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

Parkinson's Audit 2010

Audit Standards and Guidance

Parkinson's Audit 2010

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

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[3] 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.

[1] Published June 2006 and available on line at www.nice.org.uk/CG035
[2] Published March 2005 and available on line at http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Long-termNeurologicalConditionsNSF/index.htm
[3] College of OT Specialist Section for Neurological Practice, Royal College of Speech and Language Therapists, Chartered Society of Physiotherapy, Parkinson's Disease Nurse Specialist Association, British Geriatric Society Movement Disorder Section, The British and Irish Neurologists Movement Disorder Section, British Association of Social Workers, Royal Pharmaceutical Society of Great Britain.

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

Service Audit

1. To establish, by commissioning area, if local Parkinson's services allow access to NICE and NSF LTNC recommended services and treatments.
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.

Standards, guidance and data collection tool for the Service Audit will be issued in autumn 2010.

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 Master classes 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 2009 and involved 18 and 45 centers respectively. The spreadsheet has been slightly changed this year but still captures the same information.

Data source and data collection

Centers are 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 are responsible for the Audit data but it is anticipated that Parkinson's nurse or junior doctors would assist with the data collection.

Patient Audit

The Audit case capture period will run for the four-month period from 1 July 2010 to 30 October 2010. During this period participants should document the names and case record numbers of consecutive patients referred with suspected Parkinson's. The audit data can either be entered directly onto the Audit spreadsheet, or by printing out and using the Patient Data Collection Tool (see Appendix A) prior to entry onto the spreadsheet. Audit data can be entered prospectively e.g. at the end of clinic, or in batches during the case capture period, or during the month of November which has been allocated for data entry. Parkinson's Audit Flow Chart (see Appendix C) will help you running the Audit.

All participants are required to remove all information relating to named patients from the spreadsheet prior to submission. Data will be 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.

How the audit results will be communicated

Findings will be described in the audit report, which will be sent to all of the participants. Participating centers will be able to use the report for their commissioning purposes.

Details of the participating Trusts will also be sent to the appropriate SHA although this will not include the actual audit data.

Centers will be anonymised in all external publications to avoid 'naming and shaming', and only participants will be provided with their code of identification to allow them to compare their data with the anonymised data of other centers.

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

Audit criteria for Parkinson's new patients' referrals

Criterion 1a	**People with suspected Parkinson's should be seen by a specialist within 6 weeks** PD NICE Guideline recommendations R9; R11 (Table 3.1 Key NICE audit priority) NSF LTN QR2.1
Exceptions	Patient related reason for delay
Standard	100%
Definitions	Patients should be seen within 42 calendar days (not working days) from the date the referral is received. Data collection spreadsheet captures if the standard has been met and, if not the number of days in excess of 42. Patient reasons for delay: patient cancellation or refusal of appointment, patient too unwell to attend clinic.
Criterion 1b	**People with suspected Parkinson's should be referred untreated** PD NICE Guideline recommendation R11 (Table 3.1 Key NICE audit priority)
Exceptions	None
Standard	100%
Definitions	Data collection spreadsheet captures the class of drug used if referred on treatment.

The data collection tool captures the working diagnosis established at the initial clinic visit. This is defined as the diagnosis thought to be the most likely – there may still be a degree of uncertainty but the degree of suspicion should be enough to warrant referral to a Parkinson's nurse and the provision of written information regarding Parkinson's.

The remainder of the Audit data collection relates only to the subgroup of patients with a "working diagnosis of Parkinson's".

