UK PARKINSON'S
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Network

# 2017 UK Parkinson's Audit
# Patient management: Elderly Care & Neurology

## Standards and guidance

# 2017 UK Parkinson’s Audit
# Patient management:
# Elderly Care and Neurology

**Audit of national standards relating to Parkinson’s care, incorporating the Parkinson’s NICE guideline[1] and the National Service Framework for Long Term Neurological Conditions[2] quality standards.**

## Aim

The objective of the Parkinson’s patient management audit is to ascertain if the assessment and management of patients with an established diagnosis of Parkinson’s complies with national guidelines including the Parkinson’s NICE guideline and the National Service Framework for Long Term Neurological Conditions (NSF LTNC).

## Objectives

1. To encourage clinicians to audit compliance of their local Parkinson’s service against Parkinson’s guidelines, by providing a simple peer reviewed audit tool with the facility for central data analysis to allow benchmarking with other services.
2. To identify areas of good practice and areas for improvement to inform local, regional and UK-wide discussions leading to action plans to improve quality of care.
3. To establish baseline audit data to allow:
   - UK-wide mapping of variations in quality of care
   - local and UK-wide mapping of progress in service provision and patient care through participation in future audit cycles

The audit focuses on care provided by consultants who specialise in movement disorders in neurology and in elderly care, and Parkinson’s nurse specialists. It includes patients at all phases of Parkinson’s:  early treatment, maintenance, complex care and palliative care.

It incorporates monitoring the physical status and current needs for support and, as appropriate, making referrals and providing treatment, education and support, and co-ordination of services among care providers and the patient and carer. The audit excludes people newly referred to the service for purposes of diagnosis.

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[1] National Institute of Health and Clinical Excellence. *Parkinson’s Disease: Diagnosis and Management in Primary and Secondary Care Clinical Guidelines 35.* (2006) Available at https://www.nice.org.uk/guidance/CG35

[2] Department of Health. *National Service Framework for Long Term Neurological Conditions*. (2005) Available at www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

## Background

A multi-professional steering group[3] was established in 2007 under the chairmanship of Steve Ford, Chief Executive of Parkinson's UK, to develop national Parkinson's audit tools with the facility for central benchmarking. Standards are derived from the NICE guideline but incorporate other national guidance relevant to Parkinson's care, in particular the National Service Framework for Long Term Neurological Conditions (NSF LTNC) and the SIGN guidelines[4].

The audit is led by a steering group of professionals. This is the sixth round of the audit and includes parallel audits of the services provided to people with Parkinson's by occupational therapists, physiotherapists and speech and language therapists. The audit questions for this round have been refined to reflect feedback from the 2015 audit.

## Methodology

The patient management audit is designed to examine how a patient has been managed and assessed over the previous year, rather than on a single visit, as this is more representative of actual patient care. For most patients, this will capture two to three assessments over a year if the service complies with the NICE guideline requirement for at least six to 12 monthly review.

A process flow chart (*How do I take part?*) can be found on page X of this document. Please note the importance of logging your participation in this national clinical audit with your Audit Department.

### Definition of a service

There is considerable variation in how Parkinson's services are organised and delivered throughout the UK. There is, in addition, an ongoing reconfiguration of services and how they are commissioned.

A service is roughly defined as that provided by consultants with (or without) a Parkinson's nurse to a geographical area, regardless of who commissions the constituent parts. Clinicians are best placed to decide what constitutes a discrete service. To facilitate benchmarking, each patient management submission includes a brief service audit to clarify:

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

[4] Scottish Intercollegiate Guidelines Network. *Diagnosis and Pharmacological Management of Parkinson's Disease: A National Clinical Guideline 113* (2010) Available at www.sign.ac.uk/guidelines/fulltext/113/index.html

- how their service is delivered (purely medical or medical together with Parkinson's nurse)
- the geographical/commissioning areas covered
- the specialty – ie neurology or elderly care

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

The following will allow meaningful benchmarking:

1. Neurology and elderly care will be analysed as separate services. They should conduct separate audits and submit data on separate spreadsheets, even if patients share the same Parkinson's nurse input and cover the same geographical area.
2. Discrete services should be logged as separate audit sites and separate data submitted.
3. Parkinson's nurses should conduct the audit in collaboration with their patients' consultant service(s) – and vice versa.
4. The audit can be completed purely from the medical input received only in services without Parkinson's nurse cover.
5. Clinicians working across more than one discrete service - eg a consultant working with different Parkinson's nurses in different commissioning/geographical areas - should return separate audits for each service.

## Patient sample

The minimum audit sample size is 20 consecutive people with idiopathic Parkinson's seen during the audit data collection period, which runs from 1 May 2017 to 30 September 2017.

Take account of the need to capture this minimum sample when deciding locally on your start date for collecting a consecutive patient sample. The data collection tool will have the capacity to capture as many consecutive patients as clinicians wish to audit.

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

Patients should only be included if the service is responsible for the person's ongoing management - ie not if seen as tertiary referral for advice.

## Data collection and entry

The audit tool contains three sections:

- A **service audit** section, which consists of some general questions about your service (which needs to be completed only once).
- A **patient audit** section, which allows you to enter data on individual patients.
- An **instant reporting** section, which will build automatically as you enter your data, and produces pie charts for selected questions.

