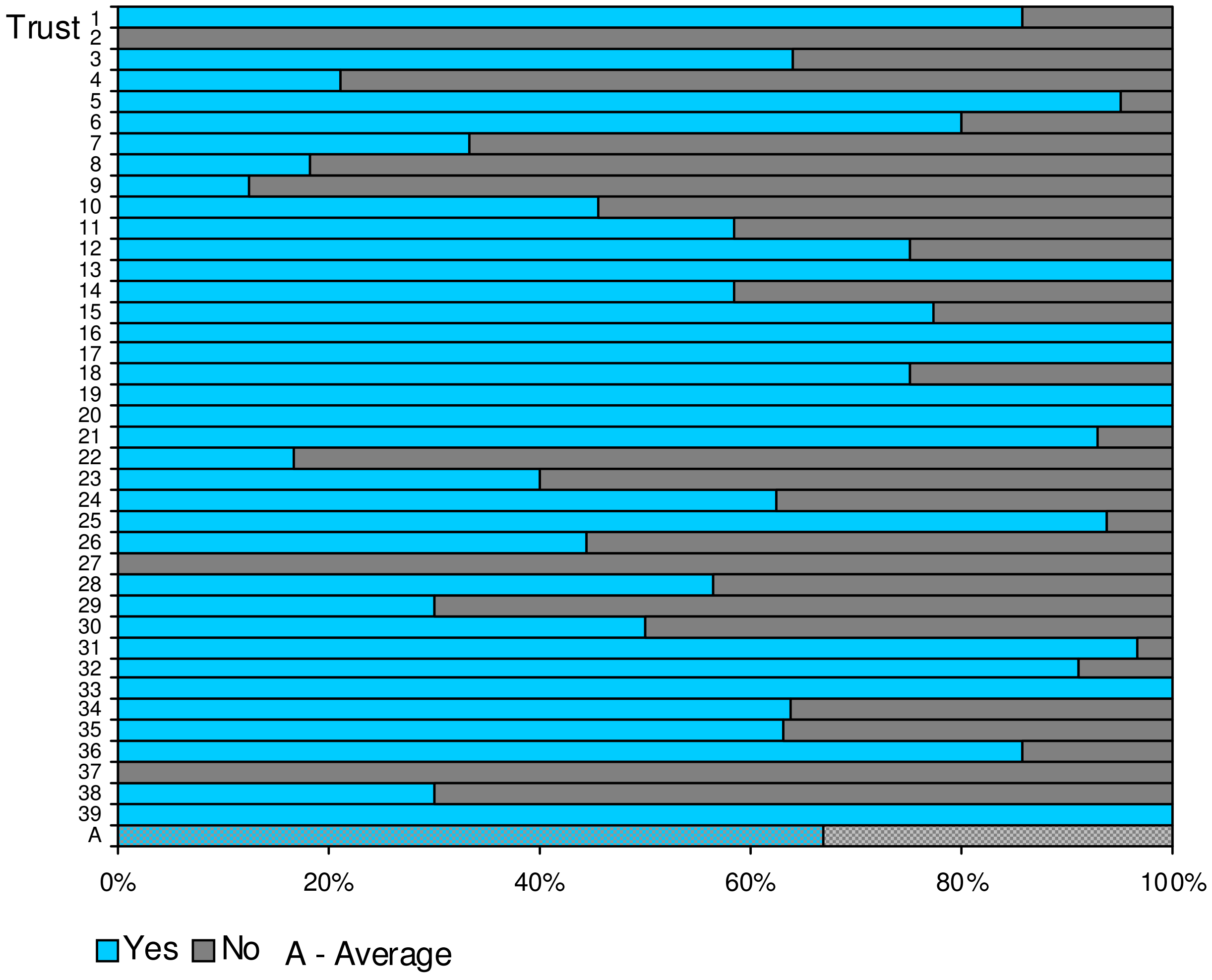

Figure 4. Documented assessment of speech and language therapy

Neurology consultants were more likely to document assessment of both communication (36% compared with 30% for elderly care consultants, p=.000) and swallowing (31% compared with 27%, p=.000) on this first visit.

Standards 4, 5 and 6

Physiotherapy, occupational therapy and speech and language therapy is available at diagnosis and at each regular review and appropriate referral activated.

Parkinson's Nice Guideline Recommendation R78 (Table 3.1 Key NICE Audit Priority) NSF LTN QR4.1; 4.2; 5.1; 5.2; 10.1; 10.2.

Data on the availability of therapy services was collected in the Service Audit. The Patient Audit captured the documentation of individual patient therapy needs at diagnosis (as defined by NICE) and if these resulted in appropriate therapy referral.

The indications for therapy referrals were as defined in the Parkinson's NICE Guideline key priorities (Appendix A).

