UK PARKINSON'S
Excellence
Network

# 2017 UK Parkinson's Audit

## Summary report

## Contents

## Foreword

The 2017 UK Parkinson’s Audit provides the largest ever dataset about the quality of care provided to people with Parkinson’s across the UK. The number of UK Parkinson's services taking part has increased with each audit since its inception in 2010. The 2017 audit has delivered a 10% uplift in participation, compared with the previous 2015 audit, with the UK Parkinson's Excellence Network providing the infrastructure to help reach and engage services not previously involved in UK benchmarking and quality improvement. The unprecedented level of participation speaks volumes about the commitment and dedication of so many UK doctors, nurses, occupational therapists, physiotherapists and speech and language therapists to improving services for people with Parkinson’s.

As in 2015, this summary report confirms many areas of good practice, with professionals working to evidence-based standards. It is encouraging, for example, that 98.1% of patients attending Elderly Care and Neurology services had received a specialist review in the preceding 12 months. The views of people with Parkinson’s, gathered as part of the audit process, also illustrate some excellent examples of care. Most are satisfied with the frequency of review by medical staff, and over three quarters rate the service provided by their health care practitioner as excellent or good.

Overall, it is pleasing to see real progress in some of the priority areas where shortfalls were identified by the 2015 audit, particularly in the context of NHS pressures. But there is still room for improvement in relation to a number of those priorities.

For example, while there has been an overall uplift in reported access to key members of a multi-disciplinary team, relatively few patients were referred in the early phase, as recommended by *The NICE guideline for Parkinson’s disease in adults*. Meanwhile, 27.8% of the Elderly Care and Neurology services taking part in the audit are ‘doctor alone’ clinics, and 10.8% see few or none of their patients in specific Parkinson’s or movement disorder clinics.

In terms of standardised assessment and practice, assessment of several non-motor areas could still be improved. Key areas include the documentation of potential side effects relating to all dopaminergic therapies, and enquiries about saliva and pain. It is encouraging that 75.8% of respondents to the Patient Reported Experience Measure (PREM) questionnaire had been asked about balance and falls. However, lack of attention to bone health continues to be an area of concern. The results also highlighted a continuing lack of specific induction and support strategies for working with people with Parkinson’s across the therapies.

The results of this audit and feedback from service users are a hugely important catalyst for change and it's crucial that the results are used to trigger quality improvement for people affected by Parkinson's. While the prospect of setting out on a quality improvement process can be daunting in the context of busy services, simple adjustments to practice and processes can often make an important difference to service quality that can be demonstrated through subsequent audits. Across the UK Parkinson's Excellence Network there are many practical and effective improvements that can be implemented locally and further support, including help with more complex service redesign, is available from Parkinson's UK service improvement advisers.

Overall, it's extremely encouraging to see progress being made towards the goal of quality services for everyone affected by Parkinson's. To fully achieve this goal a continued shared focus is needed to tackle the priority areas for improvement emerging from this audit.

## Introduction

This summary report outlines the most significant findings of the 2017 UK Parkinson's Audit. A reference report of all the audit results is also available. It includes details of the audit's design and methods, the participating services, the dataset and the Patient Reported Experience Measure (PREM) questionnaire.

The 2017 UK Parkinson's audit (the sixth to be completed) represents the largest UK audit of Parkinson's to date. This summary report refers to the PREM results where they relate to 2017 audit data, and also reports on key PREM findings (the complete PREM results are available in the reference report).

## Background

The UK-wide clinical audit was originally developed to address the concerns of professionals, patients and their representatives about the quality of care provided to people with Parkinson's. The audit uses evidence-based clinical guidelines (listed in the reference report) as the basis for measuring the quality of care in the outpatient setting. In 2015, the PREM was introduced, offering patients and carers the opportunity to identify areas of good practice or highlight deficiencies in their own care.

The NHS is under unprecedented challenge. This makes it more important than ever to look closely at what Parkinson's services are delivering and work together through the UK Parkinson's Excellence Network to share evidence and best practice that can improve standards of care.

The design of the audit has been changed from cycle to cycle. This reflects a shift in focus from early diagnosis and intervention for people newly diagnosed with Parkinson's, to the effective continuous management of patients within a multidisciplinary team. As a result this report draws on separate audits from doctors and Parkinson's nurses, occupational therapists, physiotherapists, and speech and language therapists. Where relevant, the results presented here (as percentages, as audited services differ from cycle to cycle) are compared with those from previous cycles. The questions are identical to those in the 2015 audit, with a few exceptions, which allows direct comparison. Details of any changes can be found in the reference report.

In February 2018 the *National NICE quality standard for Parkinson's disease* was published. (QS164, National Institute for Health and Care Excellence) The five quality statements describe high-quality care in priority areas for improvement. This UK-wide audit underpins the NICE quality measure process for the majority of the statements.

The audit continues to serve two main roles within the UK Parkinson's Excellence Network, providing an important baseline against which progress can be measured and informing national, regional and local service improvement priorities and plans to achieve better services for people living with the condition.

## Executive summary

This executive summary outlines the key findings of the 2017 UK Parkinson’s Audit. The audit measures the quality of care provided to people living with Parkinson’s against 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 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 9,480 people with Parkinson’s during the five month data collection period. This is 7% more than the number of patients in the 2015 audit.

In addition, 6,446 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 2015
- There is still work to be done across all specialisms in the following areas:
    - specialised multidisciplinary working
    - standardised practices
    - communication and information sharing
    - medicines management
    - anticipatory care planning
- 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***

- Documentation of advice given about potential side effects of new medication.
- Timely specialist review - 98.1% of patients audited in Elderly Care and Neurology services had received a specialist review in the preceding 12 months.
- Increased signposting to Parkinson’s UK.

- Improvement in the percentage of patients in the palliative phase given advice about Lasting Power of Attorney.

***Areas for Improvement***

- A multidisciplinary approach to working.
- Recording of blood pressure and weight in Neurology clinics and of pain and saliva in both Elderly Care and Neurology clinics.
- Uptake of Parkinson's-related continuing professional development (CPD) by clinicians.
- Documentation of advice regarding potential impulse control disorders for all dopaminergic therapy.
- Management of bone health.
- Anticipatory care planning.

**Occupational therapy**

***Evidence of good practice***

- Use of practical guidance and support.
- Access to Parkinson’s related CPD.
- Therapists are specialists in neurological conditions.

***Areas for improvement***

- Specialist induction.
- 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.

**Physiotherapy**

***Evidence of good practice***

- Increase in the number of people with Parkinson's referred to physiotherapy within two years of diagnosis.
- Increase in the number of physiotherapy services specialising in Parkinson's.
- High number of physiotherapists able to access Parkinson's-related continuing professional development (CPD) in the past 2 years.
- Increase in the number of physiotherapists using *The European physiotherapy guideline for Parkinson’s disease* to inform practice.

*Areas for improvement*

- Use of appropriate outcome measures for people with Parkinson's based on guidelines and best practice.
- Physiotherapists not using outcome measures.
- Provision of induction and support for new physiotherapists working with people with Parkinson's.
- Initial assessment by unregistered therapy support staff (e.g. Band 4).
- Referral to physiotherapy for patients in the diagnosis phase.

**Speech and Language therapy**

*Evidence of good practice*

- Patients continue to receive a timely service for communication and swallowing.
- More patients are able to access Lee Silverman Voice Treatment.
- There is consistent consideration of the impact of communication difficulties on participation in activities of daily living.
- Patients are consistently given information and support including around anticipatory planning.
- Therapists are accessing continuing professional development in the field.

*Areas for improvement*

- Patients continue to be referred in the maintenance phase rather than in the early phase as recommended by NICE.
- Inconsistent use of appropriate standardised assessments for people with Parkinson’s that are based on best practice.
- Test results, on which management plans or reports are based, are not fully documented.
- Parkinson’s-specific induction for therapists new to working with Parkinson’s.