Patient data can be entered on the data collection tool which you have downloaded and saved locally and added to at your convenience. Complete a separate entry for each patient with Parkinson's. Remember to save the data each time you add new information.

Appendix A of this document is a version of the patient questions that you can print and use to record data in your clinics, if this would be useful.

A user guide for the data collection tool will be available, providing full instructions and information.

**All data must be submitted by 30 October 2017**. No submissions will be accepted after that date.

### 'No, but…' answers

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

## Confidentiality

### Patients

Please ensure that any information submitted does not include any personally identifiable information about your patients. Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it.[5]

When you complete the patient section of the audit, you will see that there is space for a patient identifier. It is suggested that you use code letters or a number here to help you keep track (for example the patient's initials or hospital number). **This data will not be**

**included in the data you submit to Parkinson's UK – the data entry tool will prevent this.** It will help if you keep a list of the code words or numbers securely yourself, so that if there is any query about the information you have submitted, you can track back to the original patient.

**Employers**
The Healthcare Quality Improvement Partnership (HQIP) recommends that services participating in a national clinical audit should be named in the audit reports. The audit reference report will list all participating organisations. It is therefore vital that you inform your clinical audit department about your participation in the audit.

**Participants**
Individual health professionals who participate and submit data will not be named in the audit report.

## Data security

The data collection tool, which will be available for download from the audit webpage, will be password protected, allowing no one but eligible participants to enter and make changes to the data. The password will be emailed to the named lead for each service. Please make sure that the password is well protected and can't be accessed by other people. To ensure the security of your dataset, we also advise you to save and use your version of the tool on a secure computer at work and not on your personal computer at home. We ask you to comply with your organisation's Data Protection guidelines at all times.

After the data has been sent to Parkinson's UK it will be stored in password-protected files at Parkinson's UK in accordance with NHS requirements. Within Parkinson's UK, access to the raw data set is restricted to Kim Davis, Clinical Audit Manager, members of the Clinical Steering Group and Alison Smith, the Data and Analytics Adviser.

Raw data will not be accessible in the public domain. Services will be asked to report any discrepancies in the data received by the audit team in a summary sheet before data analysis begins.

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[5] Health Professionals Council. *Confidentiality – guidance for registrants*. (2012) Available at http://www.hpc-uk.org/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf [accessed 6 January 2017]

## Patient Reported Experience Measure

All services participating in the audit are encouraged to participate in the Patient Reported Experience Measure (PREM). The PREM takes the form of a short paper questionnaire to be distributed to up to 50 consecutive patients between 1 May and 30 September 2017. These patients do not necessarily have to be those included in the main clinical audit.

The questionnaire asks 11 questions about patients' views of their Parkinson's service, and should take only five to 10 minutes to complete. If a carer has accompanied the patient on their clinic visit, they may assist the patient in completion of the form. Patients should feel comfortable and not overlooked while completing their questionnaire.

No identifiable information is collected, and the patient will seal their completed questionnaire in the envelope provided. These envelopes will then need to be collected before the patient leaves the clinic, and all the envelopes will then be returned to the audit team at Parkinson's UK in the large postage-paid envelope provided.

Each service will be provided with the following resources:

- 50 x copies of a paper questionnaire.
- 50 x sealable envelopes.
- 50 x patient information leaflets.
- An A3 laminated poster.
- A large postage-paid envelope for return of sealed envelopes to the audit team.

A minimum of 10 questionnaires will need to be returned for a service's PREM data to be included in the data analysis.

## How the audit results will be communicated

The findings of both the clinical audit and the PREM will be presented in the form of a UK-wide summary report and an individual report for each service, benchmarking the results of individual services against the national average for each audit question in their specialty.

The summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. A bespoke patient and carer version of the summary report will also be produced, along with a reference report which will include all of the results, and a list of all participating services.

A link to the reports will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The reports will also be in the public domain via the Parkinson's UK website.

Data collected during the audit will be used to generate a national picture of service delivery and to compare this with the expectations detailed in national guidance. This data will provide valuable information about priority areas within the existing healthcare 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.

The UK Parkinson's Excellence Network brings together health and social care professionals to transform the care that people with Parkinson's receive across the UK. The Network is there to ensure:

- that everyone affected by Parkinson's has access to high quality Parkinson's services that meet their needs. Their care should be delivered by an expert, integrated, multi-disciplinary team including a consultant, specialist nurse and range of therapists, whose involvement is key to maximising function and maintaining independence
- there are clear pathways to timely, appropriate information, treatments and services from the point of diagnosis, including access to specialist mental health services and the full range of information and support to take control of the condition offered by Parkinson's UK
- services will be involved in continuous quality improvement through audit and engagement of service users in improvement plans

Participating in the PREM will give individual elderly care and neurology services direct feedback from their service users about the quality of care, accessibility and general satisfaction.

## Thank you for your participation in the 2017 National Parkinson's Audit

Parkinson's UK 215 Vauxhall Bridge Road, London SW1V 1EJ
**T** 020 7931 8080 **F** 020 7233 9908 **E** enquiries@parkinsons.org.uk **W** parkinsons.org.uk

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## How do I take part

### Am I eligible to take part?

Any healthcare professionals who work regularly with people with Parkinson's can take part. This includes speech and language therapists, physiotherapists, occupational therapists, Parkinson's nurses, neurologists and geriatricians. You need to submit data on a minimum of 20 (patient management) or 10 (therapies) patients seen during the audit period (1 May to 30 September 2017) for your data to be included in the audit.