As would be expected in this population of newly diagnosed patients, a therapy need was most often documented for physiotherapy (49%) and was uncommon (15%) in relation to swallowing (Table 4).

Table 4. Therapy needs identified at diagnosis

	Physiotherapy need	Occupational therapy need	Speech and language therapy need (speech)	Speech and language therapy need (swallowing)
Yes	49%	25%	21%	15%
No	41%	61%	67%	71%
Unknown	10%	14%	12%	14%

It was not possible to do a clear correlation between the identification of need and the appropriateness of the referral as patients with unknown needs could not be analysed. In general there was a pattern for the proportion of patients referred to be less than the proportion of patients with an identified need (Table 5).

Table 5. Therapy referral decisions for patients with Parkinson's

Therapy referral decision	Physiotherapy	Occupational therapy	Speech and language therapy
Yes, primarily for education	6%	2%	4%
Yes, primarily for therapy	31%	14%	11%
Not referred	46%	66%	69%

The Parkinson's NICE Guideline highlights the importance of "self-management education that provides people with problem solving and management skills for the self-care of their condition".

One fifth of the benchmarked trusts referred some patients to physiotherapy at diagnosis "primarily for education", and 14% made "primarily for education" referrals for occupational therapy (OT) and for speech and language therapy (SLT). The proportion of patients referred purely for education is small (6% for physiotherapy, 2% for OT and 4% for SLT).

Almost half of the patients were not referred for physiotherapy at diagnosis. Most of this “non” referral was appropriate as 41% of patients did not have an identified physiotherapy need (Table 4). Similarly, for OT and speech and language therapy, just over two thirds (66% OT, 69% SLT) had no referral but 61% were classified as having no OT and 67% no SLT therapy needs. However, as discussed in page 9, trusts vary in their use of tools to screen for therapy issues and it is unknown if therapists would have identified a different level of “need”.

Interpretation of this apparent under referral has the caveat that the Audit only captured what happened at the first patient visit. It may have been reasonable to await the impact of medication if patients were about to start treatment and impairments were mild. Some services may leave the Parkinson’s nurse to assess and refer on a subsequent visit. The next version of the Parkinson’s Patient Audit will capture more of the diagnosis phase.

Standard 7

Patients with a new diagnosis of Parkinson’s should be offered contact information for a local Parkinson’s nurse.

Parkinson’s NICE Guideline recommendation R6 NSF LTN QR1.2; QR 2.4.

More than two thirds (75%) of patients were offered Parkinson’s nurse contact details. However, almost one fifth (18%) did not receive this information, even though the service was locally available (Figure 5).

One participating trust had no local Parkinson’s nurse provision, and three had a Parkinson’s nurse available but only for some of their patients. Five trusts were not providing contact details for more than a half or most of their patients despite having access to this service.

Elderly care and neurology consultants were equally likely to provide new Parkinson’s patients with details of the local Parkinson’s nurse (77% and 72% respectively, p=.505).

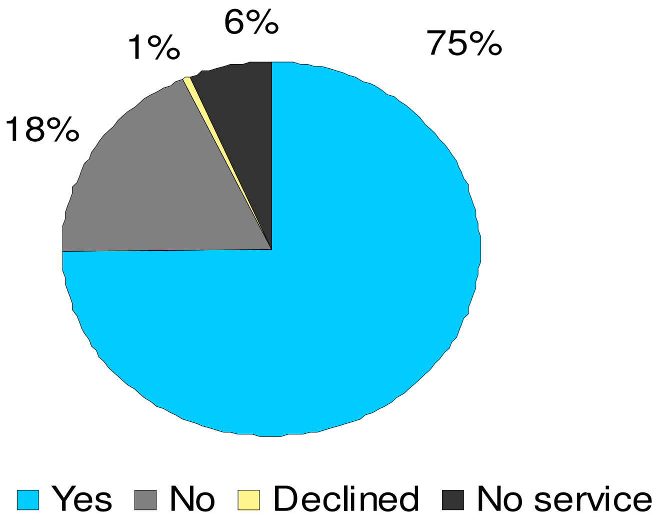

Figure 5. Parkinson’s nurse contact details offered

Standard 8

Driving status should be determined and patients who drive should be advised of the need to inform DVLA and their insurance. Driving status and discussion should be documented in the notes.

Parkinson's NICE Guideline recommendation R7.

Driving status was determined for seven out of ten Parkinson's patients (70%), and 50% had DVLA/car insurance discussed – an improvement from 2009 Audit (64% and 36% respectively). Three trusts didn't document driving status for any of their patients. The same three trusts and three additional ones didn't offer DVLA or car insurance advice to any of their patients.