**PREM**

*Areas of satisfaction*

- As in the 2015 audit, most people with Parkinson’s or their carers are satisfied with the frequency of review by medical staff and their Parkinson’s nurse, and over three quarters rate the service provided by their health care practitioners as excellent or good.
- Three quarters of respondents had been signposted to Parkinson’s UK.
- Just over three quarters had had an enquiry into balance and falls.

- There has been an improvement in the percentage of drivers advised to contact the DVLA and their insurance company from 73% in 2015 to 84% in the 2017 audit.

***Areas of concern***

- Only 61% felt they received enough information at diagnosis.
- Only two in five of those admitted to hospital in the last year always received their medication on time.
- A third felt that they were not given enough information, or were not sure if they were given enough information, when starting new medication.
- 1 in 8 felt their service needed to improve.

## Services taking part and patients included

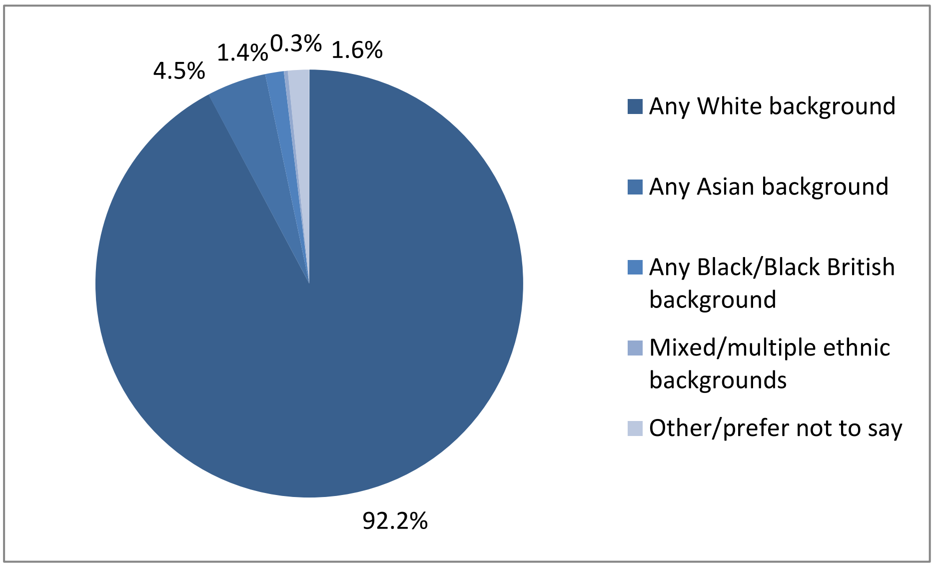
Table 1: Number of each type of service and characteristics of people with Parkinson's included in the audit

| | Elderly care | | Neurology | | Occupational therapy | | Physiotherapy | | Speech and Language therapy | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Services | 138 | | 121 | | 59 | | 95 | | 64 | | 477 | |
| Patients | 3397 | | 3046 | | 713 | | 1514 | | 810 | | 9480 | |
| Patient characteristics | | | | | | | | | | | | |
| Age (years) | | | | | | | | | | | | |
| **Mean (SD)** | 77.0 (8.1) | | 71.5 (9.9) | | 75.1 (9.6) | | 73.8 (9.4) | | 73.8 (9.6) | | 74.3 (9.5) | |
| **(range)** | (41-98) | | (23-96) | | (17–95) | | (27-97) | | (22-96) | | (17-98) | |
| Gender | | | | | | | | | | | | |
| | | % | | % | | % | | % | | % | | % |
| **Male** | 2068 | 60.9 | 1848 | 60.7 | 441 | 61.9 | 946 | 62.5 | 579 | 71.5 | 5882 | 62.0 |
| **Female** | 1329 | 39.1 | 1198 | 39.3 | 272 | 38.2 | 568 | 37.5 | 231 | 28.5 | 3598 | 38.0 |
| Duration of Parkinson's (years) | | | | | | | | | | | | |
| **Mean (SD)** | 5.6 (4.9) | | 6.1 (5.4) | | 6.2 (5.9) | | 5.2 (5.2) | | 6.0 (5.8) | | 5.8 (5.3) | |
| **Median** | 4 | | 5 | | 4 | | 4 | | 4 | | 4 | |
| **(range)** | (0–38) | | (0–42) | | (0–32) | | (0–35) | | (0–37) | | (0–42) | |
| Phase of Parkinson's | | | | | | | | | | | | |
| | | % | | % | | % | | % | | % | | % |
| **Diagnosis** | 400 | 11.8 | 372 | 12.2 | 113 | 15.9 | 255 | 16.8 | 85 | 10.5 | 1225 | 12.9 |
| **Maintenance** | 1726 | 50.8 | 1587 | 52.1 | 328 | 46.0 | 806 | 53.2 | 484 | 59.8 | 4931 | 52.0 |
| **Complex** | 1172 | 34.5 | 981 | 32.2 | 259 | 36.3 | 434 | 28.7 | 223 | 27.5 | 3069 | 32.4 |
| **Palliative** | 99 | 2.9 | 106 | 3.5 | 13 | 1.8 | 19 | 1.3 | 18 | 2.2 | 255 | 2.7 |

Note: minor discrepancies in totals are accounted for by a small amount of missing data

The services taking part are not necessarily the same ones which took part in the audit in 2015, although many are re-auditing their practice this time.