### How do I take part if I am eligible?

#### Register your service

Complete and submit a registration form at **parkinsons.org.uk/audit** by 31 March 2017 for each service you wish to audit. You will then be emailed a service number and a password for the data collection tool – you will need these to enter your audit data. In mid-April you will be sent an Audit Pack containing Patient and Carer Information Leaflets and the materials required for the Patient Reported Experience Measure (PREM).

#### Inform your audit department

Please log your participation in this clinical audit with your audit department and discuss with Information Governance to determine if Caldicott approval is required.

#### Establish a local audit project group

Include key professional and medical staff collecting data – discuss the logistics for running the audit, and plan for disseminating the results and action planning. Agree a start date for acquiring patient sample. Agree a target sample size.

#### Data collection

You will be able to download a copy of the data collection tool from parkinsons.org.uk/audit from mid-April 2017, along with a data collection tool. Data entry begins on 1 May 2017.

1. Enter brief details about your service (the Service Audit).
2. Enter details of consecutive patients seen during the audit period 1 May 2017 to 30 September 2017 (the Patient Audit).
3. During this period, hand out Patient Reported Experience Measure questionnaires to up to 50 consecutive patients – these do not need to be the same patients you include in the main audit.

### More information

If you have any queries, or for more information, please contact Kim Davis, Clinical Audit Manager, on 020 7963 3916 or email **audit@parkinsons.org.uk**

### Table 1: Service Audit – Questions, data items/answer options and help notes

| No. | Question | Data items/ Answer options | Help notes |
|---|---|---|---|
| **1. General information** | | | |
| 1.1 | Did this service take part in the Parkinson's audit 2015? | • Yes<br>• No | |
| 1.2 | Who commissions this service? | • Free text | Please provide the name of the commissioning board/Local Health Board in Wales |
| 1.3 | Geographical area covered by this Parkinson's service | • Free text | Main towns covered |
| 1.4 | What is the most common model of service provision for the medical input to this service? | • Doctor alone<br>• Joint/parallel doctor and nurse specialists clinics<br>• Integrated clinics (doctor/nurse specialist/therapy in same venue) | • Joint/parallel - we are asking if the PDNS works in clinics with the Consultant (but AHPs located elsewhere)<br>• Integrated clinics – multidisciplinary team working: neurologist or care of the elderly specialist, Parkinson’s nurse and therapist, for example, occupational therapist and/or physiotherapist and/or speech and language therapist, seeing patients within the same clinic venue |
| 1.5 | Are clinic patients seen within specific Parkinson's/ Movement Disorder clinics? | • All patients<br>• Most patients (>75%)<br>• Some patients (25-74%)<br>• Few patients (<25%)<br>• None | A specialist service would be expected to have<br>a) an identified lead clinician for training, service development and specialist opinion.<br>**AND**<br>b) The provision of specific Parkinson’s/Movement Disorder |

|  |  |  |  |
|---|---|---|---|
|  |  |  | clinics. |
| 1.6 | Is written information regarding Parkinson’s routinely available when patients attend clinic venues? | • All clinics<br>• Most clinics (>75%)<br>• Some clinics<br>• Not routinely available | Routinely available means accessible to patients such as on tables or in racks and/or accessible to staff to distribute to patients. |
| **2. Assessments** |  |  |  |
| 2.1 | Is a formal Activities of Daily Living assessment tool or check list **used** when Parkinson's patients are reviewed in this service? | • All clinics<br>• Most clinics (>75%)<br>• Some clinics<br>• Not routinely available | The use of a formal Activities of Daily Living (ADL) assessment tool is helpful in identifying practical difficulties in daily life and prompting referral for therapy input. |
| 2.2 | Is the Parkinson's non-motor symptoms questionnaire or other form of checklist **used** to screen for non-motor symptoms when Parkinson's patients are assessed? | • All clinics<br>• Most clinics (>75%)<br>• Some clinics<br>• Not routinely available |  |
| 2.3 | Is a standardised assessment tool routinely **available** in clinic venues to assess and monitor cognitive function? | • All clinics<br>• Most clinics (>75%)<br>• Some clinics<br>• Not routinely available | The 10 point Abbreviated Mental Test Score is not sufficient to meet this standard. |
| 2.4 | Is a standardised assessment tool routinely **available** in clinic venues to assess mood? | • All clinics<br>• Most clinics (>75%)<br>• Some clinics<br>• Not routinely available |  |
|  |  |  |  |

