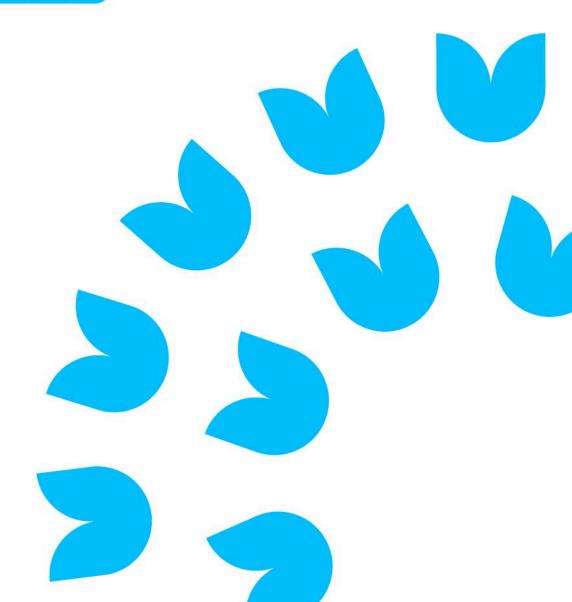




2025 UK Parkinson's Audit

Occupational therapy

Guidance document



2025 UK Parkinson's Audit Occupational therapy

Audit of national standards relating to Parkinson's care, incorporating the Parkinson's NICE guideline,¹ NICE quality standards² and other relevant evidence-based guidelines.

Aim

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

Objectives

- To encourage occupational therapists 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 and quality improvement initiatives 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 occupational therapy 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 seventh round in which occupational therapists will be able to take part, along with physiotherapists and speech and language therapists. Consultants in

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

² Nice Quality Standard QS164 <u>https://www.nice.org.uk/guidance/qs164</u>

elderly care and neurology (and their Parkinson's nurses) can participate in the parallel patient management audit and there is a separate audit for inpatient pharmacy services.

The audit questions for this round have been refined to reflect feedback from the 2022 audit.

Standards

The occupational therapy audit has been structured according to *Occupational therapy for people with Parkinson's*: *Best Practice Guide*³ and the National Service Framework for Long Term Conditions⁴. It has also been structured according to principles of occupational therapy for Parkinson's, as outlined by the NICE guideline⁵ and Quality Standards.⁶

The principles of occupational therapy for Parkinson's include:

- early intervention to establish rapport, prevent activities and roles being restricted or lost and, where needed, to develop appropriate coping strategies
- client centred assessment and intervention
- development of goals with the individual and carer, with regular review

www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-termconditions

⁶ Quality Statement 3:

³ Aragon A, Kings J (2018) Occupational therapy for people with Parkinson's: 2nd edition. London: *RCOT.* Available at

http://www.parkinsons.org.uk/sites/default/files/publications/download/english/otparkinsons_guid elines.pdf

⁴ Department of Health. *National Service Framework for Long Term Neurological Conditions*. (2005) Available at:

⁵ National Institute of Health and Care Excellence. Parkinson's Disease in Adults NG71. (2017) Available at <u>https://www.nice.org.uk/guidance/ng71</u>

https://www.nice.org.uk/guidance/qs164/chapter/Quality-statement-3-Referral-to-physiotherapyoccupational-therapy-or-speech-and-language-therapy

 employment of a wide range of interventions to address physical and psychosocial problems to enhance participation in everyday activities, such as self care, mobility, domestic and family roles, work and leisure (NICE NG71 2017, quoted in Occupational therapy for people with Parkinson's: Best Practice Guide second edition 2018 p15)

The NICE guideline (2017, p17) states that people who are in the early stages of Parkinson's disease should be referred to an occupational therapist with experience of Parkinson's disease for assessment, education and advice on motor and non-motor symptoms and to offer Parkinson's disease-specific occupational therapy for people who are having difficulties with activities of daily living.

Methodology

This audit is open to all occupational therapy services and individual occupational therapists 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 occupational therapy have been transformed into a set of audit standards and statements reviewed by specialist occupational therapists. 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 people with idiopathic Parkinson's referred to an occupational therapy service and seen during the audit data collection period, which runs from 1 May 2025 to 30 September 2025.

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 a review appointment (irrespective of whether they then go to start another episode 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).

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 by a member of the team familiar with the service set-up and running).
- The **patient audit** section allows you to enter data on individual patients. These include both newly seen people with Parkinson's and follow ups, but each person should only be documented once, even if they attend more than once during this period.

A printable version of the patient case form that you can use to record data in your clinics is available on the audit web page.

Data entry must be completed by 31 October 2025 when the data will be downloaded for analysis.

'No, but...' answers

A 'No, but...' answer implies there is a pre-determined accepted reason for noncompliance 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 all identifiable information removed from it.⁷

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.