Criterion 2	**The initial assessment of a person with suspected Parkinson's should include documentation of difficulties with activities of living, to prompt appropriate multidisciplinary referral** NSF LTN QR1.1; 5.1
Exceptions	Not Parkinson's
Standard	100%
Definitions	This standard is included as doctors commonly act as "gatekeepers" for therapy referrals. The data collection spreadsheet includes link to an Activities of Daily Living (ADL) proforma listing the **minimum** information required to meet this standard in a newly diagnosed patient (see Appendix B). Clinicians can opt to use this proforma, free text or an alternative ADL assessment (which may be more detailed), but this minimum information must be documented. Patients booked to have a functional assessment on another day as part of an integrated service are deemed to have met the standard.
Criterion 2a	**The initial assessment of a person with suspected Parkinson's should document any difficulties with speech and communication, to prompt appropriate speech and language therapy (SLT) referral** NSF LTN QR1.1; 5.1
Exceptions	"Not Parkinson's"
Standard	100%
Definitions	
Criterion 2b	**The initial assessment of a person with suspected Parkinson's should document any difficulties with swallow, to prompt appropriate SLT referral** NSF LTN QR1.1; 5.1
Exceptions	"Not Parkinson's"
Standard	100%
Definitions	Impaired swallow not expected in early Parkinson's - included as relevant to diagnosis.
Criterion 2c	**Physiotherapy is available at diagnosis and appropriate referral activated** PD 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
Exceptions	Patient declines referral or "Not Parkinson's"
Standard	100%

Definitions	The standard is deemed to have been met if a) patients with documented physiotherapy needs have been referred or b) patients without physiotherapy needs have not been referred. If a patient is not referred, the standard is only met if ADL documentation covers all aspects listed in the minimum ADL assessment list (as need is otherwise unknown). The data collection spreadsheet captures if patients have been referred primarily for education (i.e. in the absence of a specific ADL need). This is not a current requirement but is viewed as good practice (NSF LTN QR 1.4, 1.5).
Criterion 2d	**Occupational therapy (OT) is available at diagnosis and appropriate referral activated** PD 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
Exceptions	Patient declines referral or “Not Parkinson’s”
Standard	100%
Definitions	The standard is deemed to have been met if a) patients with documented OT needs have been referred or b) patients without OT needs have not been referred. If a patient is not referred, the standard is only met if ADL documentation covers all aspects listed in the minimum ADL assessment (as need is otherwise unknown). The data collection spreadsheet captures if patients have been referred primarily for education (i.e in the absence of a specific ADL indication). This is not a current requirement but is viewed as good practice (NSF LTN QR 1.4, 1.5).
Criterion 2e	**Speech and language therapy (SLT) s available at diagnosis and appropriate referral activated** PD 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
Exceptions	Patient declines referral or “Not Parkinson’s”
Standard	100%
Definitions	The standard is deemed to have been met if a) patients with documented SLT needs have been referred or b) patients without SLT needs have not been referred. If a patient is not referred, the standard is only met if the presence or absence of difficulties with speech, communication and swallow are documented (as need is otherwise unknown). The data collection spreadsheet captures if patients have been referred primarily for education (i.e in the absence of specific SLT indication). This is not a current requirement but is viewed as good practice (NSF LTN QR 1.4, 1.5).

Criterion 3a	**Patients with a new diagnosis of Parkinson's should be offered Parkinson's nurse contact information** *PD NICE Guideline recommendation R6 NSF LTN QR1.2; QR 2.4*
Exceptions	Patient declines information or "Not Parkinson's"
Standard	100%
Definitions	Parkinson's nurse includes neurology nurse if they have Parkinson's remit.
Criterion 3b	**Patients with a new diagnosis of likely Parkinson's should be given written information regarding Parkinson's** PD NICE Guideline recommendations R3 NSF LTN QR 1.4
Exceptions	Patient declines information or "Not Parkinson's"
Standard	100%
Definitions	Includes contact information for Parkinson's UK.
Criterion 4	**Driving status should be determined and patients who drive advised of need to inform DVLA and their insurance. Driving status and discussion documented in the notes** *PD NICE Guideline recommendation R7*
Exceptions	"Not Parkinson's"
Standard	100%
Definitions	All patients given a "working diagnosis of Parkinson's" should have driving status documented in the notes. All drivers with a "firm" working diagnosis of Parkinson's should be informed of the requirement to inform DVLA and car Insurance of the diagnosis. However, it is recognised that the degree of diagnostic certainty may vary on this first visit and, **if there are no safety concerns** it may be appropriate to discuss on future assessment. The data collection tool has the option "diagnosis tentative and no safety concerns" to meet this scenario.