## Consultants and Parkinson’s nurse specialists

| | | | |
|---|---|---|---|
| 3. | **Consultants** | | |
| 3.1 | Lead consultant name | | |
| 3.2 | Specialty | • Geriatrician<br>• Geriatrician with special interest in Parkinson’s<br>• Neurologist<br>• Neurologist with special interest in Parkinson’s | Tick one |
| 3.3 | Employing Trust/Board/Local Health Board | | |
| 3.4 | Contact telephone number | | |
| 3.5 | Contact email | | |
| 3.6 | How many consultants routinely provide medical input for this service? | • The number of consultants<br>• Names of the other consultants | Routinely means a regular clinic commitment.<br>**Include:**<br>Any consultant who sees Parkinson’s patients for diagnosis and ongoing management. Non specialist consultants should be included if they keep Parkinson’s patients under their care. |
| 3.7 | Have all consultants providing medical input to this service attended Movement Disorder specific external CME in the last 12 months? | • Yes<br>• No | The question refers to **external** CME i.e. regional, national or international education updates relevant to Parkinson’s. |

| | | | |
|---|---|---|---|
| 3.7a | If no, please enter X out of X consultants have attended | Free text | |
| 4. | **Parkinson’s Nurse Specialists** | | |
| 4.1 | Can patients in this service access a Parkinson's Nurse Specialist? | • Yes<br>• No | |
| 4.2 | Parkinson’s Nurse Specialist details | • Name<br>• Employing Trust/Board/Local Health Board<br>• Contact telephone number and email | |
| 4.3 | Have all Parkinson's Nurse Specialists associated with this service attended Parkinson specific external CME in the last 12 months? | • Yes<br>• No<br>• No Parkinson’s Nurse Specialist | The question refers to **external** CME i.e. regional, national or international education updates relevant to Parkinson’s. |
| 4.3a | If no, please enter X out of X Parkinson’s Nurse Specialists have attended | Free text | |
| 4.4 | What is the main arrangement for contact between Consultants and Parkinson's Nurse Specialists? | • Regular contact in Multidisciplinary meeting, joint or parallel clinic<br>• Regular face to face contact outside clinic<br>• Regular telephone/email contact with occasional face to face contact<br>• Telephone/email contact only<br>• No or rare contact<br>• No Parkinson’s Nurse Specialist | Regular is defined as at least twice a month |

## Table 2: Patient Audit - Questions, data items/answer options and help notes

| No. | Question | Data items/Answer options | Help notes |
|---|---|---|---|
| **1. Descriptive data** | | | |
| 1.1 | Patient identifier | This can be used to identify audited patients | |
| 1.2 | Gender | • Male<br>• Female | |
| 1.3 | Ethnicity | • White<br>o British,<br>o Irish<br>o Traveller<br>o Any other White background)<br>• Asian/Asian British<br>o Bangladeshi<br>o Chinese<br>o Indian<br>o Pakistani<br>o Any other Asian background<br>• Black/Black British<br>o African<br>o Caribbean<br>o any other Black background<br>• Mixed/multiple ethnic backgrounds<br>o mixed - White and Black<br>o mixed White and Asian<br>o mixed any other background)<br>• Other<br>o Arab<br>o Other | |

| | | | |
|---|---|---|---|
| | | • prefer not to say | |
| 1.4 | Year of birth | | |
| 1.5 | Year of Parkinson's diagnosis | | |
| 1.6 | Parkinson’s Phase | • Diagnosis<br>• Maintenance<br>• Complex<br>• Palliative | **Definitions of phases**<br>**Diagnosis**<br>• From first recognition of symptoms/sign/problem<br>• Diagnosis not established or accepted.<br><br>**Maintenance**<br>• Established diagnosis of Parkinson’s<br>• Reconciled to diagnosis<br>• No drugs or medication  4 or less doses/day<br>• Stable medication for >3/12<br>• Absence of postural instability.<br><br>**Complex**<br>• Drugs – 5 or more doses/day<br>• Any infusion therapy (apomorphine or duodopa)<br>• Dyskinesia<br>• Neuro-surgery considered / DBS in situ<br>• Psychiatric manifestations >mild symptoms of depression/anxiety/hallucinations/psychosis<br>• Autonomic problems – hypotension either drug or non-drug induced<br>• Unstable co-morbidities<br>• Frequent changes to medication (<3/12)<br>• Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues).<br><br>**Palliative** |

|  |  |  |  |
|---|---|---|---|
|  |  |  | • Inability to tolerate adequate dopaminergic therapy<br>• Unsuitable for surgery<br>• Advanced co-morbidity (life threatening or disabling). |
| 1.7 | Living Alone | • Yes<br>• No,<br>• No, at residential home<br>• No, at nursing home |  |
| 1.8 | Is there evidence of a documented Parkinson’s and related medication reconciliation at each patient visit? | • Yes<br>• No<br>• Patient on no medication | Resources:<br>• Medicine reconciliation standards:<br>o http://www.rpharms.com/current-campaigns-pdfs/1303---rps---transfer-of-care-10pp-professional-guidance---final-final.pdf<br>o Scotland: Criteria 19.2: “ Reconciliation of the Parkinson’s medicine and dosages is undertaken at each patient visit to ensure that the patient, GP, consultant, pharmacist and Parkinson’s disease nurse specialist and determine accurately the anti-Parkinson’s disease drugs the patient is taking.”<br>o Scotland: Scottish Government guidance on medicines reconciliation – http://www.sehd.scot.nhs.uk/cmo/CMO(2013)18.pdf |

## 2. Specialist Review

**Standard A: 100% of people with Parkinson’s must be reviewed at 6-12 monthly intervals.**
(Parkinson’s NICE:R12, R77; NSF LTC:QR2; Scotland: Clinical Standard 19.3).