Elderly care consultants perform better in determining driving status (78% compared to 62% for neurology consultants, p=.000) but are less likely to discuss DVLA and car insurance (34% compared to 50% for neurology consultants, p=.000).

Standard 9

Patients with a new diagnosis of likely Parkinson's should be offered written information regarding Parkinson's.

Parkinson's NICE Guideline recommendations R3 NSF LTN QR 1.4

Almost two thirds (60%, Figure 6) of audited patients were offered written information regarding Parkinson's (57% in 2009). The performance in various centres varied greatly: seven trusts offered information to all of their patients; two trusts did not provide any information and 16 trusts (38%) provided Parkinson's related information to half or less of their patients. Written information about the condition is freely available at Parkinson's UK. Only 35 patients (7%) declined the information offered.

Elderly care consultants were more likely to provide written information regarding Parkinson's to newly diagnosed patients compared to neurology consultants (63% and 57% respectively, p=.016).

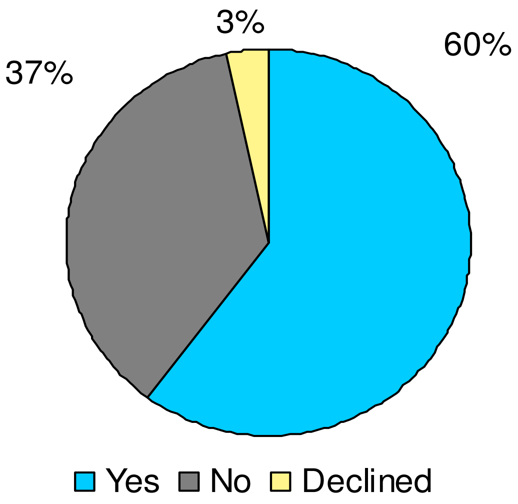

Figure 6. Written information regarding Parkinson's offered

Findings – Service Audit

Thirty-seven trusts or equivalent organisations completed the Service Audit, which evaluates patients' access to NICE recommended services and treatments. Trusts were asked to provide information on neurology and elderly care services. Thirty-seven audited their elderly care and 18 their neurology services (Appendix B).

Standard 1

Patients are able to access a neurologist and/or elderly care consultant with specialist Parkinson's expertise.

Parkinson's NICE Guideline Recommendation 11 (Table 3.1 Key NICE Audit Priority) NSF QR2.1; 2.2.

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

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

Half of the audited trusts reported provision of a Parkinson's or movement disorders specialist service via neurology and elderly care, one third via elderly care only and 6% via neurology only (Figure 7). 53% have a commissioning/referral pathway, which diverts patients to the specialist's service. Only one trust (3%) manages Parkinson's entirely via general neurology and elderly care, with no specialist provision.

Data was collected on consultant attendance at external movement disorders specific CME training as supportive evidence of specialist expertise. Most (97%) of the elderly care consultants who routinely deal with Parkinson's patients had attended such training during the 2009/2010 CME cycle compared with 75% of neurology consultants.

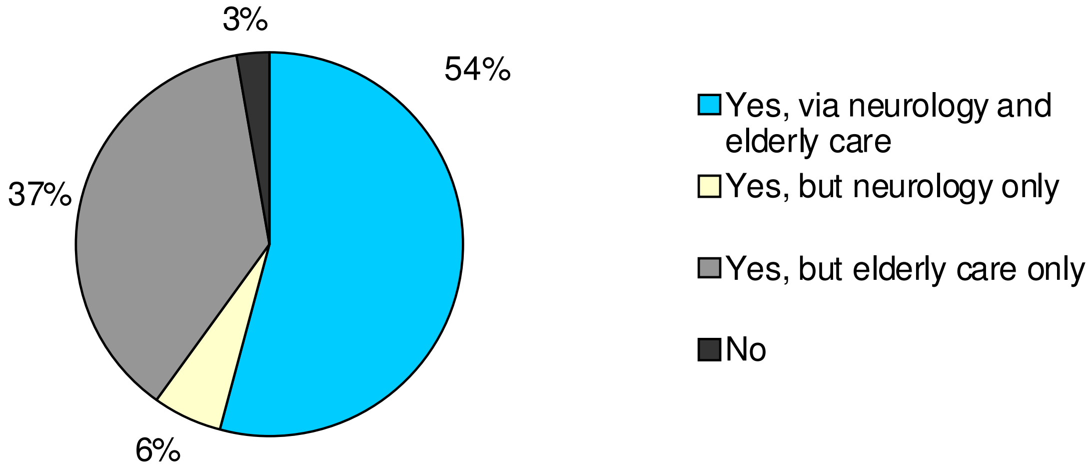

Figure 7. Trusts provide a specialist Parkinson's or movement disorders service

Trusts were asked to describe how the medical input into patient care is organised. Data was obtained for the proportion of medical reviews which take place in "doctor alone' clinics, joint doctor and Parkinson's nurse clinics or in a fully integrated "doctor/Parkinson's nurse/therapy" setting. The formulation of this question will be amended for future audits, as there was inconsistency in how it was interpreted by different participants. With this caveat there appears to be a trend for neurologists to be more likely to see patients within a traditional purely medical clinic (63% compared to 43% for elderly care). An integrated clinic model is unusual in neurology (only 1%) compared with 15% for elderly care. Neurology and elderly care services see a similar proportion of patients within joint doctor/Parkinson's nurse clinics (28% of reviews).