Figure 1: Ethnicity of people with Parkinson's included in the audit

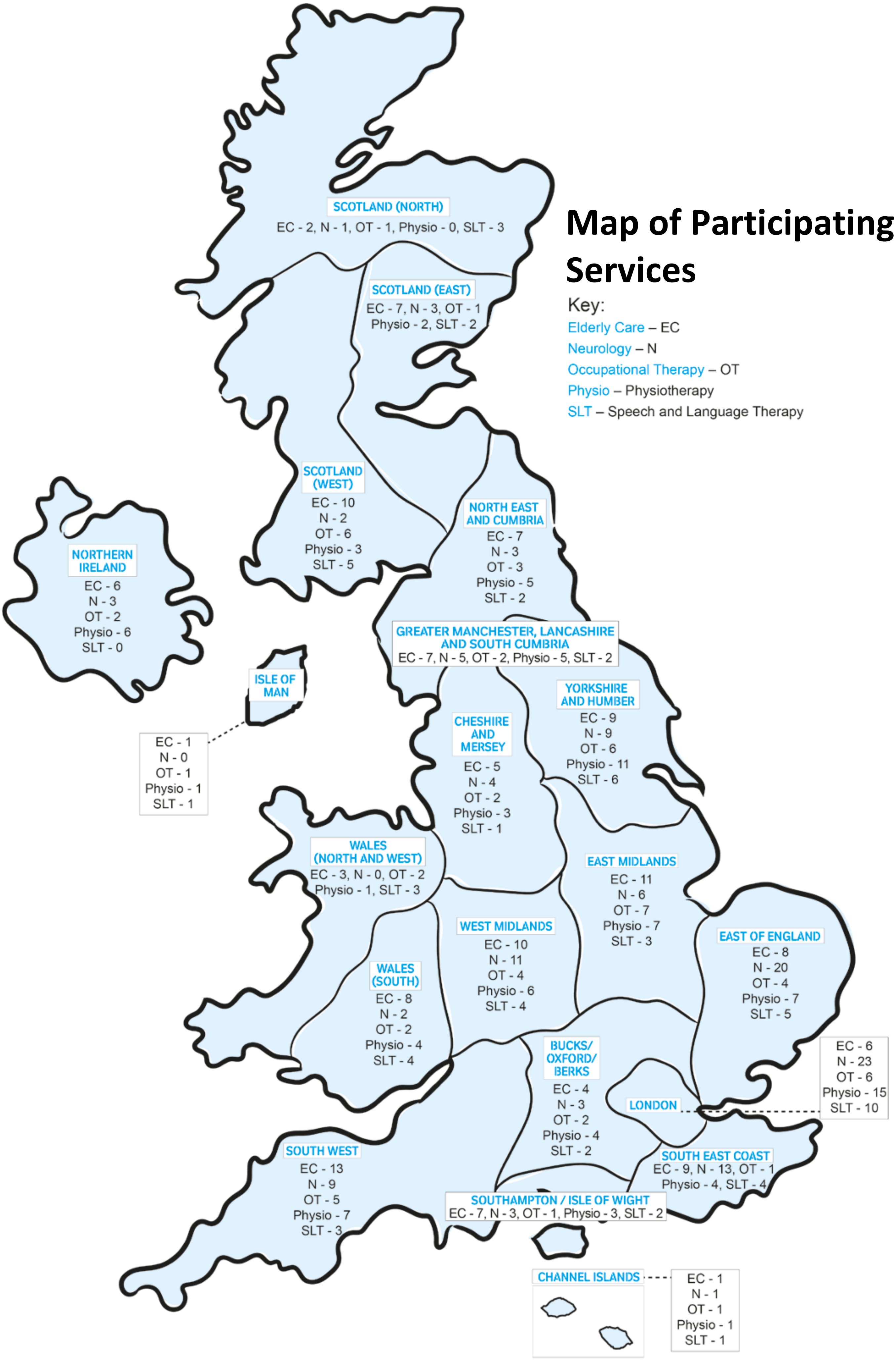


## The PREM questionnaire

In addition to the audit data, 6,446 people with Parkinson’s and their carers attending 329 (68.9%) of the participating services completed the PREM questionnaire. These are not necessarily the same patients as those included by the services in their patient audit.

# Map of Participating Services

Key:
Elderly Care – EC
Neurology – N
Occupational Therapy – OT
Physio – Physiotherapy
SLT – Speech and Language Therapy



## Selected audit findings

## Elderly Care and Neurology

### Aims

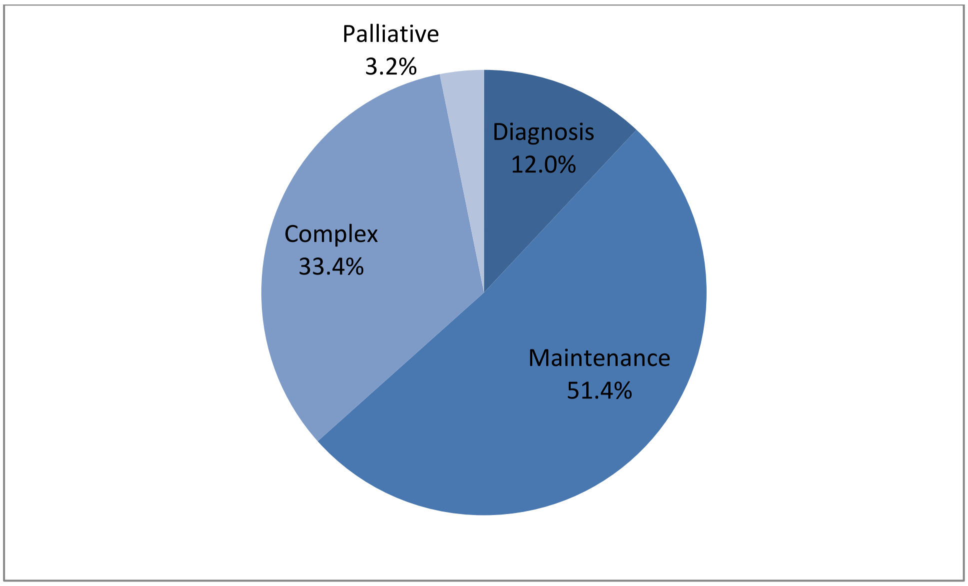
These audits are intended to measure the quality of assessment and management of people with Parkinson's attending Elderly Care[1] and Neurology clinics, and also to describe the models of service delivery used. They allow benchmarking of services against standards of good practice and guidance relating to the quality of care for people with Parkinson's.

### Demographics

Elderly Care and Neurology services saw 6,443 people with Parkinson's, who were included in the audit. These patients were aged between 23 and 98 years (mean: 74.4, standard deviation (SD) 9.4 years), and the majority were male (60.8%). Patients seen at Neurology services (mean age: 71.5, SD 9.9 years) tended to be younger than in Elderly Care (mean age: 77.0, SD 8.1 years).

Mean age at diagnosis was 68.6 years (SD 10.7 years) (Elderly Care: 71.5 SD 9.6; Neurology: 65.4 SD 9.9), and patients audited had a mean Parkinson's duration of 5.8 years (SD 5.2, range 0–49 years). The distribution of phase of Parkinson's was very similar across Elderly Care and Neurology audits (see Figure 2).

Figure 2: Patients in each Parkinson's phase (across both Elderly Care and Neurology)



---

[1] Elderly care refers to services provided by a geriatrician.

## Service audit

### *Model of service provision*

Parkinson’s is a complex, chronic condition, and people with Parkinson’s receive the best care within specialist Parkinson’s or movement disorder clinics. In the specialist clinic setting, this is supported by an integrated approach provided by an expert multidisciplinary team. This ensures the best quality of life for the person with Parkinson’s and their families.

a) Specialist clinics

95.6% of audited Elderly Care services see all or most of their patients in specialist clinics compared with 87.6% in the 2015 audit. Neurology services have remained at a similar level to previous audits with 57.9% seeing all or most of their patients in specific clinics (60% in 2012 and 62.8% in 2015). Disappointingly 10.8% of all services still see few or none of their patients in dedicated clinics, although this figure is significantly lower in Elderly Care (2.2%) than in Neurology (20.7%).This figure is similar to 2015 where 11.7% of all services saw few or none of their patients in dedicated clinics.

Table 2: Patients seen within specific Parkinson’s/movement disorder clinics

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---:|---:|---:|
| All patients | 65.9% | 31.4% | 49.8% |
| Most patients (>75%) | 29.7% | 26.5% | 28.2% |
| Some patients (25–74%) | 2.2% | 21.5% | 11.2% |
| Few patients (<25%) | 1.5% | 5.8% | 3.5% |
| None | 0.7% | 14.9% | 7.3% |
| Number: | 138 | 121 | 259 |

b) Integrated clinics

The fully integrated clinic model (i.e. a multidisciplinary team consisting of consultant(s), Parkinson’s nurse and therapists all seeing patients within the same clinic venue) is only available at 13.5% of all clinics (compared to 12.6% of services audited in 2015). Encouragingly, although this continues to be more common for Elderly Care, a growing number of Neurology services audited provide integrated services (12.4% compared with 5.5% in 2015).The most common model of service provision continues to be a joint or parallel doctor and nurse specialist clinic (58.7% of audited services in 2017, 59% in 2015). An unchanged and significant proportion of clinics in both Elderly Care and Neurology remain staffed by a doctor alone (27.5% and 28.1% respectively).

Table 3: Most common model of service provision for medical input in each service

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---|---|---|
| Doctor alone | 27.5% | 28.1% | 27.8% |
| Joint/parallel doctor and nurse specialist clinics | 58.0% | 59.5% | 58.7% |
| Integrated clinics | 14.5% | 12.4% | 13.5% |
| Number: | 138 | 121 | 259 |

The audit recorded whether services completed assessments in three domains: (i) non-motor symptoms, (ii) motor symptoms and activities of daily living and (iii) education and multidisciplinary involvement. The maximum and best score after totalling the 3 domain scores is 34 (range 0-34).

