

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

Parkinson's Audit 2009 report

Summary

- There are service inequalities in different geographical areas.
- One third of patients waited to be seen for more than six weeks following referral with suspected Parkinson's, with an average delay of 2.5 weeks.
- 13.5% of suspected Parkinson's patients received drug treatment from a general practitioner (GP) or non Parkinson's consultant before being referred for differential diagnosis.
- One in every five patients had no documented assessment of activities of daily living (ADL) to trigger referral.
- More than a half of participating centres were not using an ADL assessment proforma. Only 15% of Parkinson's patients had a formal assessment of their activities of daily living assessed using a specific proforma.
- Only 56% of Parkinson's patients had a documented assessment of speech and communication and only two out of every five (43%) had a mention of swallow function. Just over one third (38%) of audited specialists have access to the Lee Silverman voice treatment.
- 43% of new Parkinson's patients had a documented need for physiotherapy; however, only 35% were referred.
- Very few patients without a specific therapy indication were referred for proactive education purposes.
One in five patients was not offered Parkinson's nurse contact details despite the service being available.
- DVLA/car insurance was only discussed in 37% of drivers.
- Only just over a half of the audited patients was offered written information regarding Parkinson's.
- Medications indicated for complex patients (Duodopa, Rotigotine, Apomorphine, Zelapar, Rasagiline, Tolcapone) were restricted or not accessible in some centres.
- One third of the services (35%) have no or restricted access to neurosurgery for Parkinson's.

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Project title

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

Type of organisation

Medical Division NHS acute Trusts/Primary Care Trust Community Services.

Specialty/service/operational area

Elderly care and neurology outpatient services/Parkinson's nurses/Therapy services/Pharmacy formulary/access to neurosurgery and diagnostic imaging.

Disciplines involved

Medics, Parkinson's nurses, physiotherapists, occupational therapists, speech and language therapists.

Project lead

Steve Ford - Chief Executive, Parkinson's UK.

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 Data Analyst	Proforma design, data cleaning and analysis, report writing
Daiga Heisters	Parkinson's UK	National Education Advisor	Advisory and presentation
Dr Dorothy Robertson	British Geriatric Society Movement Disorders Section	Elderly Care Consultant	Advisory, proforma design, report writing
Dr Peter Fletcher	British Geriatric Society Movement Disorders Section	Chair	Advisory
Dr David Bourne	British Geriatric Society Movement Disorders Section	Elderly Care Consultant	Advisory
Dr Nin Bajaj	Association of British Neurologists, Movement Disorder Section BritModis	Neurology Consultant	Advisory
Bhanu Ramaswamy	Sheffield Hallam University	Honorary Visiting Physiotherapy Fellow	Advisory

Fiona Lindop	Clinical Specialist working with Nin Bajaj's team in Derby	Physiotherapist	Advisory
Amy Edwards	College of Occupational Therapy	Professional Affairs Officer	Advisory
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Patti Simonson	Parkinson's Disease Nurse Specialists Association	Social Worker	Advisory
Paul Hughes	Cornwall and Isles of Scilly PCT	Pharmacist	Advisory

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 swallow, memory and mood, sleep, pain and continence, which compound the movement 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 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. Early versions of the current Audit were piloted in 2007 and 2008 by

34 clinicians participating in Parkinson's Academy, a training initiative within the Movement Disorders Section of the British Geriatric Society.

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 centres.
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.
4. To pilot the methodology and infrastructure for conducting National Parkinson's Audit.

Objectives

Service Audit:

1. To establish, by commissioning area, if local Parkinson's services allow access to NICE and NSF LTNC recommended services and treatments including:
 - Specialist medical assessment
 - Specialist nurse support
 - Therapy services (physiotherapy, occupational therapy, speech and language therapy)
 - NICE approved medication
 - DaTSCAN imaging
 - Neurosurgery.
2. To explore the likely quality of Parkinson's therapy services by collecting information on access to specialist versus generic therapy and if delivered via an integrated multidisciplinary team.

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 NSF Long Term Neurological Conditions guidelines. The Audit relates to the patient's first clinic visit.

Standards base

The Audit focuses primarily on audit criteria that link to the NICE key priorities for implementation but also reflects the quality standards outlined in the NSF for Long Term Neurological Conditions.

Audit type

Criterion audit.

Sample

The audit tool was launched on 1 June 2009. Participants submitted data to Parkinson's UK by 31 November 2009. All patients referred to a specialist with suspected Parkinson's were eligible to be audited. 41 centres completed the Patient Audit and provided data on 1,256 patients from 60 commissioning areas (PCT or equivalent) from England (covering all SHAs), Northern Ireland, Scotland, Wales and Guernsey. An additional four centres completed the Service Audit only.

Methodology

The Parkinson's Academy, a training initiative within the Movement Disorders Section of the British Geriatric Society (BGS) has piloted early versions of the audit tool in their Masterclasses 10 and 12, which allowed the refinement of the tool format to achieve maximum clarity. The excel spreadsheet was created for data collection. The Parkinson's Audit was launched in its present format in 2008 and involved 18 centres.

Data source and data collection

All centres providing elderly care or neurology services as well as movement disorders clinics in UK were encouraged to participate. The audit tool was promoted in a variety of websites including Parkinson's UK, the BGS Movement Disorder Section and Parkinson's Disease Nurse Specialist Association. A printed flyer advertised the Audit at a variety of Parkinson's related educational meetings, professionals' meetings and conferences.

Centres 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 nurse specialists or junior doctors would assist with the data collection.