We had hoped to gain an understanding of the factors that influence access to the different models – e.g. does it depend on commissioning issues, the individual specialty (e.g. neurology or elderly care) or the individual consultant. Variations in how participants interpreted the question and small numbers in some categories made it unreliable to analyse.

Assessment of ADL function, non-motor symptoms, cognition and mood

Services were asked (as a surrogate marker of what would be expected in a specialist clinic) if they screen patients for ADL problems and non-motor symptoms and if cognitive and mood assessment scales are available in clinics. In the 2009 Patient Audit, 22% of patients had no documented assessment of ADL function, and only 15% were assessed using a formal ADL tool or checklist. The 2010 Audit documentation included a simple ADL assessment tool to try to improve this area of clinical practice. An additional standard was added to the Service Audit to enquire if an ADL assessment tool or check list was routinely used, with answer options of "all clinics, >75% of clinics, some clinics or not routinely available". This issue is important for improving compliance with the NICE key audit requirement that physiotherapy, occupational therapy and speech and language therapy should be available at diagnosis and at each regular review and appropriate referral activated.

In 22% of elderly care services, a formal ADL tool or checklist is routinely used in all clinics, compared with only 4% of neurology services. One third (32%) of elderly care services and two thirds (68%) of neurology services do not routinely screen for ADL problems (Table 6). It appears that the availability of ADL tools or checklists remains low, more so for neurology clinics. Provided these tools are quick and straightforward to complete, and services should consider how to make them more widely available to increase awareness of ADL issues and to trigger referrals to other healthcare professionals as necessary.

Non-motor symptoms (NMS) have a significant influence on quality of life with Parkinson's and are often under reported in a clinic setting without specific enquiry. Services were asked to indicate if they routinely used a non-motor symptom questionnaire or some form of checklist to screen for these problems. As a result, 22% of elderly care and 11% of neurology services routinely screen for non-motor symptoms in all their clinics (Table 6). However, 54% neurology and 28% of elderly care services do not use any written prompts regarding non-motor issues.

Table 6. The use of ADL and NMS assessment tools or checklists when Parkinson's patients attend clinics

	ADL				NMS			
	Neurology		Elderly care		Neurology		Elderly care	
	n	%	n	%	n	%	n	%
All clinics	1	4	8	22	3	11	8	22
Most clinics (>75%)	2	7	6	17	4	14	7	19
Some clinics	6	21	9	25	6	21	11	31
Not routinely available	19	68	13	36	15	54	10	28
Total	**28**	**100**	**36**	**100**	**28**	**100**	**36**	**100**

Services were asked to indicate if cognitive and mood assessment scales are routinely available for use when clinically indicated. Cognitive assessment tools are generally available in elderly care run clinics with 67% of services having the paperwork in all clinics (Table 7). Neurology services are less likely to have cognitive assessment tools in the clinic, although 39% of services have them in all clinics.

Mood assessment tools are less likely to be readily available in clinic, possibly reflecting clinicians' uncertainty regarding their validity in Parkinson's. Elderly care services report greater availability to mood assessment tools compared to neurology (Table 7).

Standard 2

Patients can access a Parkinson's nurse (or neurology nurse with Parkinson's remit) for clinical monitoring, continuing point of contact for support, including home visits and as a reliable source of information about social and clinical matters.

Parkinson's NICE Guideline Recommendation 77 (Table 3.1 Key NICE Audit Priority) NSF LTN* QR 1.2; 2.4; 2.5.

More than two thirds (76%) of participating trusts have equitable access to a Parkinson's nurse for neurology and elderly care patients from all local postcode areas (Figure 8). In eight of the trusts this service is available for some patients only, and in two of them access depends on the commissioning area. One trust had no local provision.