Table 4: Mean domain score totals for different models of service provision (standard deviations in brackets)

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---|---|---|
| Doctor alone | 27.2 (5.3) | 24.5 (6.5) | 25.9 (6.0) |
| Joint/parallel doctor and nurse specialist clinics | 27.9 (5.2) | 27.7 (5.6) | 27.8 (5.4) |
| Integrated clinics | 30.3 (3.1) | 27.2 (6.9) | 29 (5.3) |

Using the total domain scores is only a rough surrogate of good practice, but does seem to suggest that ‘doctor alone’ service provision consistently has a lower score.

***Access to a Parkinson’s nurse***

Similarly to previous audits, the majority of people with Parkinson’s (96.1%; 94.1% in 2015) could access a Parkinson’s nurse.

Table 5: Access to a Parkinson’s nurse in Elderly Care and Neurology services

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---|---|---|
| Yes | 96.4% | 95.9% | 96.1% |
| No | 3.6% | 4.1% | 3.9% |
| Number: | 138 | 121 | 259 |

87.6% respondents to the PREM reported that they had access to a Parkinson’s nurse. As the patients included in the clinical audit were not necessarily the same as those who completed the PREM, this apparent disparity could result from the fact that those with concerns were more likely to respond to the PREM. Alternatively it may suggest that some patients were inadequately informed about how to access a Parkinson's nurse.

### *Availability of written information*

Written information about Parkinson's and Parkinson's medication is routinely available all or most of the time at 82.2% of clinics (unchanged since 2015). But written information about Parkinson's is still not routinely available in 7.7% (5.9% in 2015) of outpatient clinics.

This was more evident in doctor alone clinics (16.7%) than joint/parallel doctor and nurse specialist clinics (5.3%) or integrated clinics (0%).

However, providing written information in the clinic may not be enough, as the PREM data suggests only 61.1% of patients feel they are given enough information at diagnosis (66.1% in 2015).

### *Uptake of continuing professional development (CPD)*

Attendance at specialist meetings about Parkinson's and movement disorders is desirable as part of the portfolio of continuing professional development (CPD) for movement disorder specialists. This audit cycle demonstrates that in over 20% of services not all clinicians have attended specific movement disorder CPD in the last 12 months. Over 90% of Parkinson's nurses have attended specific CPD in the last year.

Table 6: Services where all clinicians have attended CPD specific to movement disorders and all specialist nurses have attended Parkinson's-specific CPD in the last 12 months

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---:|---:|---:|
| Clinician | 86.2% | 71.9% | 79.5% |
| Parkinson's nurse | 93.5% | 88.4% | 91.1% |

## Patient audit

### *Review by a specialist*

All people with Parkinson's should be reviewed by a specialist (doctor or nurse) at 6–12 month intervals. Encouragingly, 98.1% of patients audited in Elderly Care and Neurology services had received a specialist review in the preceding 12 months, maintaining the high percentage seen in the 2015 audit.

### *Medicines management*

In this audit around 95% of people with Parkinson's had their current prescription checked and documented at a clinical review (medicines reconciliation) with both Elderly Care

(95.1%; 93.5% in 2015) and Neurology (94.6%; 91.6% in 2015) seeing an increase on the 2015 results.

There was evidence of information about potential side effects of new medication recorded for 86.2% of patients in the audit. This figure was 83.3% in 2015. Concerningly however, the PREM data suggests that only 69.0% of patients (64.1% in 2015) feel they are given enough information when prescribed new medication.

Table 7: Patients given information about potential adverse side effects of new medication

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---:|---:|---:|
| Yes | 85.3% | 87.2% | 86.2% |
| No | 14.7% | 12.8% | 13.8% |
| Number: | 2199 | 2069 | 4268 |

***Monitoring for compulsive behaviours***

The 2017 audit results demonstrate that 67.4% of patients on dopaminergic therapy have had a recorded discussion about compulsive behaviours in the preceding year, up from 64.2% in the 2015 cycle. Neurology services are better at documenting this (70% of patients) than Elderly Care (65.2%). Monitoring for compulsive behaviours is particularly pertinent for patients on dopamine agonists, and 19.3% of these patients still appear to have received no advice about potential compulsive behaviours related to their medication. This compares to 22.5% in the previous audit cycle. The audit also shows that for those patients on ergot Dopamine agonists (4.7% of all patients audited) there are low referral rates for echocardiograms (only 26.2%).

Table 8: Evidence recorded that people with Parkinson’s taking dopaminergic drugs are monitored for compulsive behaviours

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---:|---:|---:|
| Yes | 65.2% | 70.0% | 67.4% |
| No | 34.8% | 30.0% | 32.6% |
| Number: | 2943 | 2505 | 5448 |

Table 9: Evidence recorded that people with Parkinson’s taking dopamine agonists are monitored for compulsive behaviours

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---|---|---|
| Yes | 79.3% | 82.0% | 80.7% |
| No | 20.7% | 18.0% | 19.3% |
| Number: | 1233 | 1295 | 2528 |

### *Driving and excessive daytime sleepiness*

Questioning about excessive daytime sleepiness was recorded in just under three-quarters of cases, as in the 2015 audit (74.6% in Elderly Care; 70.2% in Neurology). Where excessive daytime sleepiness was recorded, its impact on driving was documented in 62.8% of drivers which is an increase from 56.6% in 2015.

Table 10:  Documented discussions of the impact of known excessive daytime sleepiness in people with Parkinson’s who are drivers

| | Elderly Care | Neurology | Elderly Care and Neurology |
|---|---|---|---|
| Yes | 63.9% | 61.7% | 62.8% |
| No | 36.1% | 38.3% | 37.2% |
| Number: | 809 | 826 | 1635 |

### *Advance care planning*

Of those people who had markers of advanced Parkinson's (21.0%), discussions regarding end-of-life care issues were recorded in only 36.8% (28% in 2015). This raises the question of whether advanced Parkinson’s is sufficiently well recognised, and whether appropriate conversations regarding end-of-life care are started early enough.

### *Power of Attorney*

In only 16.9% of cases (at all phases of Parkinson’s) was there evidence that the patient and/or carer had been offered information about, or had set up, a Lasting Power of Attorney (Power of Attorney in Scotland) (Elderly Care 18.4%, Neurology 15.3%). This is a change from the 2015 audit where only those with markers of advanced Parkinson’s were asked this question. By this stage many patients may have significant cognitive impairment and may no longer be able to grant Lasting Power of Attorney. This highlights the value of earlier discussions.