Service Audit

The providing centre was the unit of involvement but Service Audit data was captured separately for each PCT (or equivalent for Scotland, Wales, Northern Ireland) routinely covered by a Parkinson's service. Sub-PCT areas were captured if the service provision varied within an individual PCT area. Separate data columns were requested for neurology and elderly care Parkinson's services. Service information was entered directly onto the Audit spreadsheet.

All participants were required to remove all information relating to named patients from the spreadsheet prior to submission. Data was 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 Data Analyst and Dr Kieran Breen, Director of Research and Development at Parkinson's UK.

Patient Audit

The Audit ran for the five-month period 1 July 2009 to 30 November 2009. During this period participants were asked to document consecutive patients referred with suspected Parkinson's and to enter data about their first visit onto the electronic audit tool. Data was entered prospectively directly onto the Audit spreadsheet at the end of a clinic visit, or patient details collected and entered at a later date by examining patient's clinical notes.

Data analysis

Gerda Drutyte, Research Data Analyst, 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.

Caveat

Although centres were requested to capture data from both the local neurology and elderly care medicine Parkinson's services, this occurred for only 16 (35%) of the 45 centres who participated. 26 (58%) centres captured only elderly care and three (7%) only neurology services. As a consequence, a greater number of geriatricians than neurologists participated in the Audit.

The guidance notes did not specify a minimum sample size for the Patient Audit, which caused big variance between samples. The median sample size was 24, ranging from 6 to 100 patients. This should be taken into account when interpreting a centre's performance or comparing it with other centres.

There were some variations between centres regarding methodology of data collection (prospectively or retrospectively) and the time frame when data was collected, which ranged from one month to one year.

All suspected Parkinson's patients referred to the clinic were analysed to characterise the referral (who referred them, how long it took to see the specialists, whether they were treated before the referral and what drugs). Other service related questions in Patient Audit were analysed only for patients with initial working diagnosis of Parkinson's.

In cases where the relevant information had not been documented on the proforma, this was taken to be non-compliance to the standard for analysis of the data.

The findings may be skewed towards better developed services as clinicians were self-motivated to take part.

Findings - Service Audit

The Service Audit examines patient access to NICE recommended services and treatments. Centres were asked to provide information on neurology and elderly care services for each commissioning areas routinely covered by the providing centre. Data was available for 113 services in 80 commissioning areas within 60 PCT's (or equivalent for Northern Ireland, Scotland, Wales and Guernsey). In 33 of the commissioning areas (41%), data was available for both neurology and elderly care services, in 36 areas, (45%) for only elderly care and in 11 areas (14%) for only neurology. Overall, around two thirds of this Service Audit information relates to elderly care services (61%) and one third to neurology (39%).

Standard 1

Patients are able to access a neurologist and/or elderly care consultant(s) 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 Disorder 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 with other professionals regarding service development.

Seventy six percent (76%) of services described themselves as Parkinson's specialist, while the rest were provided by either general neurology or elderly care services.

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

One in 10 services had no access to a Parkinson's nurse (Table 1). Neurology services had slightly better Parkinson's nurse provision, but the nurses were more likely to be purely clinic based. Specialist compared with general Parkinson's services had similar access to a Parkinson's nurse (90% and 88% respectively), but nurses working with Parkinson's specialist medical services were less likely to be limited to only seeing patients in the clinic setting (6% compared with 12%).

Table 1: Access to Parkinson's nurse among elderly care and neurology consultants

Access to Parkinson's nurse	Total		Elderly care		Neurology	
	n	%	n	%	n	%
Clinic and home visits	92	81.4	58	84.1	34	77.3
Only clinic	8	7.1	2	2.9	6	13.6
No service	12	10.6	8	11.6	4	9.1
Missing	1	0.9	1	1.4	0	0
Total	113	100.0	69	100.0	44	100.0

Standards 3, 4 and 5 relate to patient access to therapy services (physiotherapy, occupational therapy and speech and language therapy). Centres were asked to describe all local therapy referral options and indicate if generic or specialist as a surrogate marker of quality. A specialist therapist was defined as: "works closely with other members of the Parkinson's service, is able to access regular, at least yearly Parkinson's specific training, and Parkinson's comprises a significant part of his/her workload". The Service Audit findings reveal variable access to therapy services in general and limited provision of Parkinson's specialist therapy. This did not differ between neurology and elderly care services.

Standard 3

Physiotherapy 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

Less than 50% of services could access a specialist Parkinson's physiotherapist and only 20% could access Parkinson's specialist physiotherapy as part of an integrated Parkinson's medical and therapy clinic. Approximately 65% of services had access to a generic outpatient physiotherapist while 60% could refer patients to a generic rehabilitation team. A few services (2.9% elderly care and 4.7% neurology) could only refer to physiotherapy via the GP.

Standard 4

Occupational therapy (OT) is available at diagnosis and at each regular review and appropriate referral is activated for people with Parkinson's.

Parkinson's Nice Guideline Recommendation R80 (Table 3.1 Key NICE Audit Priority) NSF LTN QR4.1; 4.2; 5.1; 5.2; 5.3

Less than 20% of Services could refer to a Parkinson's specialist OT, working separately or as part of an integrated Parkinson's medical and therapy clinic. It was possible for 50% of services to refer patients to social services and/or generic outpatient occupational therapy. A similar number had access to a generic rehabilitation team. A few services (2.9% elderly care and 2.3% neurology) could only refer to OT via the GP.

Standard 5

Speech and language therapy (SLT) is available at diagnosis and at each regular review and appropriate referral is 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

Less than 5% of services had access to speech and language therapy as part of an integrated medical and therapy Parkinson's clinic and only 40% could access Parkinson's "specialist" SLT, or SLT as part of a generic rehabilitation team. Speech and language therapists commonly work in isolation in OPD setting (available to 80% of services). 61% of elderly care and 53% of neurology services had no access to Lee Silverman voice treatment. There was no significant difference in access to Lee Silverman voice treatment between general and Parkinson's specialist services.