| | | | |
|---|---|---|---|
| 2.1 | Has the patient been reviewed by a specialist within the last year? (can be doctor or nurse specialist) | • Yes<br>• No | |
| 2.2 | Time since most recent medical review (by doctor or nurse specialist) | • Less than 6 months<br>• 6-12 months<br>• More than 1 year<br>• More than 2 years<br>• Never | |
| **3. New / Recent Parkinson's medication** | | | |
| **Standard B: 100% of people with Parkinson’s should be provided with both oral and written communication throughout the course of the disease, which should be individually tailored and reinforced as necessary.**(Parkinson’s NICE R3; Scotland - Clinical Standards 1.3 & 1.4) | | | |
| 3.1 | Is there documented evidence of a conversation with the patient/carer and/or provision of written information regarding potential adverse effects for any new medications? | • Yes<br>• No<br>• Not applicable – patient not started on Parkinson’s medication for the first time during the previous year | The written information can include a copy of clinic letter if adverse effects are listed, or the Parkinson’s UK medication leaflet. The manufacturer’s package insert does not meet this standard.<br>Resources: Parkinson’s UK medication leaflets https://www.parkinsons.org.uk/content/drug-treatments-parkinsons |
| **4. Specific adverse effect monitoring** | | | |
| **Standard C: 100% of people with Parkinson’s who have sudden onset of sleep should be advised not to drive and to consider any occupational hazards** (Parkinson’s NICE R72)<br>**Standard D: 100% of patients on dopaminagic therapies are monitored for impulse control behaviours including dopamine dysregulation syndrome** (Parkinson’s NICE R54, SIGN 5.1.1)<br>**Standard E: If an ergot-derived dopamine agonist is used, 100% of patients should have a minimum of renal function tests, erythrocyte sedimentation rate (ESR)and chest radiograph (CXR) performed before starting treatment, and annually thereafter** (Parkinson’s NICE R30 and 40, SIGN 5.1.2) | | | |

| | | | |
|---|---|---|---|
| 4.1 | Is this patient on Parkinson’s medication? | • Yes<br>• No | [if no, Q4.4 to Q4.6 will be greyed out] |
| 4.2 | Evidence of enquiry re excessive daytime sleepiness | • Yes<br>• No | |
| 4.3 | If excessive daytime sleepiness is documented as present and the patient is a driver, was the impact on driving discussed and advice given? | • Yes<br>• No<br>• Not applicable – no excessive daytime sleepiness and/or not a driver | |
| 4.4 | Evidence patients taking dopaminergic drugs are monitored re: compulsive behaviour | • Yes<br>• No<br>• Not applicable - not on dopaminergic drugs | Evidence means documentation that the patient was specifically asked about the presence of compulsive behaviour symptoms during the previous year if on any dopaminergic medication e.g. MAOI, Levodopa, dopamine agonist<br><br>Resources:<br>• Impulse Control Disorders in Parkinson Disease (Weintraub) https://www.ncbi.nlm.nih.gov/pubmed/20457959 |
| 4.5 | Evidence patients taking dopamine agonists are monitored re: compulsive behaviour | • Yes<br>• No<br>• Not applicable - not on a dopamine agonist | Evidence means documentation that the patient was specifically asked about the presence of compulsive behaviour symptoms during the previous year |
| 4.6 | Evidence of patients taking ergot dopamine agonists having an echocardiogram carried out for fibrosis related adverse effects | • Yes<br>• No<br>• Not applicable - not on ergot dopamine agonists | Evidence means documentation that this test has been arranged by the PD Service directly or letter sent asking GP to arrange during the previous year |
| **5. Advance Care Planning** | | | |

| **Standard F: For 100% of people with Parkinson’s end of life care requirements should be considered throughout all phases of the disease.** (Parkinson’s NICE R82)<br>**Standard G: 100% of people with Parkinson’s and their carers should be given the opportunity to discuss end-of-life issues with appropriate healthcare professionals.** (Parkinson’s NICE R 83) | | | |
|---|---|---|---|
| 5.1 | Is there evidence the patient/carer has been offered information about, or has set up a Lasting Power of Attorney? | • Yes<br>• No | Resources:<br>• https://www.gov.uk/power-of-attorney/make-lasting-power<br>• Scotland: http://www.publicguardian-scotland.gov.uk/power-of-attorney |
| 5.2 | Are there markers of advanced disease e.g. dementia, increasing frailty, impaired swallowing, nursing home level of care required? | • Yes<br>• No - skip to Section 6 | |
| 5.3 | Are there any documented discussions regarding end of life care issues/care plans? | • Yes<br>• No | Resources:<br>• NHS End of Life Care Programme Guide: Capacity, Care Planning and Advance Care Planning in life limiting illness http://www.ncpc.org.uk/sites/default/files/ACP_Booklet_June_2011.pdf<br>• http://www.parkinsons.org.uk/content/preparing-end-life-booklet<br>• Scottish Palliative Care Guidelines, including care planning and guidance on capacity: |

|  |  |  |  |
|---|---|---|---|
|  |  |  | http://www.palliativecareguidelines.scot.nhs.uk<br>• Wales: http://gov.wales/topics/health/nhswales/plans/end-of-life-care/?lang=en |