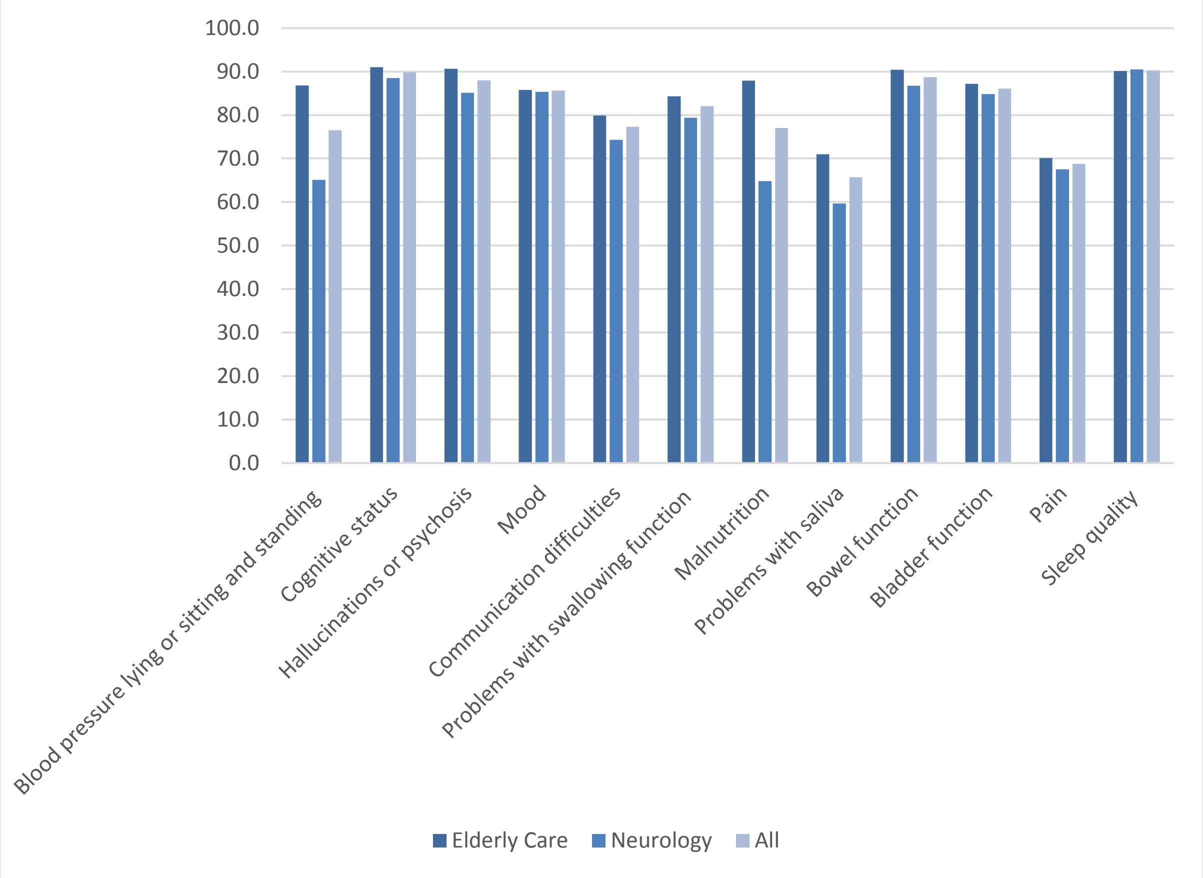
However, 56.1% of patients in the palliative phase had been offered information about, or had set up, a Lasting Power of Attorney (26.3% in 2015).

***Domain scores***

The audit recorded whether services completed assessments in three domains: (i) non-motor symptoms, (ii) motor symptoms and activities of daily living and (iii) education and multidisciplinary involvement.

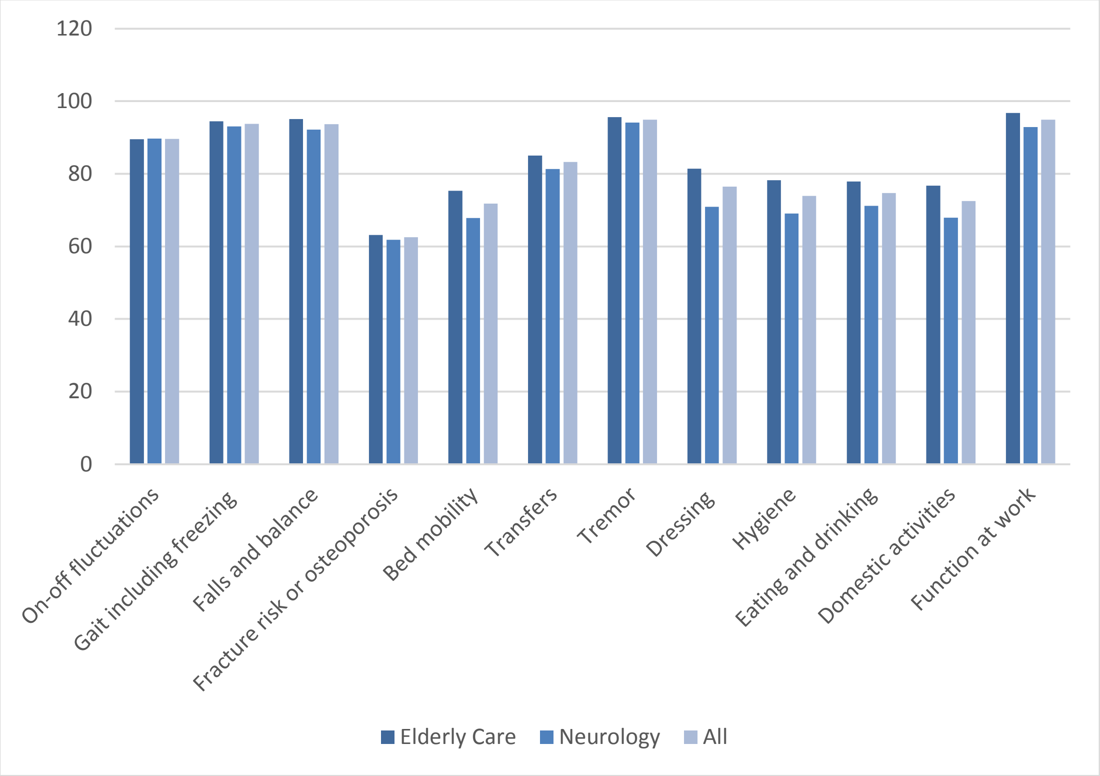
For each element within a domain, total scores were calculated by summing passes (a score of 1) and fails (a score of 0) for each patient. A pass was achieved if the assessment was done. However, a pass was also achieved if an assessment was not done but was considered and not felt to be indicated or appropriate. A fail indicates when an assessment was not done and not considered. Total domain scores were then calculated for each domain.

Figure 3: Domain 1 – Non-motor assessments during the previous year



Blood pressure assessment is better documented in Elderly Care (86.8%) than Neurology clinics (65.1%) though both have improved from 2015 (Elderly Care 85.1%; Neurology 57.2%). The same is true for malnutrition screening where Elderly Care screen 87.9% of patients and Neurology services screen only 64.8%. Again, both have improved from 2015 (Elderly Care 85.1%; Neurology 54%). Assessments of pain and saliva problems were poorly documented by both services in 2015. The services audited in 2017 show modest improvements at 68.8% and 65.7% respectively.

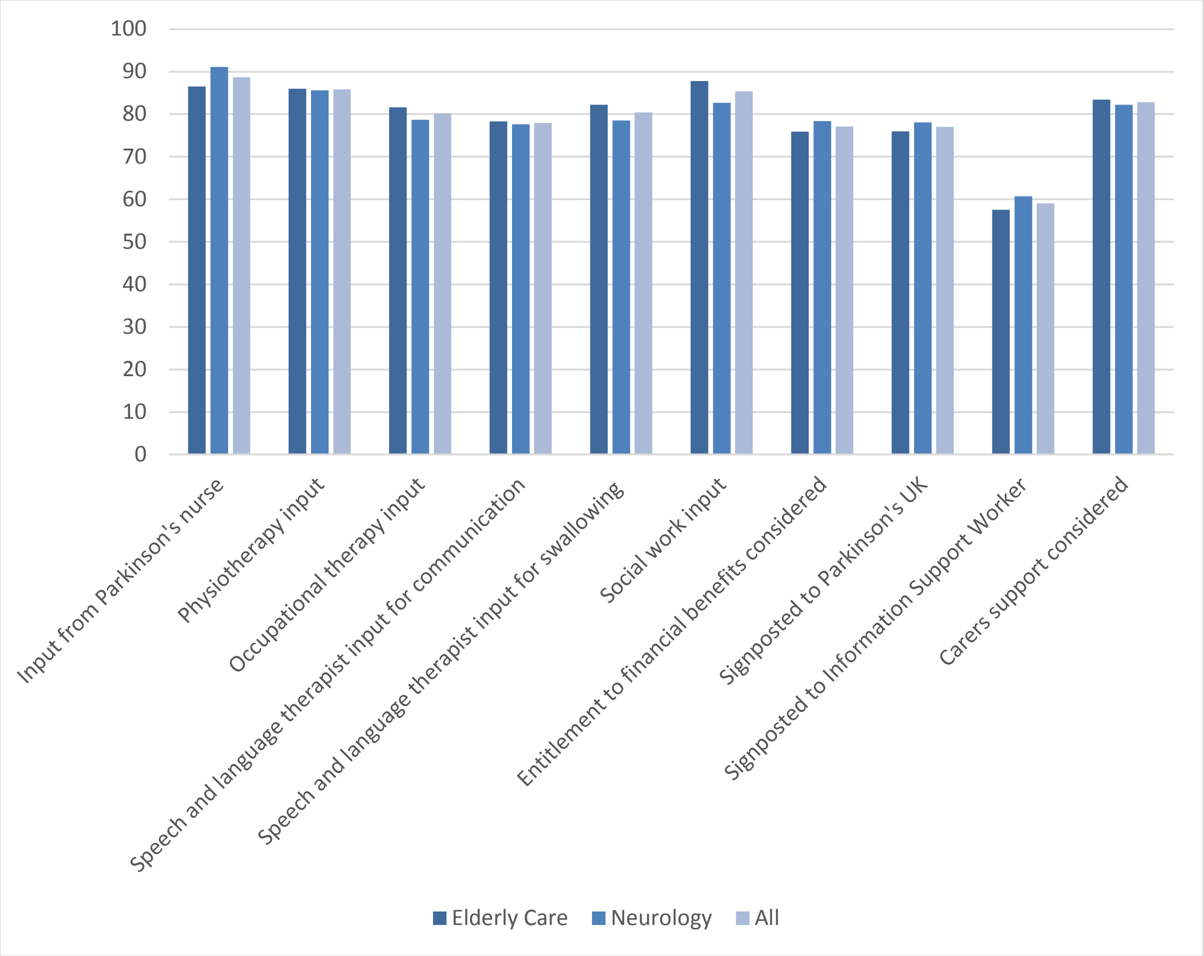
Figure 4: Domain 2 – Assessment of motor symptoms and Activities of Daily Living (ADL) during the previous year