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Appendix A

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

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Patient Data Collection Tool

This form can be used for your own convenience when collecting patient's data. Complete one form for each patient. Information from this form **must be entered directly into the Parkinson's Audit spreadsheet**. Please DO NOT SEND these forms to Parkinson's UK.

Name of clinician seeing patient:	Clinic venue:	Patient identifier:

The above information is for local use when evaluating results and formulating action plans.
REMOVE IT BEFORE SENDING ENCRYPTED DATA TO PARKIBNSON'S UK.

Gender:	Ethnicity:	Age:
PCT of patient residence (or equivalent in Scotland, Wales, Northern Ireland). Use sub PCT area if your service relates to only part of the PCT area or commissioned services differ in sub PCT areas:		
Name of Trust providing clinic:	**Specialty of clinic:** **Elderly Care** ☐ **Neurology** ☐	**Referred by:** **GP** ☐ **Consultant** ☐ **Other** ☐

No.	Data item no.	Criteria	Yes	No	NA/ Exceptions
Referral for diagnosis					
1	1.1	Was the patient seen within 6 weeks of referral? (i.e 42 working days or less from receipt of referral)	☐	☐	**Patient reason for delay**
	1.2	What was the delay in days if NOT seen within 42 days?	.....		**Patient reason for delay**
	1.3	Was the patient referred untreated?	☐	☐	
	1.4 and 1.5	What medication class had been started if referred on treatment: Ldopa/DCI ☐ Dopamine agonist ☐ MAOB inhibitor ☐ Anticholinergic ☐ Ldopa/DCI/Entacapone ☐	Working diagnosis on first clinic visit: Idiopathic Parkinson's Disease (IPD) ☐ Vascular parkinsonism ☐ Progressive Supranuclear Palsy (PSP) ☐ Multiple System Atrophy (MSA) ☐ Dementia with Lewy Bodies (DLB) ☐ Drug induced parkinsonism ☐ Other ☐		

The remainder of the Audit data collection relates only to the subgroup of patients with a "working diagnosis of Parkinson's".

No.	Data item no.	Criteria	Yes	No		NA/ Exceptions
Functional assessment and referral to therapy						
2	2.1	Is there a documented daily living activities assessment which includes all items listed in the minimum ADL assessment list? (see Appendix B)	☐	☐		Not IPD ☐
	2.2	Is there a documented assessment of speech and communication?	☐	☐		Not IPD ☐
	2.3	Is there a documented enquiry regarding swallow function?	☐	☐		Not IPD ☐
					Unknown need	
	2.4.1	Does the patient have an ADL physiotherapy need (i.e. problem with gait/balance/posture/ transfers) documented? (see Appendix B) Need is unknown if assessment does not meet minimum requirement.	☐	☐	☐	Not IPD ☐
	2.4.2	If the patient had a physiotherapy need was he/she referred for physiotherapy? Note: document if referred primarily for education (i.e. no ADL indication for physiotherapy).	☐	☐	☐	Declined ☐ Education ☐ Not IPD ☐
	2.5.1	Does the patient have a documented occupational therapy (OT) need? (see Appendix B) Need is unknown if assessment does not meet minimum requirement.	☐	☐	☐	Not IPD ☐
	2.5.2	If the patient had an OT need was he/she referred? Note: document if referred primarily for education (i.e. no ADL indication for OT).	☐	☐	☐	Declined ☐ Education ☐ Not IPD ☐
	2.6.1	Does the patient have a documented speech and language therapy (SLT) need for communication (voice/speech/clarity/language)? (see Appendix B) Need is unknown if assessment does not meet minimum requirement.	☐	☐	☐	Not IPD ☐
	2.6.2	Does the patient have a documented SLT need for swallow? (see Appendix B) Need is unknown if assessment does not meet minimum requirement.	☐	☐	☐	Not IPD ☐
	2.6.3	If the patient had a SLT need was he/she referred? Note: document if referred primarily for education (i.e. no ADL indication for SLT)	☐	☐	☐	Declined ☐ Education ☐ Not IPD ☐

