2019 UK Parkinson's Audit Physiotherapy

Standards and guidance

2019 UK Parkinson's Audit

Physiotherapy

Audit of national standards relating to Parkinson's care incorporating the Parkinson's NICE guideline and the National Service Framework for Long Term Neurological Conditions quality standards.

Aim

The aim of the physiotherapy audit is to establish if physiotherapy services are providing quality services for people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

Objectives

1. To evaluate if physiotherapy services are currently providing assessment and interventions appropriate to the needs of people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

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

Background

The Parkinson's physiotherapy audit is part of the UK Parkinson's Audit coordinated by Parkinson's UK and led by a steering group of professionals.

This is the fifth round in which physiotherapists will be able to take part, along with occupational therapists and speech and language therapists. Consultants in elderly care and neurology (and their Parkinson's nurses) can participate in the parallel patient management audit. The audit questions for this round of the audit have been refined to reflect feedback from the 2017 audit.

Standards

The Parkinson's NICE guideline[1] recommends:

- Consider referring people who are in the early stages of Parkinson's disease to a physiotherapist with experience of Parkinson's disease for assessment, education and advice, including information about physical activity.
- Offer Parkinson's disease-specific physiotherapy for people who are experiencing balance or motor function problems.
- Consider the Alexander Technique for people with Parkinson's disease who are experiencing balance or motor function problems.

The 2018 NICE Quality Standards[2] recommend that "Adults with Parkinson's disease are referred to physiotherapy, occupational therapy or speech and language therapy if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva."

NICE states that the rationale for this is that: "Adults with Parkinson's disease may experience a wide range of symptoms. Physiotherapy... can help people to manage their symptoms, maintain their independence and avoid hospital admission. After a referral to therapy services, it is important to ensure that therapists are included as part of the person's multidisciplinary team."

NICE also states that "Adults with Parkinson's disease should have contact with a physiotherapist...with experience of Parkinson's disease to ensure disease-specific care is given."

The European Physiotherapy Guideline for Parkinson's Disease[3] is an evidence-based guideline developed according to international standards, including practice recommendations for physiotherapists.

The National Service Framework for Long Term Neurological Conditions (NSF LTNC)[4] is a key tool for delivering the government's strategy to support people with long term conditions such as Parkinson's. In particular, aspects of the quality requirements 1, 4, 5 and 7 have been highlighted as important when considering the needs of people with long term conditions.

A group of key clinical, academic and research physiotherapists undertook work to

[1] National Institute of Health and Care Excellence. *Parkinson's Disease in Adults NG71.* (2017) Available at https://www.nice.org.uk/guidance/ng71

[2] https://www.nice.org.uk/guidance/qs164/chapter/Quality-statement-3-Referral-to-physiotherapy-occupational-therapy-or-speech-and-language-therapy

[3] Keus S et al. European Physiotherapy Guideline for Parkinson's Disease. (2014) KNGF/ ParkinsonNet, The Netherlands

[4] 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

adapt the Dutch guidelines for physical therapy in Parkinson's disease *Quick Reference Cards*[5], principally in relation to the use of outcome measures, for use by physiotherapists working with people with Parkinson's in the UK[6]. In addition, this group worked to provide standards for service delivery.

Methodology

This audit is open to all physiotherapy services and individual physiotherapists that work with people with Parkinson's in the UK, whether hospital or community based, clinic or domiciliary service (excluding acute hospital inpatients).

Standards agreed to be pertinent to physiotherapy have been transformed into a set of audit standards and statements reviewed by specialist physiotherapists. The full list of questions is given in Table 1 (Service audit) and Table 2 (Patient audit) at the end of this document.

Please note the importance of logging your participation in this national clinical audit with your Audit Department.

Patient sample

The minimum audit sample size is 10 consecutive patients with idiopathic Parkinson's , referred to a physiotherapy service and seen during the audit data collection period, which runs from 1 May 2019 to 30 September 2019.

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 therapists wish to audit.

The inclusion criteria for audited patients are as follows:
a)   Patients who are currently receiving active intervention (including education/counselling) at the start of the audit period.
b)   Those who are seen on review appointment (irrespective of whether they then go on to start another period of active treatment) during the audit period.
c)   Patients newly referred to your service who undergo full assessment (again irrespective of whether they then proceed to immediate active intervention rather than being placed on review).

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[5] Keus S et al. 'Guidelines for physical therapy in patients with Parkinson's disease.' *Dutch Journal of Physiotherapy.* (2004) 114 (3): Supplement 1–94.
[6] Ramaswamy B et al. *Quick Reference Cards (UK) and guidance notes for physiotherapists working with people with Parkinson's disease.* (2009) Available at
https://www.parkinsons.org.uk/professionals/resources/quick-reference-cards-uk-physiotherapists

Data entry

Data is entered on an on-line tool; the link is available from www.parkinsons.org.uk/audit.