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

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

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

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

**Total process score: 34**
These assessments underpin achieving compliance with Parkinson’s NICE standards contained in
Section 4: Communication with people with Parkinson’s and their carers
Section 9: Non-motor features of Parkinson’s
Section 10: Other key interventions - Parkinson’s nursing, physiotherapy, occupational therapy

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

- **“Yes”** and **“No but”** answers will score 1

- **“No”** answers will score 0

**Domain 1: Non-motor assessments during the previous year (Maximum score = 12)**

|  |  |  |  |
|---|---|---|---|
| 6.1.1 | Blood pressure documented lying (or sitting) and standing | • Yes<br>• No<br>• No but, doesn't stand |  |
| 6.1.2 | Evidence of | • Yes |  |

| | | | |
|---|---|---|---|
| | enquiry/assessment re cognitive status | • No | |
| 6.1.3 | Evidence of enquiry re hallucinations/psychosis | • Yes<br>• No | |
| 6.1.4 | Evidence of enquiry re: mood - this should include depression | • Yes<br>• No | |
| 6.1.5 | Evidence of enquiry re communication difficulties | • Yes<br>• No | |
| 6.1.6 | Evidence of enquiry re problems with swallowing function | • Yes<br>• No | |
| 6.1.7 | Evidence of screening for malnutrition (weight checked at least yearly) | • Yes<br>• No | |
| 6.1.8 | Evidence of enquiry re problems with saliva | • Yes<br>• No | |
| 6.1.9 | Evidence of enquiry re bowel function | • Yes<br>• No | |
| 6.1.10 | Evidence of enquiry re bladder function | • Yes<br>• No | |
| 6.1.11 | Evidence of enquiry re pain | • Yes<br>• No | |
| 6.1.12 | Evidence of enquiry re sleep quality | • Yes<br>• No | |

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| **Domain 2: Motor and ADL assessment during the previous year (12)** |  |  |  |
| 6.2.1 | Evidence of enquiry re “On/Off” fluctuations | • Yes<br>• No<br>• No, but not yet on treatment<br>• No, but less than 3 years from starting medication |  |
| 6.2.2 | Evidence of enquiry/assessment re problems with gait including freezing | • Yes<br>• No<br>• No, but doesn't walk |  |
| 6.2.3 | Evidence of enquiry re falls and balance | • Yes<br>• No<br>• No, but assisted for transfers and doesn't walk |  |
| 6.2.4 | Evidence fracture risk/osteoporosis considered | • Yes<br>• No<br>• No, but notes document not falling and no concern re balance |  |
| 6.2.5 | Evidence of enquiry re problems with bed mobility (e.g. getting in/out of bed, moving/rolling from side to side once in bed) | • Yes<br>• No |  |
| 6.2.6 | Evidence of enquiry re problems with transfers (e.g. out of chair/off toilet/car) | • Yes<br>• No<br>• No, but early/mild disease, active lifestyle |  |
| 6.2.7 | Evidence of enquiry/assessment of tremor | • Yes<br>• No<br>• No, but no tremor |  |

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| 6.2.8 | Evidence of enquiry re problems with dressing | • Yes<br>• No<br>• No, but in care home |  |
| 6.2.9 | Evidence of enquiry re problems with hygiene (e.g. washing/bathing/hair/ nails) | • Yes<br>• No<br>• No, but in nursing home |  |
| 6.2.10 | Evidence of enquiry re difficulty eating and drinking (i.e. cutlery/managing drinks etc. not swallowing) | • Yes<br>• No<br>• No, but PEG fed |  |
| 6.2.11 | Evidence of enquiry re domestic activities (cooking/cleaning/shopping) | • Yes<br>• No<br>• No, but in care home |  |
| 6.2.12 | Evidence of enquiry re problems with function at work | • Yes<br>• No<br>• No, but retired or doesn't work |  |
| **Domain 3: Education and multi-disciplinary involvement during the previous year (10)** |  |  |  |
| 6.3.1 | Evidence of referral/input from Parkinson's nurse | • Yes<br>• No<br>• No, but declined |  |
| 6.3.2 | Evidence of physiotherapy referral/assessment/input | • Yes, for therapy/assessment<br>• No<br>• No, but declined<br>• No, but clear documentation no therapy need<br>• No, but no achievable physiotherapy goals | The option "No but clear documentation no therapy need" should only be used if there is clear documentation of relevant enquiries/assessments re physiotherapy related problems (gait / balance/ posture/transfers)<br><br>Use **"No but no achievable physiotherapy goals"** option only if no change and extensive prior physiotherapy input |
| 6.3.3 | Evidence of | • Yes, for therapy/assessment | The option "No but clear documentation no therapy need" can |