Where there were concerns about falls and/or balance, fracture risk or osteoporosis was documented as a consideration in only 42.9% of people with Parkinson's (45.7% in Elderly Care; 39.5% in Neurology). While these low figures are concerning, it should be noted that they demonstrate some improvement from 2015 (40.6% Elderly Care and 31.4% Neurology)

Please note: the percentages above in the bar chart reflect the total percentage of patients in whom evidence of fracture risk/osteoporosis was considered and includes those in whom the notes document no falls and no concerns re balance, and therefore bone health was not considered.

Figure 5: Domain 3 – Education and multidisciplinary involvement during the previous year



The results show that 77.0% of patients and/or carers had been signposted to Parkinson’s UK in the last year, or had been previously signposted.

## Service improvement in Elderly Care and Neurology services resulting from the 2015 audit

The 2015 audit highlighted shortcomings in the following areas:

- integrated services
- standardised practices
- communication and sharing of information
- inpatient management
- palliative care planning

The following are examples from services that reported implementing improvement measures to tackle these priority issues:

- In their service improvement plans many services highlighted that they were going to start using the 'Impulsive and compulsive behaviour in Parkinson's monitoring and information tool' available from the UK Parkinson's Excellence Network.
- Several services have started using the information leaflets provided by Parkinson's UK on advanced care planning, and other services sourced specific Lasting Power of Attorney information to give to people affected by Parkinson's and their carers.
- Stobhill Hospital, Glasgow, contacted Parkinson's UK for assistance in developing posters for the waiting area. These highlighted the two Parkinson's local advisers that covered the clinic population giving their name, contact details, postcodes they covered and details of their remit.
- The South Wales Parkinson's Nurse Forum has developed a driving tool. It supports sharing and collecting information to promote safer driving. The document can be kept with the patient notes and can be shared amongst the team to ensure that everyone has access to information, and that conversations can be had with both patients and the DVLA when licenses are up for renewal.
- *Bath Bone Book* is being developed by Royal Bath hospital as an information resource for both patients and clinicians about the importance of good bone health in Parkinson's. It has received support from a UK Parkinson's Excellence Network service improvement grant.
- Gloucester Royal Hospital now routinely uses the non-motor symptoms questionnaire in outpatient clinics at least once a year. This has highlighted the high prevalence of lower urinary tract symptoms (LUTS) and they know that referrals to continence clinics usually have long waits. They also have a high number of admissions due to urinary tract infections (UTIs). This year they are investing in a bladder scanner and training staff how to use this to identify patients with issues earlier and provide treatment and advice. It is hoped that this will see a drop in emergency admission for UTIs.
- *Greater Manchester Parkinson's MDT Pathways Project* aims to improve access to effective MDT across the whole of Greater Manchester. With the backdrop of

health devolution forming the *Greater Manchester Health and Social Care Partnership*, there are opportunities to shape Parkinson’s services, and work together across the boroughs and ten clinical commissioning group areas to achieve consistent access.

## Occupational therapy

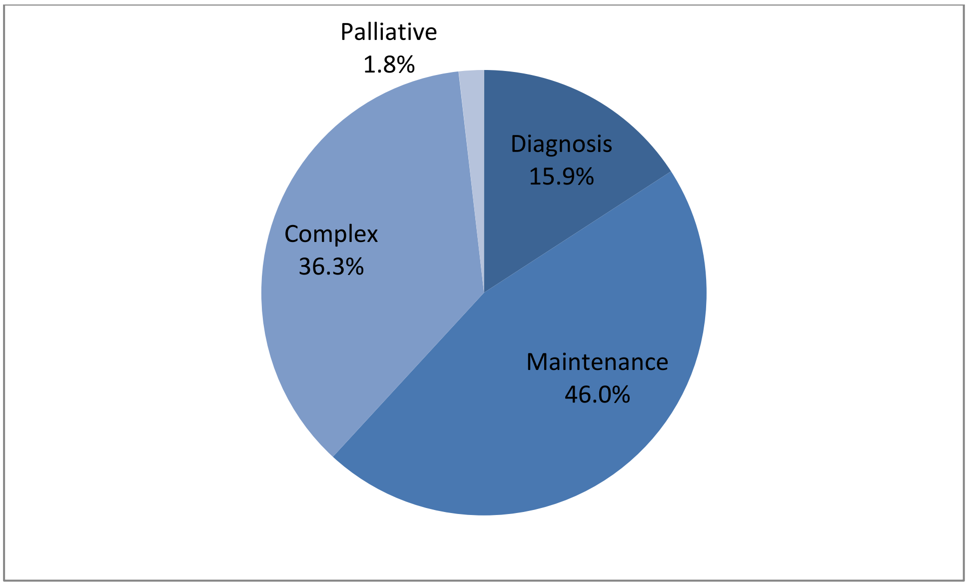
### Aims

The occupational therapy audit measures the referral to and assessment and management of people with Parkinson's in occupational therapy services. It also aims to describe the models of service delivery used. It identifies the measures used in assessment and outcomes, the guidance and education available to occupational therapists, and adherence to national guidelines.

### Demographics

Occupational therapy services saw 713 people with Parkinson's who were included in the audit. The majority were over 70 years of age (mean age 75.1 years), male (61.9%) and white (95.2%). The mean length of time between diagnosis and referral for this episode of occupational therapy was 6.5 years. Typically people seen by occupational therapy services live in their own homes (93.0%).

Figure 6: Phase of Parkinson's on referral to occupational therapy



### Service audit

#### *Models of service provision*

Only 10.2% of occupational therapy services reported working in an integrated Parkinson's clinic. The majority of occupational therapy services (71.2%; 63.8% in 2015) were based in the community, within rehabilitation, reablement or day hospital teams.

Overall, 69.5% of the occupational therapy services audited specialise in neurological conditions, with 72.4% specialising in the treatment of Parkinson's.

### *Accessing Parkinson's-related Continuing Professional Development (CPD)*

Of the occupational therapists audited, 84.8% reported having opportunities to undertake Parkinson's-related CPD (91.5% in 2015).