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

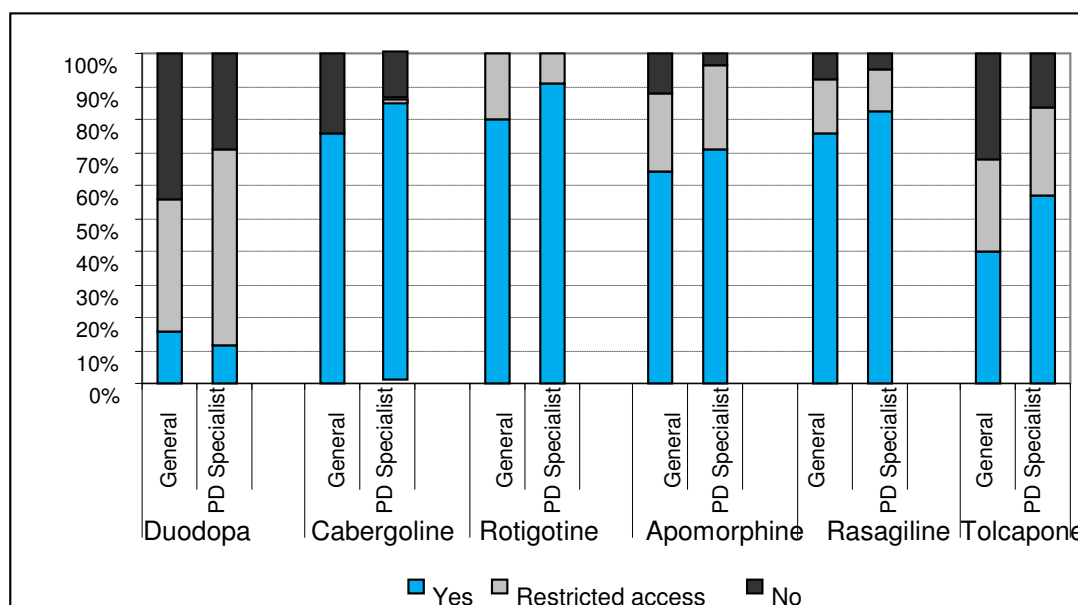
Table 2 describes Parkinson's service access to second line Parkinson's medications. Restricted access was recorded for Tolcapone, Apomorphine, Rotigotine and Rasagiline. Duodopa, Zelapar, Tolcapone and Cabergoline were not accessible in some centres at all (Table 2).

The difference in access to pharmacological treatment between elderly care and neurology services is minimal for most drugs although Duodopa seems to be more accessible to neurology services while Zelapar is slightly more accessible to elderly care services. Some of the drugs tend to be more accessible to Parkinson's specialists, but the difference is statistically not significant (Figure 1).

Table 2: Access to pharmacological treatment for Parkinson's

Drug	Yes		No		Restricted access	
	n	%	n	%	n	%
Parkinson's motor symptoms treatment						
Duodopa	18	15.4	37	31.6	62	53.0
Ropinirole (standard)	115	98.2	1	0.9	1	0.9
Ropinirole PR	111	94.9	2	1.7	4	3.4
Pramipexole	115	98.2	1	0.9	1	0.9
Cabergoline	97	82.9	19	16.2	1	0.9
Rotigotine	101	87.1	2	1.7	13	11.2
Apomorphine	80	69.6	7	6.1	28	24.3
MOAB						
Selegiline	115	99.1	1	0.9	0	0.0
Zelapar	78	67.3	31	26.7	7	6.0
Rasagiline	94	81.0	6	5.2	16	13.8
COMT inhibitors						
Entacapone	114	98.2	1	0.9	1	0.9
Stalevo	114	98.3	0	0.0	2	1.7
Tolcapone	62	53.9	23	20.0	30	26.1
Amantadine	111	99.1	0	0.0	1	0.9

Figure 1: Different access to drugs, which do not have open prescription access, for Parkinson's between general and Parkinson's specialist services



Oral Dopamine agonists

More than 98% of services were able to prescribe Ropinirole and Pramipexole standard release. Access to Ropinirole Prolonged Release was slightly less but 95% of services could still prescribe it (Pramipexole Prolonged Release was not available at the time of the Audit).

No access or restricted access was slightly more common for Rotigotine and Cabergoline although with a different pattern. Services with restricted access to Rotigotine were generally being allowed to use it in the context of patients with an unsafe swallow.

Subcutaneous Dopamine agonists

6% of services have no access to Apomorphine therapy for complex patients with “on/off” fluctuations with 24% of services reporting restricted access, often due to this treatment being limited to secondary care prescribing only.

MAOB inhibitors

Standard Selegiline is generally available. Rasagiline is more likely to be the second line alternative to Selegiline with only 5% of services unable to prescribe compared with 27% of services for Zelapar.

COMT inhibitors

Both Entacapone and Stalevo are generally available. Tolcapone requires intensive monitoring and has appropriate restrictions on prescribing to secondary care but 20% of services are unable to prescribe this medication.

Amantadine

This medication is generally available.

Duodopa

Duodopa is the least available drug primarily due to its high cost and because it is the newest drug on the market. 32% of services are unable to prescribe Duodopa, even for people with very advanced disabilities. 53% have restricted access with funding dependant on submission of a business case to PCT exceptions committee.

Acetylcholinesterase inhibitors

Only 73% of services are able to prescribe acetylcholinesterase inhibitors for patients with Parkinson’s dementia. Access is similar for neurology and elderly care. In 22% of elderly care services and 27% of neurology services access requires referral to Mental Health.