Participating therapists

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

⁷ Health Professionals Council. Available at

https://www.hcpc-uk.org/registration/meeting-our-standards/guidance-on-confidentiality and can't be accessed by other people. Colleagues will be able to collect and enter data for the audit, and you will be able to 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 the Clinical Audit Manager, members of the Clinical Steering Group and the Data Analyst who will carry out the data analysis

Raw data will not be accessible in the public domain.

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 2022. These patients do not necessarily have to be those included in the main clinical audit.

The questionnaire asks 10 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 patient information leaflets
- 50 x sealable envelopes
- 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. Services from different specialties who work as part of one multidisciplinary team and see the same cohort of patients can combine their PREM forms - just enter all of the appropriate service numbers on each form.

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

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. The full data tables will also be available, along with a list of 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 UK-wide reports will also be in the public domain via the Parkinson's UK website. Individual Service Reports are only accessible within the relevant Trust.

How the data will be used

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, as well as guide the development of UK-wide quality improvement initiatives.

Parkinson's UK Excellence Network

The Parkinson's UK 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 with 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 Parkinson's UK's full range of <u>information and support</u> to allow people to take control of the condition
- services will be involved in continuous quality improvement through audit and engagement of service users in improvement projects.

Thank you for your participation in the 2025 UK Parkinson's Audit

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Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A company limited by guarantee. Registered in England and Wales (948776). Registered office: 50 Broadway, London SW1H 0DB. A charity registered in England and Wales (258197) and in Scotland (SC037554)

Occupational therapy - Service Audit

No.	Question	Data items/answer options	Help notes
You	r details		
1.1	Name of Lead Therapist completing the Service Audit	Free text	
1.2	Contact email of Lead Therapist completing the service audit	Free text	
Serv	ice Description		
2.1	Describe the setting in which you usually see individuals with Parkinson's	 Integrated medical and therapy Parkinson's clinic Outpatient rehabilitation in acute services Community rehabilitation service Social services including reablement Individual's home 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?	YesNo	

2.3	Does your service specialise in the treatment of individuals with Parkinson's?	YesNo	
Indiv	viduals 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% 	
Οςςι	pational therapy Professionals		
4.1	Within your service, can you access Parkinson's related continuing professional development (at least yearly)?	YesNo	Training includes in-service within the Trust/similar body/Board/Health Board or external courses
4.1a	If yes, have you accessed Parkinson's-related continuing professional development in the last 18 months?	YesNo	
4.2	Are there any documented induction and support strategies for new occupational therapists working with individuals with Parkinson's?	 Yes, specifically in relation to patients with Parkinson's Yes, as part of more general competencies 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
Clini	cal Practice		
5.1	How does your service approach assessment of an individual with Parkinson's?	MDT assessmentOT specific assessmentBoth	Choose one
5.2	How is the assessment undertaken?	 Interview with patient and carer Assessment during group work Functional assessment Standardised assessment 	Tick all that apply

5.3	How do you usually see your patients with Parkinson's?	IndividuallyIn a group settingBoth individually and in groups	Choose one
5.4	How are patients seen?	 In person Virtually - by video Virtually - by telephone 	Tick all that apply
5.5	Are outcome measures being used?	YesNo	https://www.rcslt.org/wp-content/upload s/media/docs/selecting-outcome-meas ures.pdf
5.5a	If yes, what type?	 Self reported Clinician administered Report by family/carer Service data 	Self report includes Patient Reported Outcome Measure (PROM), Patient Reported Experience Measure (PREM), satisfaction measures
5.7	Where do you carry out the intervention?	 Individual's home Community setting (e.g. workplace or day centre) Outpatient/day hospital/centre Hospital 	Choose one
5.8	Do you use any digital technology within your service?	 Yes Not available locally, but would like to No 	

5.8a	If yes, do you use any of the following:	 Digital assistants (Alexa, Google Home) Wearable devices (Smart watch) Mobile health apps
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Occupational therapy - patient audit

	Question	Data items/answer options	Help notes
1.	Demographics		
1.1	Patient identifier		Used locally to identify audited patients
1.2	Gender	 Male Female Other/patient prefers not to say 	
1.3	Ethnicity	 White British Irish Gypsy or Irish Traveller Roma Any other White background Asian/Asian British Bangladeshi Chinese Indian Pakistani Any other Asian background Black/Black British/Caribbean/African African 	

		 Caribbean any other Black background Mixed/Multiple ethnic groups Asian and White Black African and White Black Caribbean and White Any other Mixed/Multiple background Other ethnic group Arab Any other ethnic group prefer not to say
1.4	Year of birth	
1.5	What setting does this patient live in?	 Own home Residential care home Nursing home Other (please specify)
1.6	In what setting was the individual seen?	 NHS - outpatient NHS - community Private clinic At home Other (please specify)

1.7	How was this person assessed?	 In person Virtually - by video Virtually - by telephone 	Tick all that apply
1.8	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. Re1	ferral		
	- · ·		Parkinson's disease to an occupational therapist d advice on motor and non-motor symptoms.
		ave access to all relevant records and	ant health agencies leading to individual care d background information about the person's
	improving the quality of life of p with long term neurological cor	eople with longterm neurological cor aditions is provided when local health	port needs and to the delivery of services is key to nditions. The most effective support for people and social services teams communicate; have ogether to provide coordinated services. (NSF QR1
2.1	Year of Parkinson's diagnosis		

2.2	Has the person received previous occupational therapy specifically for Parkinson's?	 Yes No (go to Q2.4) Offered but declined (go to Q2.4) Unknown (go to Q2.4) 	
2.2a	If yes, what was the year of first referral?		Year or unknown
2.3	When the person was first referred to any OT service, at what stage of their Parkinson's were they?	 Diagnosis Maintenance Complex Palliative Unknown 	
Curre	ent episode of care		
2.4	Who made the referral to OT?	 Elderly care consultant Neurologist Parkinson's nurse specialist General/non-PDNS nurse GP Allied health professional colleague (physio/SLT) Dietician Social care worker Self-referral/relative Other (please specify) Unknown 	
2.5	What was the time between the date of the referral and the date	 1 to 4 weeks 5 to 8 weeks	

of the initial appointment for this episode of care?	9 to 12 weeks13 to 18 weeksMore than 18 weeks	Where an open referral system is operating, this is the current episode of care, i.e. each episode of care is considered a 'new' referral
Vhat was the reason for referral o OT?	 Staying well: Health and well-being promotion Education Self-management Family roles and relationships Sexual intimacy Work Leisure activities Community skills Driving Optimising function: Mobility Falls prevention Transfers Bed mobility Posture and seating Eating and drinking Personal care Domestic skills Fatigue management Handwriting and communication 	Tick all that apply

		 Cognitive and emotional well-being Engagement / motivation Equipment provision/ environmental adaptations Carer support Moving and handling guidance Pressure care management 	
2.7	Was a letter sent to the referrer?	YesNo	
2.7a	lf no:	 Not current practice Therapy ongoing but letter to be sent on completion No requirement as discussed directly with referrer at MDT review 	
	If yes:		
2.7b	Did the letter include details of the therapy assessment?	YesNo	
2.7c	Did the letter include therapy outcome scores?	YesNo	
2.7d	Did the letter include an intervention plan?	YesNo	

2.8	Was the reason for referral reflective of patient need?	 Yes - OT intervention for referral reason only Yes - but additional OT needs identified No - referral to OT was not appropriate 	
3. Go	als identified		
	their family members and care 1.1.5) Standard D: Development of go	rs (as appropriate), and specialist ar als in collaboration with the individue	nensive care plan agreed between the person, nd secondary healthcare providers. (NICE NG71 al and carer with regular review. (Occupational of Occupational Therapists, 2018, p15).
3.1	Were therapy goals set in collaboration with the patient and/or carer?	YesNo	
3.2	Were standardised assessments used with this patient?	YesNo	
3.2a	If yes, what areas were you assessing for?	 Activity, function, participation Cognition Mood Fatigue Goal setting Health and wellbeing 	Tick all that apply

4. In	tervention strategies used		
	idard E: Offer Parkinson's disease / living. (NICE NG71 1.7.6)	-specific occupational therapy for pe	eople who are having difficulties with activities of
4.1	What was the main approach of your therapeutic interventions?	EducationalRestorativeCompensatory	Choose one
4.2	Which areas of intervention were addressed?	 Staying well: Health and well-being promotion Education Self-management Family roles and relationships Sexual intimacy Work Leisure activities Community skills Driving 	Tick all that apply
		 Optimising function: Mobility Falls prevention Transfers Bed mobility Posture and seating 	

	 Eating and drinking Personal care Domestic skills Fatigue management Handwriting and communication Cognitive and emotional well-being Engagement / motivation Equipment provision/ environmental adaptations Carer support Moving and handling guidance Pressure care management
 5. About the Occupational Therapy 5.1 What band (grade) is the occupational therapist who carried out the initial assessment of this person? 	 4 5 0

5.2	Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?	0-19% 20-39% 40-59% 60-79% 80-99% 100% Unknown	
6. Ev	idence base		
6.1	Which of the following did the audited therapist use to inform clinical practice or guide intervention?	Own Clinical experienceTick all that applyAdvice from colleague orsupervisorOccupational therapy for peoplewith Parkinson's - best practiceguide 2nd edition (2018)national Service Framework forLong term Conditions (2005)NICE - Parkinson's disease:diagnosis and management inprimary and secondary care(2017)Progressive NeurologicalConditions toolkit 2019Allied Health Professionals'competency framework forprogressive neurologicalconditions0	

	 Published evidence in a peer reviewed journal (read within last 12 months) Information from Parkison's UK website' Postgraduate training (eg attending course/lectures specific to Parkinson's) within last 24 months Other (please specify) None 	
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