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| | occupational therapy referral/assessment/input | • No<br>• No, but, declined<br>• No, but clear documentation no therapy need<br>• No, but no achievable occupational therapy goals | only be used if there is clear documentation of assessment/enquiry re problems with activities of daily living and/or difficulties at work if working<br>Use **"No but, no achievable occupational therapy goals"** option only if no change and extensive prior occupational therapy input |
| 6.3.4 | Evidence of speech and language therapy referral/input **for communication** | • Yes, for therapy/assessment<br>• No<br>• No, but declined<br>• No, but clear documentation no therapy need<br>• No, but no achievable SLT goals | The option "No but clear documentation no therapy need" can only be used if there is clear documentation of assessment/enquiry re communication<br>Use **"No but, no achievable SLT goals"** option only if no change, extensive prior SLT input and alternative communication means already explored |
| 6.3.5 | Evidence of speech and language therapy referral/input **for swallowing** | • Yes<br>• No<br>• No, but declined<br>• No, but swallow documented normal<br>• No, but PEG fed or adequate care plan in place | |
| 6.3.6 | Evidence of social work referral/input | • Yes<br>• No<br>• No, but declined<br>• No, but documented as self funding and referred to other sources of support and information re care<br>• No, but social work input not required, as social care needs are being met. | Use **"No but social work input not required, as social care needs are being met"** option only if there is evidence that current care arrangements are working well or that the person is independent in mobility and personal care. |
| 6.3.7 | Evidence that patient's and carer's entitlement to financial benefits has been considered and advice given | • Yes<br>• No<br>• No, but independent in mobility and personal care<br>• No, but previously addressed | Resources:<br>http://www.parkinsons.org.uk/content/financial-help-and-support-carers<br>http://www.parkinsons.org.uk/content/social-fund-and-local-welfare-provision-information-sheet |

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| 6.3.8 | Evidence that patient and/or carer has been signposted to Parkinson's UK | • Yes<br>• No<br>• No, but previously signposted | |
| 6.3.9 | Evidence that patient and/or carer has been signposted to Information Support Worker | • Yes<br>• No<br>• No, but previously signposted | |
| 6.3.10 | Evidence of communication with carers about their entitlement to carer assessment and support services | • Yes<br>• No<br>• No, but in care home<br>• No, but patient not in complex or palliative stage<br>• No, but, no carer<br>• No, but previously addressed, or no new issues | |

## Appendix A: Printable Patient Audit sheet

| No. | Question | Data items/Answer options | |
|---|---|---|---|
| **1. Descriptive data** | | | |
| 1.1 | Patient identifier | | |
| 1.2 | Gender | • Male<br>• Female | |
| 1.3 | Ethnicity | • White<br>o British,<br>o Irish<br>o Traveller<br>o Any other White background)<br>• Asian/Asian British<br>o Bangladeshi<br>o Chinese<br>o Indian<br>o Pakistani<br>o Any other Asian background<br>• Black/Black British<br>o African<br>o Caribbean<br>o any other Black background<br>• Mixed/multiple ethnic backgrounds<br>o mixed - White and Black<br>o mixed White and Asian<br>o mixed any other background)<br>• Other<br>o Arab<br>o Other<br>o prefer not to say | |
| 1.4 | Year of birth | | |
| 1.5 | Year of Parkinson's diagnosis | | |
| 1.6 | Parkinson’s Phase | • Diagnosis<br>• Maintenance<br>• Complex<br>• Palliative | |
| 1.7 | Living Alone | • Yes<br>• No,<br>• No, at residential home<br>• No, at nursing home | |
| 1.8 | Is there evidence of a documented Parkinson’s and related medication | • Yes<br>• No | |

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|  | reconciliation at each patient visit? | Patient on no medication |
| **2. Specialist Review** |  |  |
| 2.1 | Has the patient been reviewed by a specialist within the last year? (can be doctor or nurse specialist) | • Yes<br>• No |
| 2.2 | Time since most recent medical review (by doctor or nurse specialist) | • Less than 6 months<br>• 6-12 months<br>• More than 1 year<br>• More than 2 years<br>• Never |
| **3. New / Recent Parkinson's medication** |  |  |
| 3.1 | Is there documented evidence of a conversation with the patient/carer and/or provision of written information regarding potential adverse effects for any new medications? | • Yes<br>• No<br>• Not applicable – patient not started on Parkinson’s medication for the first time during the previous year |
| **4. Specific adverse effect monitoring** |  |  |
| 4.1 | Is this patient on Parkinson’s medication? | • Yes<br>• No |
| 4.2 | Evidence of enquiry re excessive daytime sleepiness | • Yes<br>• No |
| 4.3 | If excessive daytime sleepiness is documented as present and the patient is a driver, was the impact on driving discussed and advice given? | • Yes<br>• No<br>• Not applicable – no excessive daytime sleepiness and/or not a driver |
| 4.4 | Evidence patients taking dopaminergic drugs are monitored re: compulsive behaviour | • Yes<br>• No<br>• Not applicable - not on dopaminergic drugs |
| 4.5 | Evidence patients taking dopamine agonists are monitored re: compulsive behaviour | • Yes<br>• No<br>• Not applicable - not on a dopamine agonist |
| 4.6 | Evidence of patients taking ergot dopamine agonists having an echocardiogram carried out for fibrosis related | • Yes<br>• No<br>• Not applicable - not on ergot dopamine agonists |