- The **service audit** section consists of general questions about your service (and needs to be completed only once).

- The **patient audit** section allows you to enter data on individual patients.

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.

Data entry must be completed by 31 October 2019 when the data will be downloaded for analysis.

'No, but…' answers
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.

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) – please do not use NHS numbers. 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 therapists who participate and submit data will not be named in the audit report.

Data Security

The data collection forms, which will be available online for data entry, will be accessed using a username and password chosen by each user. The password will require a minimum length and complexity according to usual online security methods. Please make sure that your username and password are well protected and can't be accessed by other people. You will be able to indicate that you will work with colleagues on the audit, and you will therefore be able to view entries made by colleagues in your local team. We ask that you comply with your organisation's Data Protection guidelines at all times.

After the data has been accessed by 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 Sigita Stankeviciute, 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.

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 2019. 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 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 reference report 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

The data from the physiotherapy audit will enable individual services to assess how well their service complies with guidance and whether physiotherapists working within that service are using appropriate outcome measures and treatment strategies. It will also give important information about access to training in Parkinson's related physiotherapy.

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

Thank you for your participation in the 2019 National Parkinson's Audit

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Physiotherapy - Service Audit

No	Question	Data items/ Answer options	Help notes
Your details			
1.1	Name of Lead Therapist completing the Service Audit	Free text	
1.2	Contact email of Lead Therapist	Free text	
Service Description			
2.1	Describe the setting in which you usually see individuals with Parkinson's	• Integrated medical and therapy Parkinson's clinic • Acute outpatient rehabilitation • Community rehabilitation service • Social services • Other (please specify)	Choose one – the most common setting for the service
2.2	Does your service specialise in the treatment of individuals with neurological conditions?	• Yes • No	
2.3	Does your service specialise in the treatment of individuals with Parkinson's?	• Yes • No	
Individuals with Parkinson's			
3.1	Approximately what percentage of the individuals referred to your service annually have a diagnosis of Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-100%	

	Physiotherapy professionals		
4.1	Within your service, can you access Parkinson's related continuing professional development (at least yearly)?	• Yes • No	Training includes in-service within the Trust/similar body/Board/Local Health Board or external courses
4.2	Are there any documented induction and support strategies for new physiotherapists working with individuals with Parkinson's?	• Yes • No	
4.3	What support (e.g. education, advice) is available to individual therapists working in the service?	• They can consult any member of the Parkinson's specialist MDT as they are a member • They can consult members of a general neurology/elderly care specialist service of which they are a member • They do not work directly in Parkinson's clinics but can readily access a Parkinson's MDT/Parkinson's Nurse Specialist • They do not work directly in a specialist clinic but can readily access advice from a specialist neurology or elderly care MDT • No support available	Choose one
	Clinical Practice		
5.1	How does your service offer assessment of a patient with Parkinson's?	• MDT assessment • Physiotherapy assessment • Other (please specify)	Tick all that apply
5.2	How do you usually see your clients with Parkinson's?	• Individually • In a group setting • Both individually and in groups	

		• In either a group or individual setting, but can refer to the other	
5.3	If your intervention includes group work, what needs are addressed in these groups?	• Education • Exercise • No group work • Other (please specify)	
5.4	Do you provide information about non-NHS/external services e.g. Parkinson's UK, leisure centre classes?	• Yes • No	
5.5	What physical self-management advice do you typically provide for your patients	• High intensity • LSVT-BIG • Parkinson's wellness and recovery (PWR) • Boxing • Alexander Technique • Tai Chi • Other (please specify)	Tick all that apply

Physiotherapy - patient audit

No.	Question	Answer options	Help notes
1. Demographics			
1.1	Patient identifier	This can be used by you to identify audited patients	This data will be removed by the data entry tool when you submit your data
1.2	Gender	• Male • Female • Other/patient prefers not to say	
1.3	Ethnicity	• White o British, o Irish o Traveller o Any other White background) • Asian/Asian British o Bangladeshi o Chinese o Indian o Pakistani o Any other Asian background • Black/Black British o African o Caribbean o any other Black background • Mixed/multiple ethnic backgrounds o mixed - White and Black o mixed White and Asian o mixed any other background) • Other	