Table 7. The use of cognitive function and mood assessment tools when Parkinson's patients attend clinics

	Cognitive function				Mood			
	Neurology		Elderly care		Neurology		Elderly care	
	n	%	n	%	n	%	n	%
All clinics	11	39	24	67	4	14	10	29
Most clinics (>75%)	6	22	7	19	2	7	4	11
Some clinics	5	18	5	14	8	29	8	23
Not routinely available	6	21	0	0	14	50	13	37
Total	**28**	**100**	**36**	**100**	**28**	**100**	**35**	**100**

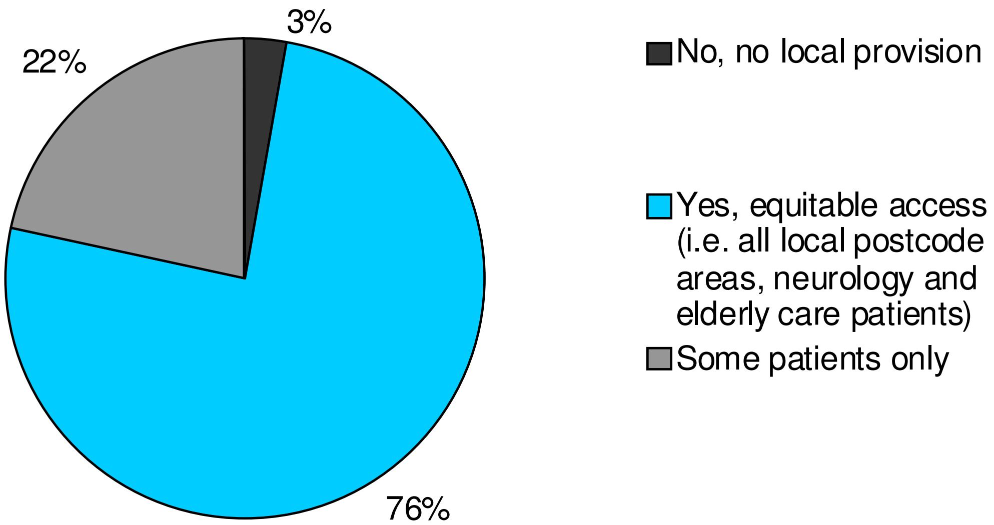

Figure 8. Patients access to Parkinson's nurse support

Standard 3, 4 and 5

Physiotherapy, occupational therapy and speech and language therapy is available at diagnosis and at each regular review and appropriate referral activated for people with Parkinson's.

Parkinson's Nice Guideline Recommendation R78 (Table 3.1 Key NICE Audit Priority) NSF LTN QR4.1; 4.2; 5.1; 5.2; 5.3.

The Audit assumed that non-specialist therapy services would be available in all areas, albeit in varying amounts. As general services tend to focus on more "acute" therapy needs, trusts were asked about patient access to therapists with specialist knowledge and expertise in Parkinson's chronic disease management. Expert therapy was defined as:

- Parkinson's forms a significant part of the therapists work load and
- Therapists can access Parkinson's related CPD (at least yearly)
- Therapy practice is based on the Parkinson's NICE Guideline.

Most (84%) of the trusts report some local provision of "expert" physiotherapy compared with 68% for OT, 76% for SLT in relation to swallowing function and 81% for SLT regarding speech (Table 8).

Of the 84% of trusts that had access to expert physiotherapy, 52% had universal access. Of the trusts without universal access, 64% were dependent on the commissioning area (i.e. patient postcode), 21% were restricted by both commissioning area and service speciality, and 14% were only able to access expert physiotherapy through elderly care services. Although these figures are encouraging, there were still a further 16% of trusts that had no access to expert physiotherapy. We still need to strive for equality of access to expert physiotherapy for all people with Parkinson's.

Access to expert therapy was lowest for occupational therapy - 32% of trusts have no "expert" OT (Table 8). Occupational therapists work in a wide variety of settings, including social services and community rehabilitation teams. This may be reflected in their caseloads, which can be generic in nature. In these circumstances, it may be difficult for some occupational therapists to fulfill the requirements for being 'expert' therapists, as defined in this report. What these findings suggest is that more occupational therapists are needed who have the capacity to specialize in the

Table 8. "Expert" versus general therapy provision

	General therapy service only	"Expert therapy" universal access	"Expert therapy" some patients only
Physiotherapy	16%	52%	32%
OT	32%	41%	27%
SLT (swallowing)	24%	57%	19%
SLT (speech)	19%	49%	32%

treatment of people with Parkinson’s, and that occupational therapists must be given the necessary CPD opportunities to ensure that they have the necessary expertise for patients with this condition.

SLT services described as “expert” were not all able to provide Lee Silverman voice therapy. Only 30% of trusts had universal access to Lee Silverman voice therapy with a further 27% having access for some patients.

A local postcode variation in a commissioning area is the commonest reasons for “expert” therapy being available locally but only for some patients (Table 9). Neurology patients have more limited access to “expert” therapy compared with elderly care, probably reflecting the finding that an integrated doctor/Parkinson’s nurse/therapy clinic model is rare in neurology but was reported by 15% of trusts for elderly care.

Interpretation of this data has the caveat that it relates to a relatively small sample of 42 trusts who may not be representative of trusts less motivated to take part in the Audit. Although concerns persist regarding patient access to “expert” therapy support, the findings suggest a gradual improvement in the provision of specialist need therapy services compared with previous surveys.

Table 9. Factors influencing lack of universal access to “expert” therapy

	Physiotherapy	OT	SLT speech	SLT Lee Silverman	SLT swallowing
Commissioning area (patients postcode)	57%	50%	58%	36%	60%
Neurology service only	0%	0%	8%	0%	0%
Elderly care service only	14%	17%	17%	27%	20%
Post code and specialty dependent variations	29%	33%	17%	37%	20%

Standard 6
Patients can access Parkinson’s medications approved by NICE based on clinical need.

Parkinson’s NICE Guideline recommendations Table 7.1 and Table 7.4; R26; 28; 32; 34; 35; 38; 39; 43; 44; 46; 47; 48; 49; 50; 68. NSF LTN QR 2.3.

Table 10 describes whether listed medicines are available for prescription based on clinical need.

Dopamine agonists

Patients are generally able to access oral and patch dopamine agonist treatment as per clinical need (Table 10). There were no reported formulary restrictions for standard release Ropinirole and Pramipexole. Prolonged release Ropinirole is generally available (97%) with lower figures for the newer prolonged release Pramipexole preparation (introduced December 2009) which is either unavailable (8%) or has restricted access in 11% of trusts. The difference in access is likely to continue if Ropinirole/Pramipexole price discrepancies remain.

Table 10. Access to Parkinson's medication

Access to Parkinson's medication				
	Yes primary and secondary care*	Yes secondary care only	Restricted (individual funding approval)	No
Dopamine agonists				
Ropinirole (standard)	100 %	_	_	_
Ropinirole (prolonged release)	97%	_	3%	_
Pramipexole (standard)	100 %	_	_	_
Pramipexole (Prolonged release)	82%	5%	5%	8%
Rotigotine	95%	3%	2%	_
Cabergoline	74%	3%	3%	20%
Apomorphine	73%	19%	5%	3%
COMT inhibitors				
Entacapone	100%	_	_	_
Stalevo	100%	_	_	_
Tolcapone	40%	21%	9%	30%
MAOB inhibitors				
Selegiline	100%	_	_	_

Zelapar	73%	3%	9%	15%
Rasagiline	83%	3%	8%	6%
Amantadine	100%	_	_	_
Duodopa	12%	_	76%	12%
Cholinesterase inhibitors	81%	19%	_	_
Clozapine	78% only prescribed via mental health 11% other secondary care			11%

* Often after initial prescription and stabilisation in secondary care

Access to the patch preparation Rotigotine has improved compared to the previous Audit (95% in 2010 versus 87% in 2009). The use of Cabergoline continues to decline reflecting its more complex monitoring requirements and the arrival of once daily formulations of Ropinirole and Pramipexole. It is now unavailable for prescription in 20% of trusts (16% in 2009).

Apomorphine should be available for selected patients. Access has improved since 2009 but 3% of trusts report being unable to prescribe (6% in 2009) and 5% require individual funding approval.

COMT inhibitors

Entacapone and Stalevo can be prescribed in primary and secondary care**.** Tolcapone requires intensive monitoring and has appropriate restrictions on initial prescribing in primary care but the proportion of trusts reporting that they are unable to prescribe has increased to 30% compared to 20% in 2009.

MAOB inhibitors

Standard Selegiline is generally available. Rasagiline is more likely to be the second line alternative to Selegiline with only 6% of services unable to prescribe compared with 15% of services for Zelapar.

Duodopa

Duodopa is classed as an orphan drug and it is to be expected that 76% of trusts need to apply for individual funding approval. It is concerning that 12% of trusts are unable to use Duodopa therapy in appropriate patients, although this has improved from 32% in 2009.

Cholinesterase inhibitors

Cholinesterase inhibitor therapy is generally available, although prescription is limited to secondary care in 19% of trusts and one third of trusts need to refer patients to mental health.

Clozapine

Clozapine is mainly prescribed via mental health but 11% of trusts described it as unavailable.

Standard 7

Patients can be referred by a movement disorders specialist for a DaTSCAN.

Parkinson's NICE Guideline recommendations R13; R14 NSF LTN QR 2.2.

Most (87%) of the participating trusts reported being able to refer their Parkinson's patients for a DaTSCAN and almost half (49%) had local provision via the trust radiology department. Four trusts (11%) had a limit to the number of scans funded per year and one trust was unable to refer. The situation has improved from 2009 when 21% of services had no access to DaTSCAN.

Standard 8

Patients can be considered for neurosurgery based on clinical need.

Parkinson's NICE Guideline recommendations R 55; 56; 57; 58 NSF LTN QR 2.3.

Sixteen percent of participating trusts or equivalent organisations directly provide neurosurgery for Parkinson's and their patients were able to access neurosurgery based on clinical need. Most of the remaining trusts can refer and access funding for suitable patients regardless of their postcode (Figure 9). Four trusts reported service restrictions based on where the patient lives.

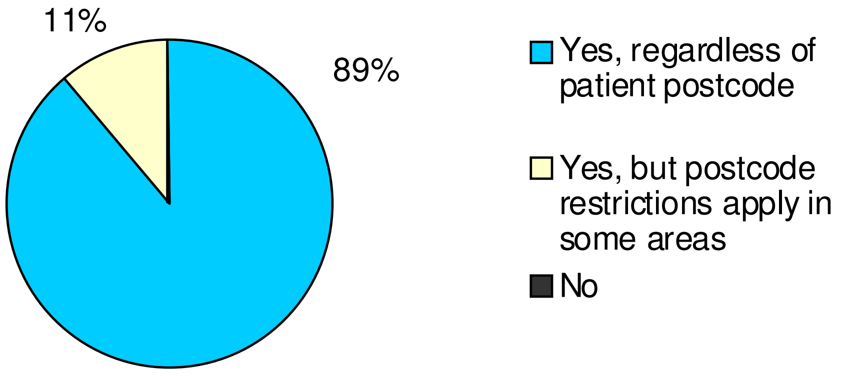

Figure 9. Can patients be referred and funded for neurosurgery based on clinical need?

Standard 9

100% of Parkinson’s patients are reviewed at 6–12 monthly intervals.

Parkinson’s NICE Guideline recommendations R12; R77 (Table 3.1 Key NICE Audit priority) NSF LTC QR 2.5.

Most trusts (89%) keep their patients under 6-12 monthly specialist review regardless of the patient’s postcode and only a small proportion (11%) of trusts reported postcode variations in their ability to meet the standard. Elderly care and neurology services performed similarly.

Only half of the audited services can provide specialist review (includes Parkinson’s nurse) at home for all patients unable to attend clinic. The main limiting factor is where the patient lives (Table 11). This may partly reflect postcode variations in Parkinson’s nurse provision.

Table 11. Can Parkinson's patients access specialist review at home if unable to attend clinic?

	Neurology		Elderly care	
	n	%	n	%
Yes, regardless of local patient postcode	14	50	20	54
Yes, but depends on patient post code	13	46	13	35
No	1	4	4	11
Total	**28**	**100**	**37**	**100**

Standard 10

New referrals in later disease with complex problems can access review within two weeks.

Parkinson’s NICE Guideline recommendation (Table 3.1 Key NICE Audit priority) NSF LTN QR 2.1; 2.4.

In urgent and complex situations most services (79% of neurology and 84% of elderly care services) were able to give advice/or review their Parkinson’s patients within two weeks. In 11% of neurology and 16% of elderly care services this depended on where the patient lived (Figure 10). Three neurology services were unable to meet the standard.

Elderly care services were more able to offer urgent outpatient or home visit support compared to neurology consultants (91% and 84% respectively), and 16% of neurology services could only advise by telephone.