Atypical neuroleptics

Access to atypical neuroleptics for Parkinson’s psychosis was similar for neurology and elderly care. Quetiapine is generally available (97%) but only two thirds of services can prescribe clozapine, either directly (around 20%) or via Mental Health.

Modafanil

68% of elderly care and 75% of neurology services are able to prescribe Modafanil for hypersomnolence in Parkinson’s.

Standard 7

Patients can be referred by a Movement Disorder Specialist for a DaTSCAN.

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

Two out of ten services (21%) have no access to DaTSCANS. Elderly care services have less access than neurology (75% and 84% respectively). Parkinson's specialists are slightly more able to refer for a DaTSCAN (79% versus 76% respectively).

The situation differs between centres and while some are able to perform DaTSCANS locally, others need to refer their patients to another region. Some centres report an artificial limit to the number of DaTSCANS which will be funded each year. A few centres reported that funding for DaTSCAN has been withdrawn.

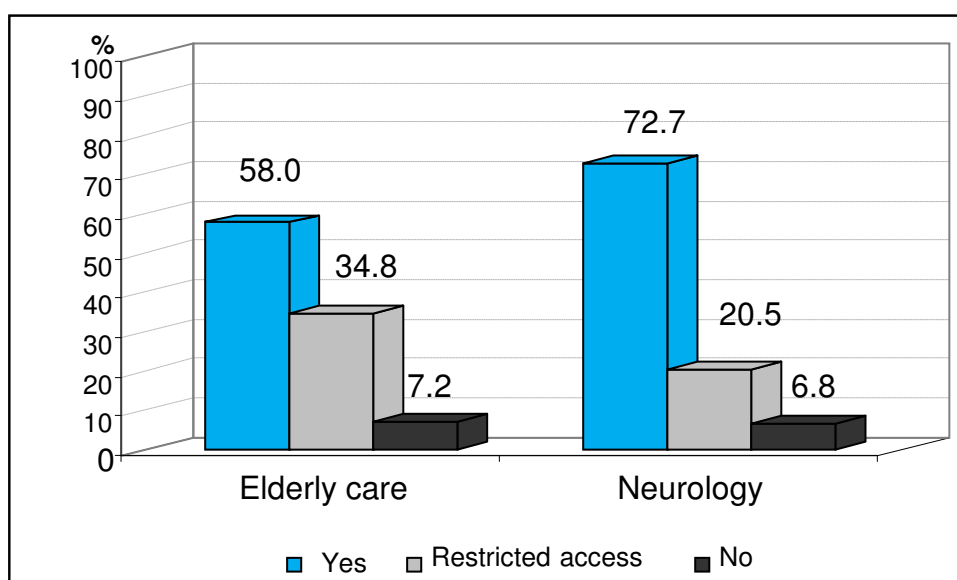
Standard 8

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

Only two thirds of services (65%) are able to refer for neurosurgery with neurologists having greater access than geriatricians (Figure 2).

Figure 2: Access to neurosurgery for Parkinson's



Considerable regional variation was reported. For example, patients from Wales need All Wales Medicine Strategy Group approval individually before being referred to Bristol, which may take 3-6 months. On the other hand specialists from bigger cities generally have good access to neurosurgery.

35% of elderly care and 20% of neurology services describe restricted access with individual funding agreement required from the PCT. Patients from 7% of services (neurology and elderly care) have no access to neurosurgery.

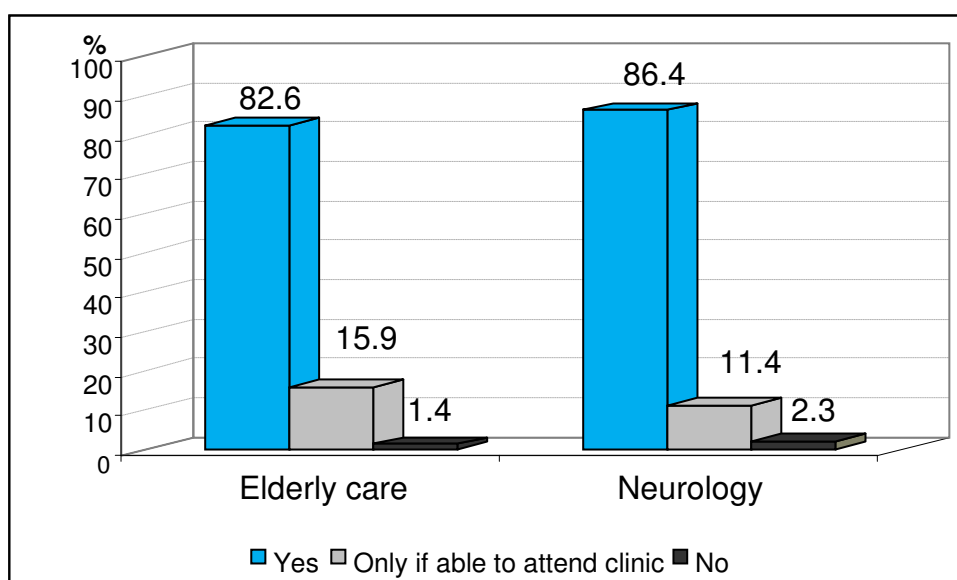
Standard 9

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

84% of services keep patients under 6 – 12 monthly specialist review, but 14% of services could only maintain review for patients able to attend the clinic. Elderly care and neurology services performed similarly (Figure 3).

Figure 3: Ongoing review every 6-12 months among elderly care and neurology services



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 centres (99%) were able to advise their patients within two weeks. However, 25% of neurology services could only advise by telephone, compared with 12% of elderly care services who were more able to offer urgent outpatient or home visit support.