Support (e.g. education, advice) was available to individual therapists through their specialist multidisciplinary team by 66.1% of occupational therapists (78.7% in 2015).

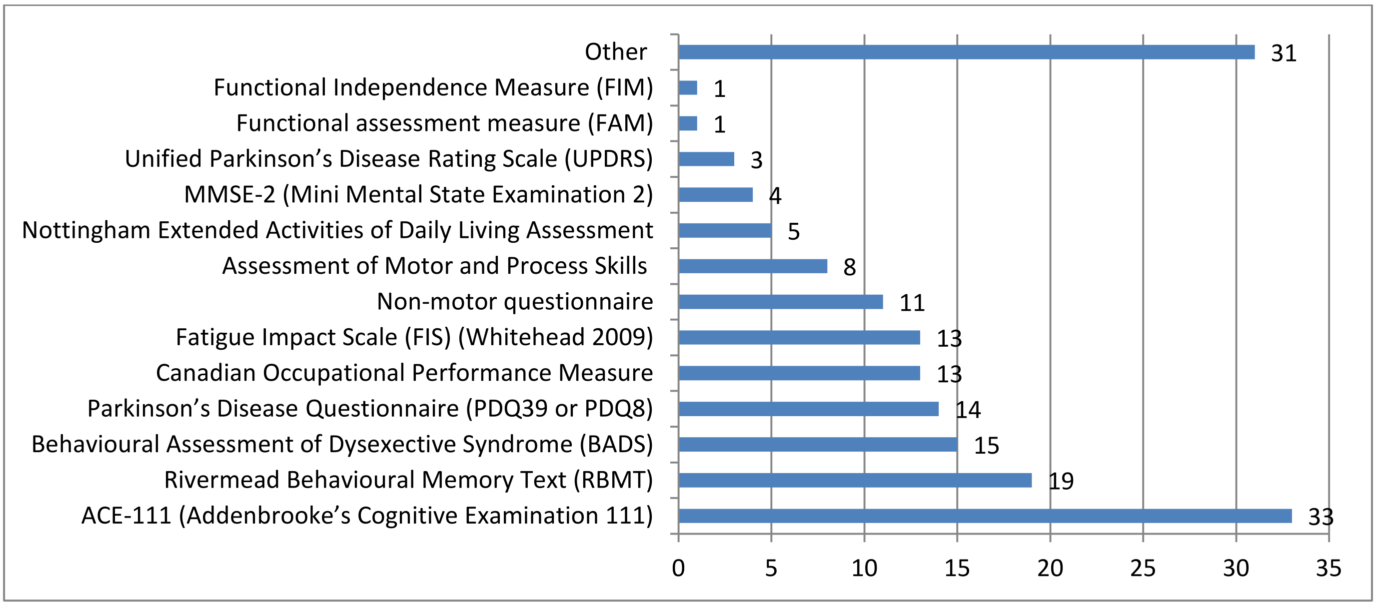
Specific induction and support strategies for working with people with Parkinson's were available to new staff in 30.5% of occupational therapy services (an increase on the 23.4% reported in 2015) and 37.3% included Parkinson's within their general competencies, a similar percentage to 2015.

### *Use of standardised assessments and outcome measures*

Occupational therapy services are using a wide range of standardised assessments. 84.7% of services used a least one of the listed standardised assessments (i.e. not 'other') with people with Parkinson's (an increase from 55.3% in 2015). 'Other' assessments used included assessments of mood, cognition, falls and general health.

From the audit data it is unclear, when the standardised assessments are completed, whether they are repeated as outcome measures, and how they are used to guide patient treatment and service development.  This makes it difficult to ascertain which measures best reflect meaningful changes in occupational performance.

Figure 7: Number of occupational therapy services using standardised assessments/ outcome measures



### *Evidence used to inform practice*

Table 11: Evidence used in occupational therapy to inform clinical practice and guide choice of intervention for patients

| Type of evidence | Patients |
|---|---:|
| Clinical experience | 95.7% |
| Advice from colleague or supervisor | 71.0% |
| Recommendations given in *Occupational therapy for people with Parkinson's: best practice guidelines* | 75.6% |
| Information from Parkinson's UK website | 62.3% |
| NICE – Parkinson's disease NG71 (2017) | 55.4% |
| Training courses | 54.7% |
| NSF LTNC (2005) | 47.4% |
| Published evidence in a peer-reviewed journal | 29.3% |
| Webinars, social media | 12.6% |
| None | 0.4% |
| Other | 1.8% |

Occupational therapists rely heavily on clinical experience and peer support to guide practice. This is supported through the use of practical guidance in preference to more evidence-based documents such as the NICE guideline for Parkinson's.

## Patient audit

### *Referral to occupational therapy*

Referrals to occupational therapy are made by a wide variety of professionals including neurologists, geriatricians, Parkinson's nurses, physiotherapists, GPs and social care workers (as well as self-referral) with the majority triggered as a result of a medical review (62.3%; 59.6% in 2015). Referred patients had a range of condition durations.

Table 12: Time from diagnosis and occupational therapy referral to this episode

| Duration of Parkinson's | Patients |
|---|---:|
| Less than 1 year | 7.0% |
| 1-2 years | 24.1% |
| 3-5 years | 24.5% |
| 6-10 years | 22.6% |
| 11-15 years | 12.6% |
| 16-20 years | 5.6% |
| More than 20 years | 3.6% |
| Number | 673 |

Overall 70.3% of referrals had most of the information required for assessment and intervention. The majority of referrals were judged to have been made at the appropriate time (89.9%).

***Intervention strategies***

Table 13: Needs addressed through occupational therapy - reasons for referral

| | **Patients** |
|---|---:|
| Transfers and mobility | 74.1% |
| Personal self-care activities | 44.3% |
| Environmental issues | 39.4% |
| Domestic activities of daily living | 28.9% |
| Mental wellbeing | 27.4% |
| Leisure activities | 13.9% |
| Management of fatigue | 12.6% |
| Family roles | 7.2% |
| Work roles | 3.1% |
| Other | 14.2% |

The main needs addressed by occupational therapists were transfers and mobility, followed by personal self-care activities. However, a range of needs and occupational performance areas were addressed through occupational therapy intervention, and it is important to note that the areas most frequently addressed are not necessarily the ones of greatest importance to the individual with Parkinson's.

***Occupational therapist Band***

Table 14: NHS Band of the therapist assessing the patient

| | **Patients** |
|---|---:|
| Band 4 | 4.4% |
| Band 5 | 15.2% |
| Band 6 | 52.6% |
| Band 7 | 27.2% |
| Band 8a | 0.7% |
| Number: | 713 |

Half of people seen were assessed by a Band 6 occupational therapsist. These therapists will generally have at least two years experience. The level of experience of the Band 4 occupational therapy technicians is unclear. What assessments they were undertaking is also unclear.

### Service improvement in occupational therapy services resulting from the 2015 audit

From shortcomings highlighted in the 2015 audit occupational therapy services reported implementing the following service improvement measures:

- Inconsistent use of appropriate standardised assessments for people with Parkinson's based on best practice.
    - Services reported moving to the use of appropriate validated outcome measures and standardised assessments, including a fatigue impact scale.
- Lack of an integrated model of service delivery.
    - Services reported working to raise the profile of occupational therapy to potential referring clinicians and improving links with the community and voluntary sector by setting up a database. This included information on how to access services, and fostering better multi-disciplinary team working by exploring collaboration with physiotherapy services.

- Whilst the audit shows that most people with Parkinson's are treated in community settings, it is recognised that support is needed for those who are receiving care in acute settings as outpatients or during an admission. In Leeds they are introducing a specialist occupational therapist within the outpatient clinic setting, as part of the multi-disciplinary team, to assess and support people with activities of daily living. They are also adding occupational therapy as part of multi-disciplinary inpatient care to support discharge planning and independence and aim to achieve a reduction in length of stay and readmissions as a result.