		- Arab - Other - prefer not to say)	
1.4	Year of birth		
1.5	What setting does this client live in?	- Own home - Residential care home - Nursing home - Other (please specify)	
1.6	In what health setting was the patient seen?	- NHS – outpatient - NHS – community - Private clinic - At home - Other (please specify)	
1.7	Parkinson's phase	- Diagnosis - Maintenance - Complex - Palliative	Definitions of phases **Diagnosis** - From first recognition of symptoms/sign/problem - Diagnosis not established or accepted. **Maintenance** - Established diagnosis of Parkinson's - Reconciled to diagnosis - No drugs or medication 4 or less doses/day - Stable medication for >3/12 - Absence of postural instability. **Complex** - Drugs – 5 or more doses/day - Any infusion therapy (apomorphine or duodopa) - Dyskinesia - Neuro-surgery considered / DBS in situ - Psychiatric manifestations >mild symptoms of

		depression/anxiety/hallucinations/psychosis
		• Autonomic problems – hypotension either drug or non-drug induced
		• Unstable co-morbidities
		• Frequent changes to medication (<3/12)
		• Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues).
		Palliative
		• Inability to tolerate adequate dopaminergic therapy
		• Unsuitable for surgery
		• Advanced co-morbidity (life threatening or disabling).

2. Referral

Standard A: Consider referring people who are in the early stages of Parkinson's disease to a physiotherapist with experience of Parkinson's disease for assessment, education and advice, including information about physical activity (NICE 1.7.2)

2.1	Year of Parkinson's diagnosis		
2.2	Has the person received previous physiotherapy specifically for Parkinson's?	• Yes, please go to Q 2.3 • No, please skip to Q 3 • Offered but declined • Unknown	This question asks whether the person with Parkinson's had physiotherapy specifically for Parkinson's before the current referral.
2.3	Date of the first physiotherapy referral letter following initial diagnosis	(dd/mm/yyyy)	We are trying to establish the length of time between diagnosis and first referral to physiotherapy. If the actual date is not known please give the estimated year of that initial referral in the following format - 01/07/2018 (for July 2018)

3. Time from referral to initial assessment

3.1	Length of time between referral and the initial assessment	(Number of days)	

3.2	Was the referral urgent or routine?	• Urgent • Routine • Unknown	Urgent or routine may be stated on referral letter or the physiotherapy department/ physiotherapist may have decided whether to treat as urgent of routine according to details in the letter
3.3	Date of initial physiotherapy assessment	(dd/mm/yyyy)	If the actual date is not known please give the estimated month/year of that initial referral in the following – 01/07/2018 (for July 2018).
3.4	Did it meet your local standard for time from referral to initial assessment for urgent or routine?	• Yes • No • No local standard	The department /physiotherapist may have a local standard of seeing people with Parkinson's within a certain time frame e.g. 4 weeks from receipt of referral
3.5	Were reports made back to the referrer/other key people at the conclusion of the intervention period (or in interim reports where treatment lasts a longer time)?	• Yes • No, but will be done at the end of this intervention • No	

4. Implementation of national recommendations

Standard B: People with Parkinson's disease should have a comprehensive care plan agreed between the person, their family members and carers (as appropriate), and specialist and secondary healthcare providers. (NICE 1.1.5)

Standard C: Offer Parkinson's disease-specific physiotherapy for people who are experiencing balance or motor function problems. (NICE 1.7.3)

4.1	Do the physiotherapy notes include an action/goal plan?	• Yes • No	
4.2	Were Parkinson's-specific	• Yes (go to 4.3)	

	outcome measures used in this case?	• No (go to 4.4)	
4.3	If yes, please tick all that apply	• UPDRS • MDS – UPDRS • Lindop Parkinson's Assessment (LPAS) • Berg • Six minute walk distance • 10 metre walk • Time Up and Go (TUG) • Modified Parkinson's Activity Scale (M-PAS) Gait • Modified Parkinson's Activity Scale (M-PAS) Chair • Modified Parkinson's Activity Scale (M-PAS) Bed • Activities Balance Confidence scale (ABC) • Retropulsion Test • Push & Release Test • Tragus to wall • Five times sit to stand test (FTSTS) • Dynamic Gait index • Functional Gait Assessment • New Freezing of Gait Questionnaire • Rapid turns test • History of Falls Questionnaire • 3-Step Falls Prediction model • Goal attainment scaling • The Falls Efficacy Scale - International (Short FES-I) • Mini BEST • EQ-5D tool • Patient Specific Index for Parkinson's Disease (PSI-PD) • Other (please list)	