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| | adverse effects | |
| **5. Advanced Care Planning** | | |
| 5.1 | Is there evidence the patient/carer has been offered information about, or has set up a Lasting Power of Attorney? | • Yes<br>• No |
| 5.2 | Are there markers of advanced disease e.g. dementia, increasing frailty, impaired swallowing, nursing home level of care required? | • Yes<br>• No - skip to Section 6 |
| 5.3 | Are there any documented discussions regarding end of life care issues/care plans? | • Yes<br>• No |
| **6. Parkinson’s assessment and care planning process scores (complete from medical and Parkinson’s nurse notes)** | | |
| **Domain 1: Non-motor assessments during the previous year (Maximum score = 12)** | | |
| 1 | Blood pressure documented lying (or sitting) and standing | • Yes<br>• No<br>• No but, doesn't stand |
| 2 | Evidence of enquiry/assessment re cognitive status | • Yes<br>• No |
| 3 | Evidence of enquiry re hallucinations/psychosis | • Yes<br>• No |
| 4 | Evidence of enquiry re: mood - this should include depression | • Yes<br>• No |
| 5 | Evidence of enquiry re communication difficulties | • Yes<br>• No |
| 6 | Evidence of enquiry re problems with swallowing function | • Yes<br>• No |
| 7 | Evidence of screening for malnutrition (weight checked at least yearly) | • Yes<br>• No |
| 8 | Evidence of enquiry re problems with saliva | • Yes |

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| | | • No |
| 9 | Evidence of enquiry re bowel function | • Yes<br>• No |
| 10 | Evidence of enquiry re bladder function | • Yes<br>• No |
| 11 | Evidence of enquiry re pain | • Yes<br>• No |
| 12 | Evidence of enquiry re sleep quality | • Yes<br>• No |
| **Domain 2: Motor and ADL assessment during the previous year (12)** | | |
| 1 | Evidence of enquiry re "On/Off" fluctuations | • Yes<br>• No<br>• No, but not yet on treatment<br>• No, but less than 3 years from starting medication |
| 2 | Evidence of enquiry/assessment re problems with gait including freezing | • Yes<br>• No<br>• No, but doesn't walk |
| 3 | Evidence of enquiry re falls and balance | • Yes<br>• No<br>• No, but assisted for transfers and doesn't walk |
| 4 | Evidence fracture risk/osteoporosis considered | • Yes<br>• No<br>• No, but notes document not falling and no concern re balance |
| 5 | Evidence of enquiry re problems with bed mobility (e.g. getting in/out of bed, moving/rolling from side to side once in bed) | • Yes<br>• No |
| 6 | Evidence of enquiry re problems with transfers (e.g. out of chair/off toilet/car) | • Yes<br>• No<br>• No, but early/mild disease, active lifestyle<br>• |
| 7 | Evidence of | |

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|---|---|---|
| | enquiry/assessment of tremor | • Yes<br>• No<br>• No, but no tremor |
| 8 | Evidence of enquiry re problems with dressing | • Yes<br>• No<br>• No, but in care home |
| 9 | Evidence of enquiry re problems with hygiene (e.g. washing/bathing/hair/nails) | • Yes<br>• No<br>• No, but in nursing home |
| 10 | Evidence of enquiry re difficulty eating and drinking (i.e. cutlery/managing drinks etc. not swallowing) | • Yes<br>• No<br>• No, but PEG fed |
| 11 | Evidence of enquiry re domestic activities (cooking/cleaning/shopping) | • Yes<br>• No<br>• No, but in care home |
| 12 | Evidence of enquiry re problems with function at work | • Yes<br>• No<br>• No, but retired or doesn’t work |
| **Domain 3: Education and multi-disciplinary involvement during the previous year (10)** | | |
| 1 | Evidence of referral/input from Parkinson's nurse | • Yes<br>• No<br>• No, but declined |
| 2 | Evidence of physiotherapy referral/assessment/input | • Yes, for therapy/assessment<br>• No<br>• No, but declined<br>• No, but clear documentation no therapy need<br>• No, but no achievable physiotherapy goals |
| 3 | Evidence of occupational therapy referral/assessment/input | • Yes, for therapy/assessment<br>• No<br>• No, but, declined<br>• No, but clear documentation no therapy need<br>• No, but  no achievable occupational therapy goals |
| 4 | Evidence of speech and language therapy referral/input **for communication** | • Yes, for therapy/assessment<br>• No<br>• No, but declined |

| | | |
|---|---|---|
| | | No, but clear documentation no therapy need<br>No, but no achievable SLT goals |
| 5 | Evidence of speech and language therapy referral/input **for swallowing** | Yes<br>No<br>No, but declined<br>No, but swallow documented normal<br>No, but PEG fed or adequate care plan in place |
| 6 | Evidence of social work referral/input | Yes<br>No<br>No, but declined<br>No, but documented as self funding and referred to other sources of support and information re care<br>No, but social work input not required, as social care needs are being met. |
| 7 | Evidence that patient's and carer's entitlement to financial benefits has been considered and advice given | Yes<br>No<br>No, but independent in mobility and personal care<br>No, but previously addressed |
| 8 | Evidence that patient and/or carer has been signposted to Parkinson's UK | Yes<br>No<br>No, but previously signposted |
| 9 | Evidence that patient and/or carer has been signposted to Information Support Worker | Yes<br>No<br>No, but previously signposted |
| 10 | Evidence of communication with carers about their entitlement to carer assessment and support services | Yes<br>No<br>No, but in care home<br>No, but patient not in complex or palliative stage<br>No, but, no carer<br>No, but previously addressed, or no new issues |