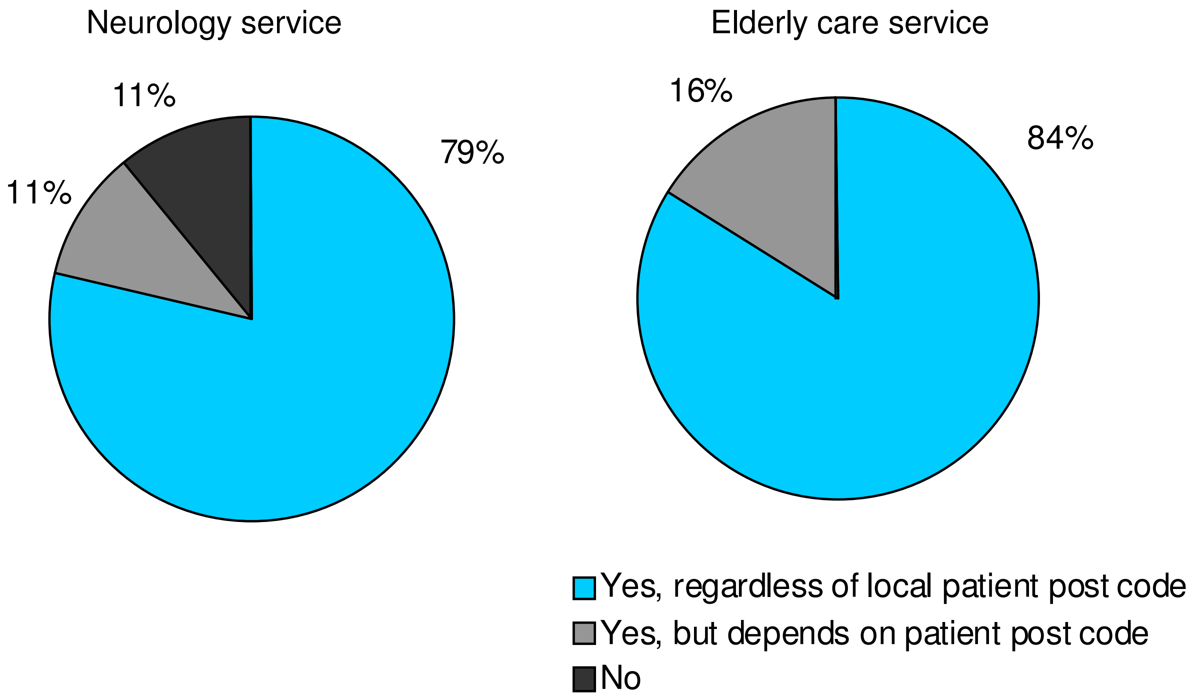

Figure 10. Can Parkinson's patients access urgent specialist review within 2 weeks?

Methodology

Data source and data collection

All healthcare organisations providing elderly care or neurology services as well as movement disorders clinics in the UK were encouraged to participate. The audit tool was promoted in a variety of websites including Parkinson's UK, the BGS Movement Disorders Section and Healthcare Quality Improvement Partnership (HQIP). A printed flyer advertised the Audit at a variety of Parkinson's related educational meetings, professionals' meetings and conferences.

Organisations were asked to complete the Audit in consultation with local therapy leads, Parkinson's nurses and medical colleagues across neurology and elderly care. The audit leads for neurology and elderly care were responsible for the audit data but it was anticipated that Parkinson's nurses or junior doctors would assist with the data collection. An excel spreadsheet was created to capture patients' and services' data, and was sent to participants via e-mail.

Patient Audit

The Audit ran for a five-month period from 1 July to 30 November 2010. During this period participants were asked to document consecutive patients newly referred with suspected Parkinson's. Data was prospectively entered directly onto the audit spreadsheet at the end of a clinic visit, or patient details collected and entered at a later date by examining patients' clinical notes.

Service Audit

The trust or other equivalent organisation was the unit of involvement. Separate sheets had to be completed for neurology and elderly care services. Information was entered directly onto the audit spreadsheet.

Data security

All participants were required to remove all information relating to named patients from the spreadsheet prior to submission. Data in password-protected sheets were sent to pdaudit@parkinsons.org.uk and saved in encrypted password-protected files in accordance with NHS requirements. Access to the raw data set is restricted to Gerda Drutyte, Research Associate and Dr Kieran Breen, Director of Research and Development at Parkinson’s UK.

Data analysis

Gerda Drutyte, Research Associate, was responsible for processing and analysing submitted data. Data was analysed using Excel 2005 and PASW 18 programs. Pearson and Likelihood Ratio Chi-Square tests were used to test the difference between groups. A p-value of less than 0.05 was considered as statistically significant.

Audit steering group

Name	Organisation	Role	Involvement in the Audit
Dr Kieran Breen	Parkinson’s UK	Research Director	Report writing and presentation
Gerda Drutyte	Parkinson’s UK	Research Associate	Proforma design, data processing and analysis, report writing
Dr Dorothy Robertson	British Geriatric Society, Movement Disorders Section	Elderly Care Consultant	Advisory, proforma design, report writing
Fiona Lindop	Derby Hospitals NHS Foundation Trust (Derby Parkinson's Service)	Clinical Specialist Physiotherapist	Advisory, report writing
Amy Edwards	College of Occupational Therapy	Professional Affairs Officer	Advisory, report writing
Prof Nick Miller	Royal College of Speech and Language Therapists	Speech and Language Therapist	Advisory, report writing
Dr Nin Bajaj	Association of British Neurologists, Movement Disorders Section BritModis	Neurology Consultant	Advisory
Daiga Heisters	Parkinson's UK	National Education Advisor	Advisory and presentation

Dr Anna Jones	Northumbria University	Advisor to physiotherapy team	Advisory
Bhanu Ramaswamy	Independent Physiotherapy Consultant		Advisory
Lisa Brown	Derby Hospitals NHS Foundation Trust (Derby Parkinson's Service)	Parkinson's Nurse	Advisory

We would also like to thank Donald Grosset and Yoav Ben-Schlomo for their contribution when writing the report.