4.4	If no, why were no outcome measures used?	• Free text	
4.5	Was exercise advice/intervention offered to this individual?	• Yes • No	
	If yes, please tick all that apply	• High intensity • LSVT-BIG • Parkinson's wellness and recovery (PWR) • Boxing • Alexander Technique • Tai Chi • Other (please specify)	
5. About the physiotherapist			
5.1	What band (grade) is the physiotherapist who carried out the initial assessment of this person?	• 4 • 5 • 6 • 7 • 8a • 8b • 8c • Other	The Chartered Society of Physiotherapy Supervision, Accountability & Delegation – PD126, April 2017 document states that "initial assessment is expected to be made by a registered practitioner" who may then delegate ongoing treatment and re-assessment to support staff, such as Band 4.
5.2	Approximately what percentage of people seen by the audited physiotherapist in a year have Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown	

6. Evidence base			
6.1	Which of the following did the audited therapist use to inform clinical practice or guide intervention?	• Clinical experience • Advice from colleague or supervisor • European Physiotherapy Guideline for Parkinson's Disease (2013) • Quick Reference Cards (UK, 2009) • Information from Parkinson's UK website • NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017) • Published evidence in a peer reviewed journal (read within last 12 months) • Postgraduate training (e.g. attending courses/lectures specific to Parkinson's) within last 24 months • Other (please state) • None	Tick all that apply

Appendix A: Printable Patient Audit sheet
Use this to record your patient cases before entering the data on the online tool.

1. Demographics		
1.1	Patient identifier	
1.2	Gender	• Male • Female • Other/patient prefers not to say

1.3	Ethnicity	• White
		   o British,
		   o Irish
		   o Traveller
		   o Any other White background)
		• Asian/Asian British
		   o Bangladeshi
		   o Chinese
		   o Indian
		   o Pakistani
		   o Any other Asian background
		• Black/Black British
		   o African
		   o Caribbean
		   o any other Black background
		• Mixed/multiple ethnic backgrounds
		   o mixed - White and Black
		   o mixed White and Asian
		   o mixed any other background)
		• Other
		   o Arab
		   o Other
		   o prefer not to say

1.4	Year of birth	
1.5	What setting does this client live in?	• Own home • Residential care home • Nursing home • Other (please specify)
1.6	In what health setting was the patient seen?	• NHS – outpatient • NHS – community • Private clinic • At home • Other (please specify)
1.7	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative

2. Referral		
2.1	Year of Parkinson's diagnosis	
2.2	Has the person received previous physiotherapy specifically for Parkinson's?	• Yes, please go to Q 2.3 • No, please skip to Q 3 • Offered but declined • Unknown
2.3	Date of the first physiotherapy referral letter following initial diagnosis	(dd/mm/yyyy)

3. Time from referral to initial assessment		
3.1	Length of time between referral and the initial assessment (number of days)	
3.2	Was the referral urgent or routine?	• Urgent • Routine • Unknown
3.3	Date of initial physiotherapy assessment	(dd/mm/yyyy)
3.4	Did it meet your local standard for time from referral to initial assessment for urgent or routine?	• Yes • No • No local standard
3.5	Were reports made back to the referrer/other key people at the conclusion of the intervention period (or in interim reports where treatment lasts a longer time)?	• Yes • No, but will be done at the end of this intervention • No

4. Implementation of national recommendations		
4.1	Do the physiotherapy notes include an action/goal plan?	• Yes • No
4.2	Were Parkinson's-specific outcome measures used in this case?	• Yes (go to 4.3) • No (go to 4.4)

4.3	If yes, please tick all that apply	• UPDRS • MDS – UPDRS • Lindop Parkinson's Assessment (LPAS) • Berg • Six minute walk distance • 10 metre walk • Time Up and Go (TUG) • Modified Parkinson's Activity Scale (M-PAS) Gait • Modified Parkinson's Activity Scale (M-PAS) Chair • Modified Parkinson's Activity Scale (M-PAS) Bed • Activities Balance Confidence scale (ABC) • Retropulsion Test • Push & Release Test • Tragus to wall • Five times sit to stand test (FTSTS) • Dynamic Gait index • Functional Gait Assessment • New Freezing of Gait Questionnaire • Rapid turns test • History of Falls Questionnaire • 3-Step Falls Prediction model • Goal attainment scaling • The Falls Efficacy Scale - International (Short FES-I) • Mini BEST • EQ-5D tool • Patient Specific Index for Parkinson's Disease (PSI-PD) • Other (please list)
4.4	If no, why were no outcome measures used? (free text)	
4.5	Was exercise advice/intervention offered to this individual?	• Yes • No
	If yes, please tick all that apply	• High intensity • LSVT-BIG • Parkinson's wellness and recovery (PWR) • Boxing • Alexander Technique • Tai Chi • Other (please specify)

5.	About the physiotherapist	
5.1	What band (grade) is the physiotherapist who carried out the initial assessment of this person?	• 4 • 5 • 6 • 7 • 8a • 8b • 8c • Other
5.2	Approximately what percentage of people seen by the audited physiotherapist in a year have Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown