

2019 UK Parkinson's Audit

Executive summary

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This executive summary outlines the key findings of the 2019 UK Parkinson's Audit. The audit measures the quality of care provided to people living with Parkinson's in comparison with a range of evidence-based guidance about the care of people with the condition.

This UK-wide audit takes a multi-professional approach, involving Elderly Care and Neurology consultants, who care for people with movement disorders. It also includes Parkinson's nurses, occupational therapists, physiotherapists and speech and language therapists who also care for people with Parkinson's. The audit engages services within these professions to measure the quality of their practice, within their model of care provision, and trigger service improvement plans.

This audit reports on the care provided to 10,335 people with Parkinson's during the five month data collection period. This is a 9% increase in the number of patients compared with the 2017 audit.

8,247 people with Parkinson's and their carers contributed to the Patient Reported Experience Measure (PREM) questionnaire, giving them the opportunity to provide their views on the service they attend.

Key messages:

- There have been improvements in many areas since 2017
- There is still work to be done across all specialties in the following areas:
 - specialised multidisciplinary working
 - standardised practices
 - communication and information sharing
 - medicines management
 - supporting the workforce
- The Summary Report provides examples of work being done in response to the challenges highlighted by the audit.

Elderly Care and Neurology

Evidence of good practice

- Timely specialist review.
- Access to a Parkinson's Nurse or equivalent.
- Written information routinely available.

- Significant improvement in the percentage of patients given advice about Lasting Power of Attorney.
- Signposting to Parkinson's UK.

Areas for Improvement

- Multidisciplinary team approach.
- Documentation regarding potential side effects of medication.
- Mental Health: screening, referral access and clozapine.
- Review of bone health.
- Care of people in work who have Parkinson's.
- Uptake of Parkinson's related continuing professional development (CPD) by clinicians, especially Neurologists.

Occupational therapy

Evidence of good practice

- Increase in occupational therapy services participating in the audit.
- Use of practical guidance and support.
- Access to Parkinson's related CPD.
- Goals are set in collaboration with the individual and carer.

Areas for improvement

- Provision of induction and support for new occupational therapists working with people with Parkinson's.
- Use of evidence-based practice rather than reliance on clinical experience and peer support.
- Use of standardised assessments and outcome measures to guide occupation-based intervention.
- Use of outcome measures to support service development.
- Earlier referral to occupational therapy with optimal communication exchange.

Physiotherapy

Evidence of good practice

- Increase in physiotherapy therapy services participating in the audit.
- Provision of advice and intervention regarding physical activity and exercise.
- Increase in the number of people with Parkinson's referred to physiotherapy within two years of diagnosis.

Areas for improvement

- Provision of induction and support for new physiotherapists working with people with Parkinson's.
- Initial assessment should be carried out by qualified physiotherapist rather than unregistered therapy support staff (e.g. Band 4).
- Use of appropriate outcome measures for people with Parkinson's based on guidelines and best practice.

Speech and Language therapy

Evidence of good practice

- For the first time more than half of services offer Lee Silverman Voice Treatment.
- Good documentation of the impact of Parkinson's on communication and communication participation.
- There was a clear plan of management based on assessment outcomes documented for most patients.

Areas for improvement

- Provision of induction and support for new speech and language therapists working with people with Parkinson's
- Earlier referral: most continue to be referred in the maintenance phase.
- Recording whether patients were "on" or "off" at assessment.
- Use of standardised intelligibility assessments for people with Parkinson's.
- Few communication assessments included an audio/video recording.
- Few had word finding difficulties included as part of communication assessment.

PREM

Areas of satisfaction

- As in the 2015 and 2017 audit, most people with Parkinson's or their carers are satisfied with the frequency of review by their Parkinson's nurse.
- Small but significant increase in access to physiotherapy and speech and language therapy and ability to contact these services between scheduled visits.
- Three quarters of respondents had been signposted to Parkinson's UK.
- Just over three quarters had an enquiry into balance and falls.

Areas of concern

- A small but significant decrease in the percentage of respondents who feel that the frequency of review by their Parkinson's specialist doctor meets their needs, despite 90.4% rating that the quality of service they receive is excellent or good.
- As in 2017 only 61% felt that they received enough information at diagnosis.
- One third felt that they were not given enough information, or were not sure if they were given enough information, when starting new medication.
- Just less than half of those admitted to hospital always received their medication on time.
- Only two in five were asked and/or raised concerns regarding constipation.

For more detail on these key findings, and the recommended actions, please see the audit Summary Report. The complete data tables, details of the audit design and methods, participating services, and the audit and PREM questions can be found at **parkinsons.org.uk/audit**

The UK Parkinson's Excellence Network is the driving force for improving Parkinson's care, connecting and equipping professionals to provide the services people affected by the condition want to see.

The tools, education and data it provides are crucial for better services and professional development.

The network links key professionals and people affected by Parkinson's, bringing new opportunities to learn from each other and work together for change.

parkinsons.org.uk/excellencenetwork