No.	Data item no.	Criteria	Yes	No	NA/ Exceptions
Information support on diagnosis					
3	3.1	If the patient was given a working diagnosis of Parkinson's were they provided with Parkinson's nurse contact information?	☐	☐	Declined ☐ No service ☐ Not IPD ☐
	3.2	If the patient was given a working diagnosis of Parkinson's were they provided with written information regarding Parkinson's?	☐	☐	Declined ☐ Not IPD ☐
Driving documentation and advice					
4	4.1	Is the patients driving status documented	☐	☐	Not IPD ☐
	4.2	Has the patient been informed of the need to inform DVLA and car insurance of PD diagnosis	☐	☐	NA ☐ Tentative diagnosis, no safety concerns ☐ Not IPD ☐

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Parkinson's Activities of Daily Living Proforma

This proforma lists the **minimum** information required to meet National Service Framework for Long Term Neurological Conditions standard (NSF LTN QR1.1; 5.1) when assessing a person with suspected Parkinson's. Clinicians can opt to use this proforma, free text or an alternative ADL assessment (which may be more detailed), but this minimum information must be documented.

Parkinson's Audit does not require filling in this form but allows you to use it for your own convenience. **Please DO NOT SEND these forms to Parkinson's UK.**

Activity	Observed	Problem?		Comments
		No	Yes	
Indoor Mobility				
Posture				
In/out chair				
Handwriting				
	Discussed			
Outdoor Mobility				
Bed Mobility				
Stairs				
Toileting (night and day)				
Bathing/showering				
Dressing				
Domestic Activities (meal preparation, etc)				
Eating/drinking (i.e. ability to use crockery, cutlery etc)				
Falls in last 6 months				

NB: Swallowing should be checked separately.

Appendix C

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Parkinson's Audit 2010

Process Flow Chart

This flow chart shows what actions should be taken in order to take part in the Parkinson's Audit, to allow you to plan the process. It also gives you the list of actions that Parkinson's UK together with the steering group is going to take as well as expected time frames.

	√	Date
Nominate local Parkinson's Audit leads Neurology: Elderly care: Exception: Single lead clinician possible only if local commissioning pathway diverts Parkinson's referrals to single specialty.		
Send audit registration form to Parkinson's UK Email Gerda Drutyte, Research Data Analyst at pdaudit@parkinsons.org.uk Indicate if participating in Patient Audit, Service Audit or both.		
Log audit participation with local audit committees Local PCT audit leads Local Provider Trust		
Establish local audit project group E.g. Parkinson's nurse, junior medical staff collecting data, neurology manager therapists or therapy manager.		
Local audit planning meeting Discuss logistics for running audit, and plan for disseminating results.		

Patient Audit case capture: 1 July – 30 October 2010

Use patient audit log sheets to record the name and case number of consecutive new patients referred with the query "does this patient have Parkinson's?" (*regardless of the actual working diagnosis given in clinic*). Include consecutive patients from ALL local clinic venues routinely seeing new Parkinson's patient referrals (neurology and elderly care).

Minimum Patient Audit data sample is 30 patients. Discuss with Parkinson's UK if anticipating problems with sample size.

Patient Audit data entry: 1 November – 31 November 2010

Enter Patient Audit data either directly onto the spreadsheet or by printing out and using the Patient Data Collection Tool prior to entry onto the spreadsheet.

NB: Audit data can also be entered during case capture stage e.g. at end of clinic or in batches during case capture phase.

Service Audit: 1 November – 31 November 2010

Complete in consultation with local audit project group and relevant local managers.

Send Patient and Service Audit data to Parkinson's UK before 1st December 2010

Patient Audit spreadsheet

Patient identification removed (column 1) ☐

Clinician and venue identification removed (column 2 and 3) ☐

Data encrypted (email pdaudit@parkinsons.org.uk for advice) ☐

Service Audit spreadsheet

Data encrypted ☐

Parkinson's Audit Process Flow Chart