Findings - Patient Audit

83% of audited patients were referred from their general practitioner, 13% from another consultant and 4% from a variety of other sources (day hospital's staff, information and support workers from Parkinson's UK, community falls team, speech and language therapist, nursing home staff, medical consultant or an orthopedic consultant).

Standard 1

Patients with suspected Parkinson's should be seen by a Movement Disorder Specialist within 6 weeks.

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

Two thirds (63%) of patients with suspected Parkinson's 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 17.5 days (range 1 to 133 days). Only 2% of delays were patient related.

Six out of 41 centres achieved 100% compliance with the 6 week target. However, in 8 centres one third of the patients or less were seen within this time frame. The median delay (over the targeted 6 weeks period) between centres varied from 2 to 44 days (4 days median shortest wait, 42 days median longest wait).

Geriatricians were more likely to see referred patients within the recommended 6 weeks compared to neurologists (Table 3, $p < 0.005$) with no significance difference comparing patients seen by a "general" geriatrician or neurologist and those seen by a Parkinson's specialist consultant (65% and 62% respectively seen within 6 weeks, $p > 0.05$).

Table 3: Patients seen by elderly care and neurology consultants for differential diagnosis

Seen within six weeks	Elderly care		Neurology	
	n	%	n	%
No	277	31.6	152	41.5
No, patients reason for delay	22	2.5	2	0.5
Yes	578	65.9	213	58.0
Total	877	100	367	100

The median delay waiting to see a neurologist was 21 days, five days longer than the median delay to see a geriatrician ($p < 0.05$).

Standard 2

Patients with suspected Parkinson's should be referred untreated.

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

86.5% of patients were referred untreated. All patients were referred untreated in 10 out of 41 geographical centres. Of the 13.5% of patients who were treated, 11% had been started on Levodopa (Table 4). Treated patients had on average longer delay for referral compared to those referred untreated (mean of 31 days compared to 23 days, $p < 0.05$), which means that patients could have started treatment because of the delay in referral. Only three fourths (77%) of the treated patients were initially diagnosed with Parkinson's.

Table 4: Drugs that were used to treat patients before referring them to a specialist

Drug	n	%
Levodopa/DDI	140	11.1
Dopamine agonist	18	1.4
MAOB inhibitor	5	0.4
Other	6	0.5
Total	169	13.5

Nearly two thirds of patients had their suspected Parkinson’s diagnosis confirmed at the clinic visit but 37.8% received an alternative diagnosis, the most common being vascular parkinsonism and drug induced parkinsonism (Table 5).

Table 5: Initial working diagnosis following specialist’s assessment

Working diagnosis	n	%
Idiopathic Parkinson’s	781	62.2
Vascular parkinsonism	98	7.8
Progressive supranuclear palsy	15	1.2
Multiple system atrophy	15	1.2
Dementia with Lewy bodies	24	1.9
Drug induced parkinsonism	68	5.4
Other diagnosis	254	20.2
Missing	1	0.1
Total	1256	62.2

Other diagnosis included essential tremor, chronic alcohol abuse, multiple sclerosis, reduced mobility after hip fracture, anxiety and depression.

Standard 3

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

NSF LTN QR1.1; 5.1

One in every five patients (22%) had no documented assessment of the impact of their suspected Parkinson’s on performance of activities of daily living (ADL). A further 15% were assessed using a structured proforma to reliably capture ADL problems. The remaining 63% of patients had some evidence of informal documentation relating to activities of daily living. As the current audit tool did not specify a “minimum standard” of specific ADL tool, the quality of these “informal” ADL assessments by mainly medical staff is questionable.

24 participating centres never used a specific proforma, and it was used to assess the majority (over 80%) of the patients in only three centres.

Geriatricians were more likely to document assessment of activities of daily living than neurologists and were also more likely to use a specific proforma (Figure 4, $p < 0.005$). Parkinson’s specialists made greater use of a formal ADL proforma than non Parkinson’s specialists ($p < 0.05$), who were also less likely to document any problems relating to ADL function (Table 6).

Figure 4: Assessment of daily living between elderly care and neurology consultants

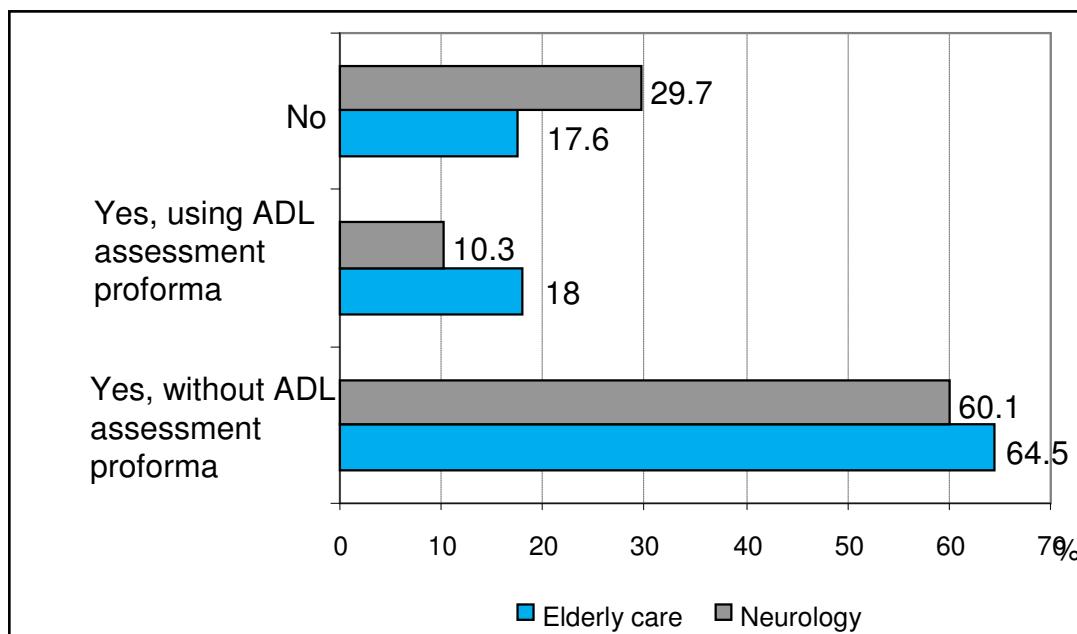


Table 6: Assessment of daily living between general and Parkinson's specialists

Is there an assessment of daily living?	General		Parkinson's specialist	
	n	%	n	%
No	92	81.4	58	84.1
Yes, using ADL assessment proforma	8	7.1	2	2.9
Yes, without ADL assessment proforma	12	10.6	8	11.6
Total	1	0.9	1	1.4

ADL – Activities of daily living

Documentation was also poor in relation to issues with speech, communication and swallow, with only 56% of patient notes recording speech and 43% commenting on swallow.

Five geographical centres documented speech in all patients, while three centres made no comments on any (Figure 5). Similar variation was found for documentation of swallow function. Five centres (three of them the same) documented an enquiry about swallow in all of their patients, whilst the same three had no documentation of swallow function in any patient. The remainders varied in their performance.

Parkinson's specialists were more likely to comment on speech and communication compared with non specialists (54.5% compared to 28%, $p < 0.005$) and neurologists performed better than geriatricians (65% versus 52%, $p < 0.005$). Parkinson's specialists were twice more likely to document swallow function compared with general neurologists and non Parkinson's specialist geriatricians (44% and 22% respectively, $p < 0.005$) with no difference between geriatricians and neurologists overall (44% versus 42%, $p > 0.05$).

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

Physiotherapy referrals

The referral decision met the standard in 79.9% of patients (Table 7). An additional 2% of patients had no immediate physiotherapy need but were referred for proactive education. However, 17.3% of patient notes failed the standard, either because a physiotherapy need was documented but no referral offered (8.2%) or because of inadequate documentation of function (9.1%).

Occupational therapy

The referral decision met the standard in 76.4% of patients (Table 7). An additional 1.7% of patients had no immediate OT need but were referred for proactive education. However, 21.9% of patient notes failed the standard, either because an OT need was documented but no referral was offered (7.6%) or because of inadequate documentation of function (14.3%).

Speech and language therapy

The referral decision met the standard in 74.1% of patients (Table 7). An additional 1.2% of patients had no immediate SLT need but were referred for proactive education. However, 25.4% of patient notes failed the standard, either because an SLT need was documented but no referral offered (6.7%) or because of inadequate documentation of function (18.2%).

Table 7: The need for therapies identified and referral activated

Need identified and referral activated	Physiotherapy		Occupational therapy		Speech and language therapy	
	n	%	n	%	n	%
Yes, referred	273	35.0	161	20.6	91	11.7
Yes, not referred	64	8.2	59	7.6	52	6.7
No, not referred	331	42.4	413	52.9	471	60.3
No, but referred for education	16	2.0	13	1.7	9	1.2
No assessment of need documented	71	9.1	112	14.3	142	18.2
Participating in therapy research trial	1	0.1	1	0.1	2	0.3
Declined by the patient	22	2.8	22	2.8	14	1.8
Missing	3	0.4	0	0	0	0
Total	781	100	781	100	781	100

Although 42% of patients were designated as not having a physiotherapy need, and 52.9% and 60.3% as not having OT or SLT need respectively, these findings should be interpreted with caution in view of the low usage of any formal assessment tools to

highlight problems with ADL or speech. The use of an ADL proforma was associated with higher referral rates compared with no or informal needs assessment (58% versus 36% referral for physiotherapy, 49% versus 20% for OT, $p < 0.005$). Similarly, patients with a documented assessment of speech and communication were more likely to be referred for speech and language therapy (18% compared with 2% with no written assessment, $p < 0.005$).

Geriatricians were almost twice as likely to refer patients to physiotherapy, either for a specific problem or for education compared with neurologists (44% compared to 24%, $p < 0.005$). Geriatricians were also more likely to refer patients for occupational therapy (27% and 14% respectively, $p < 0.005$). Neurologists are possibly more likely to refer for speech and language therapy but the difference was small and statistically not significant (14% compared to 12.2%, $p > 0.05$). This may reflect the age at which the patient was referred to the specialist.

Parkinson's specialists identified need and referred more patients for all forms of therapy compared with general neurologists and non Parkinson's specialist geriatricians (Physiotherapy: 35% compared to 18%, $p < 0.05$; OT: 22% compared with 7%, $p < 0.005$ and SLT: 12% and 9%, $p < 0.05$).

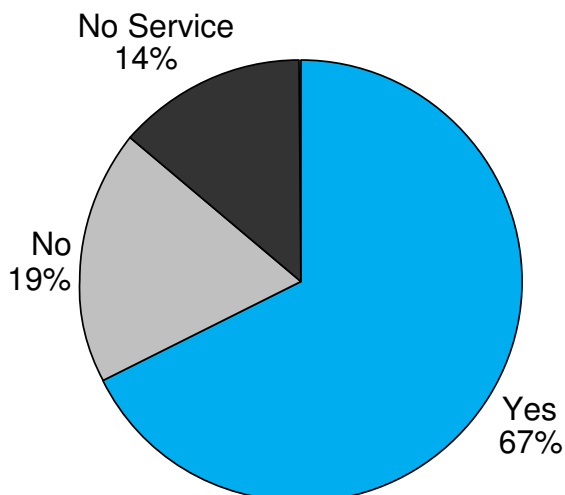
Standard 7

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

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

Two thirds of patients were offered Parkinson's nurse specialist contact details. In 19% there was no documentation that this information had been given, even though the service was available locally (Figure 6).

Figure 6: Parkinson's nurse contact offered



Three participating centres had no access to a Parkinson's nurse, and five others, despite access were not providing contact details for more than a half or most of their patients (Figure 7).

Figure 5: Assessment of speech and communication between centres

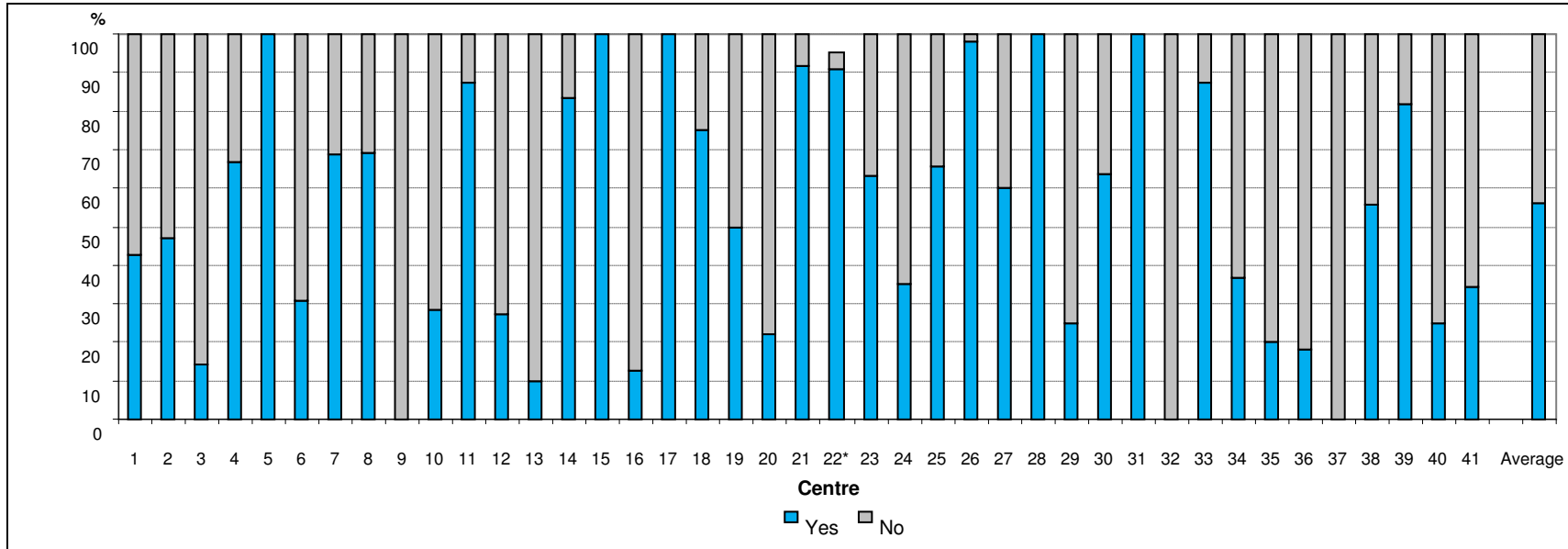
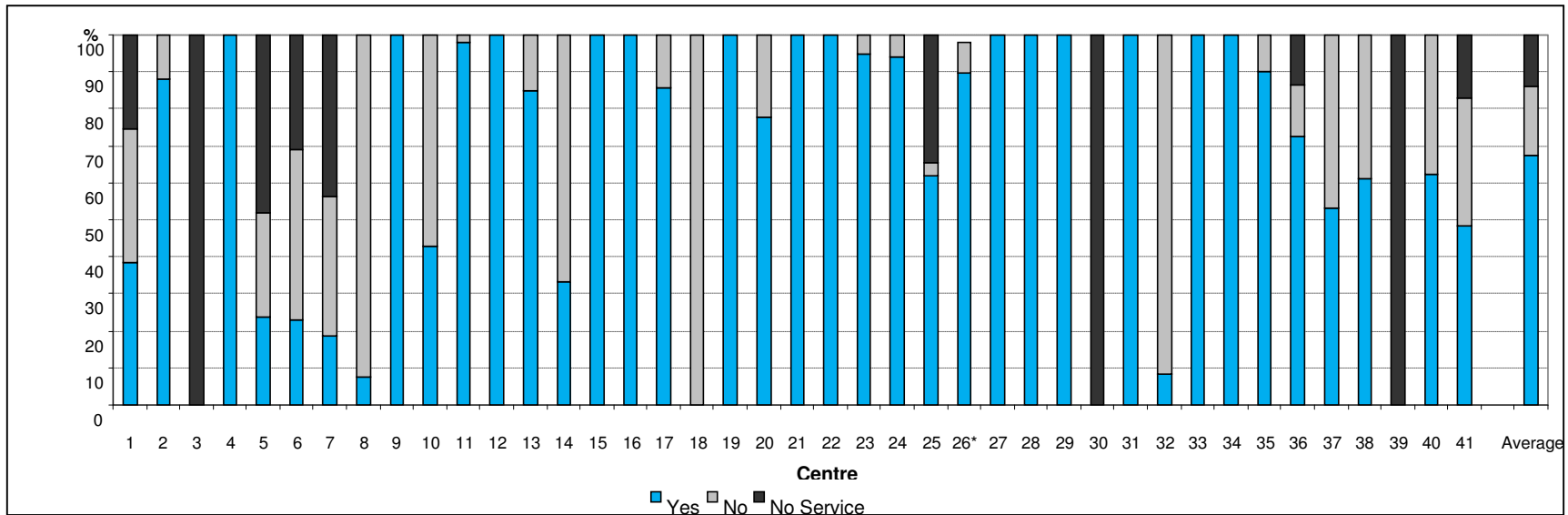


Figure 7: Parkinson's nurse contact details offered between centres



* - Some data is missing

Geriatricians and neurologists were equally likely to provide this information (68% compared with 66%). Parkinson’s specialists were less likely to document provision of Parkinson’s nurse specialist contact information compared with non specialists (74% compared to 62%, $p>0.05$).

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 three out of five Parkinson’s patients (64%), and one third had DVLA/car insurance discussed (Table 8).

Table 8: DVLA/car insurance discussed with the person with Parkinson’s

DVLA/car insurance discussed	n	%
Yes	277	35.5
No	255	32.7
Not applicable (non driver)	192	24.6
No, diagnosis tentative and no safety concerns	53	6.8
Missing	4	0.5
Total	781	100

Neurologists were overall better at documenting driving status for their Parkinson’s patients more often than geriatricians (69% compared to 61%, $p<0.05$). The same pattern was seen with DVLA/car insurance - neurologists discussed it with their patients more often (45% and 31% respectively, $p<0.005$), concerning that the proportion of non drivers was very similar in both groups.

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

Just over a half of the audited patients (57%) was offered written information regarding Parkinson’s. The performance in various centres varied greatly: eight centres offered some information to all of their patients; five centres did not provide any written information and others varied in this percentage. There was no difference in providing written information about Parkinson’s between general and Parkinson’s specialists, nor between neurologists and geriatricians.

Conclusions

Areas of good practice:

- 42 out of 45 participating centres can refer to a Parkinson’s nurse.

- Nine in every ten services that describe themselves as “Parkinson’s specialist” have access to a Parkinson’s nurse.
- The majority (84%) of audited centres see their patients every 6-12 months for diagnosis review.
- In an urgent or complex situation, most services (99%) feel they are able to provide advice for their patients within two weeks, either by telephone or face to face.
- Most clinicians can prescribe Levodopa, Ropinirole, Pramipexole, Selegiline, Entacapone, Stalevo and Amantadine without restriction, according to individual patient need.
- The difference in access to pharmacological treatment between geriatricians and neurologists is minor.
- Almost eight in every ten clinicians (79%) have access to DaTSCAN.
- The pattern of service provided for people with Parkinson’s is in most cases similar for elderly care and neurology.

Areas for improvement:

- There are service inequalities in different geographical areas.

Diagnosis

- One third of patients waited to be seen for more than six weeks following referral with suspected Parkinson’s, with an average delay of 2.5 weeks.
- 13.5% of suspected Parkinson’s patients received drug treatment from a GP or non Parkinson’s consultant before being referred for differential diagnosis.

Therapy services

- One in every five patients had no documented assessment of ADL function to trigger referral.
- More than a half of participating centres were not using an ADL assessment proforma. Only 15% of Parkinson’s patients had a formal assessment of their activities of daily living assessed using a proforma.
- Only 56% of Parkinson’s patients had a documented assessment of speech and communication and only two out of every five (43%) had a mention of swallow function. Just over one third (38%) of audited specialists have access to the Lee Silverman voice treatment.
- 43% of new Parkinson’s patients had a documented need for physiotherapy; however, only 35% were referred.
- Very few patients without a specific therapy indication were referred for proactive education purposes.

Parkinson’s nurse specialist referral:

- One in every five patients was not offered Parkinson’s nurse contact details despite the service being available.

Information needs:

- DVLA/car insurance was only discussed in 37% of drivers.

- Only just over a half of the audited patients was offered written information regarding Parkinson's.

Treatment options:

- Medications indicated for complex patients (Duodopa, Rotigotine, Apomorphine, Zelapar, Rasagiline, Tolcapone) were restricted or not accessible in some centres.
- One third of the services (35%) have no, restricted access to neurosurgery for Parkinson's.

Recommendations

1. All Patients with suspected Parkinson's should be seen by a specialist within six weeks. Centres not achieving this standard should explore how this target can be achieved locally
2. An integrated Parkinson's pathway should be available which clarifies referral pathways
3. All people with Parkinson's should have access to a Parkinson's nurse who can visit at home when needed. All patients should be offered contact details for a Parkinson's nurse.
4. All patients should be seen by a member of the specialist Parkinson's service at least every 6-12 months, even if they can't attend the clinic.
5. Every services should have access to DaTSCAN.
6. All Parkinson's patients should have their activities of daily living, swallow, speech and communication assessed during every visit. The assessment should be documented in a specific proforma, which should be short, easy to use and effective in tracking changes in person's condition.
7. All the patients with physiotherapy, occupational or speech and language therapy needs should be referred.
8. DVLA/ car insurance should be discussed with all drivers upon diagnosis with Parkinson's.
9. Written information should be offered to every newly diagnosed patient. A range of resources are available via Parkinson's UK
10. The Lee Silverman voice treatment should be available to all services if indicated..

References

The National Institute for Clinical Excellence (NICE). Clinical guideline 35. Chapter 5. 'Parkinson's disease', June 2006 <http://www.nice.org.uk>

National Service Framework for Long Term Neurological Conditions
<http://www.dh.gov.uk/en/Healthcare/Longtermconditions/Long-TermNeurologicalConditionsNSF/index.htm>

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