## Physiotherapy

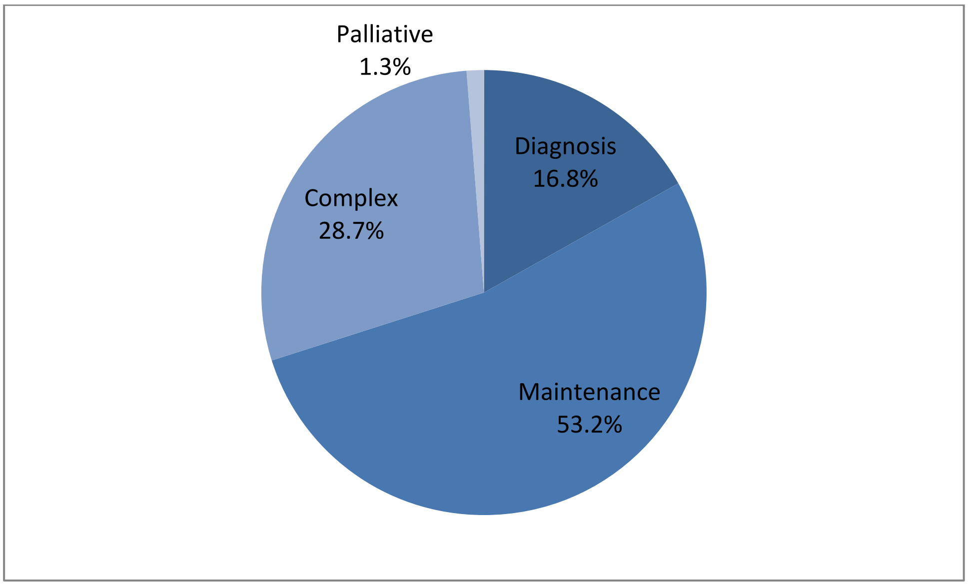
### Aims

The physiotherapy audit intended to establish whether physiotherapy services are currently providing quality services for people with Parkinson’s (taking into account recommendations from evidence-based guidelines and using standardised assessments). It allows benchmarking of local services against good practice standards and guidance for physiotherapy in Parkinson’s, as well as local and national mapping of service provision, patient management and access to continuing professional education.

### Demographics

Physiotherapists in the 95 services registered for the audit reported on 1,514 people with Parkinson’s receiving physiotherapy. Patients were aged between 27 and 97 years (mean age 73.8 years) and just 3.0% were living in residential or nursing homes. This raises some questions about access to physiotherapy for people with Parkinson's living in these settings. The majority were male (62.5%) and white (92.9%). Mean age at diagnosis was 68.7 years and audited patients had a mean Parkinson’s duration of 5.2 years (range 0–35 years).

Figure 8: Phase of Parkinson’s on referral to physiotherapy



### Service Audit

#### *Model of service provision*

Only 13.7% of physiotherapy services reported working in an integrated Parkinson’s clinic but 56.8% of services offered assessment as part of a multidisciplinary team. The majority of services (59.0%) were based in the community, within rehabilitation or day hospital teams.

72.6% of the physiotherapy services audited specialise in neurological conditions, with 64.2% specialising in the treatment of Parkinson’s. This is an encouraging increase in the proportion of services specialising in Parkinson’s since 2015 (57.8%). But the overall percentage of physiotherapists working in integrated Parkinson’s services is disappointingly low.

### *Accessing Parkinson’s-related continuing professional development (CPD)*

Although 89.5% of services offered access to Parkinson’s-related CPD (88% in 2015), induction and support strategies were not available for new physiotherapists working with people with Parkinson’s in 49.5% of services (39.8% in 2015). Two services reported no access to specialised advice and support for individual therapists. It is encouraging that such a high number of therapists can access Parkinson's-related CPD, and that this is an increase since 2015. However, the lack of induction and support services is an area of concern as it shows, over the last two years, a significant decrease of availability for new physiotherapists who may have little or no knowledge of intervention for Parkinson’s. Although it is imperative that individual services aim to provide necessary inductions and support for staff, this is also an area that could be improved by provision of support, online training and signposting to resources and guidelines. For example, information and support available, through the UK Parkinson's Excellence Network.

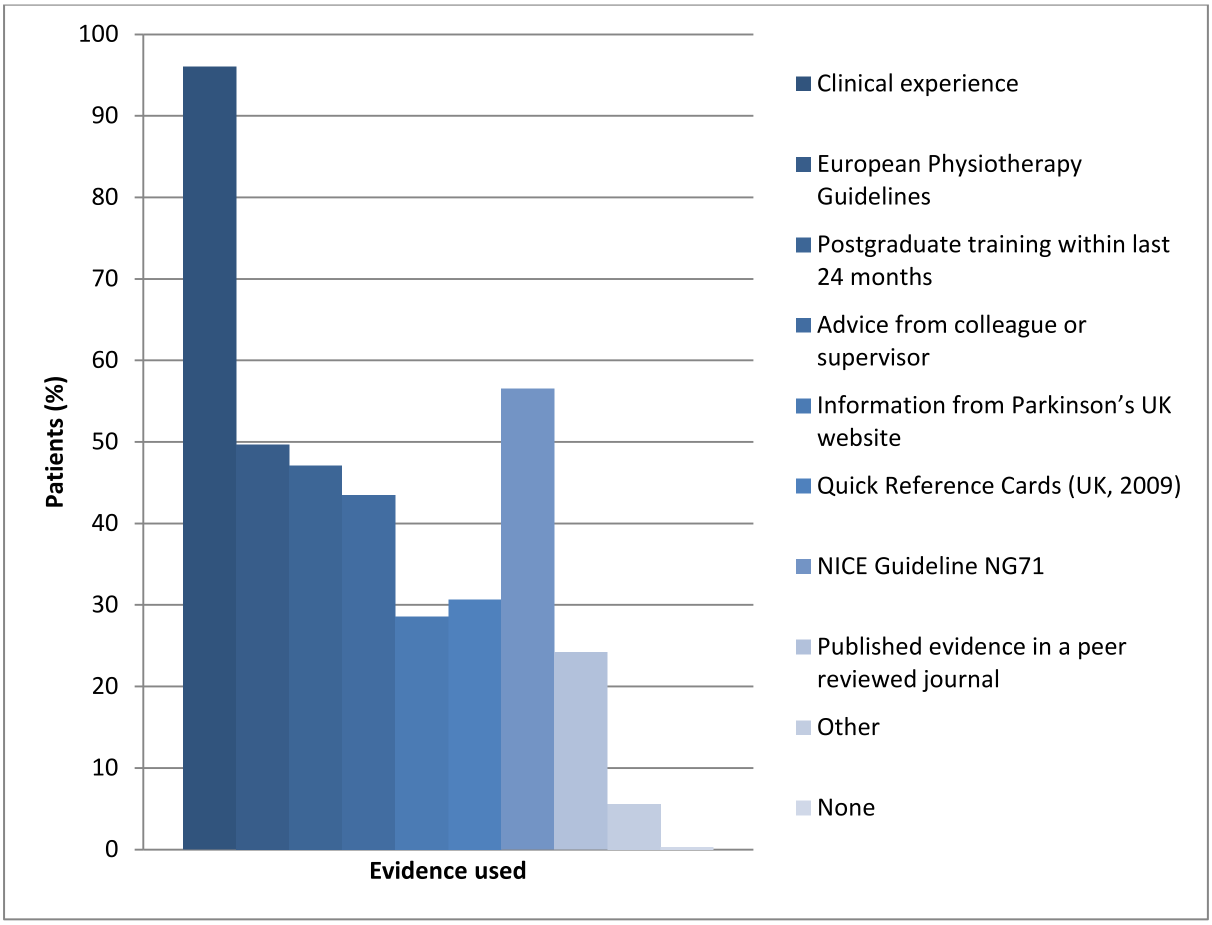
Table 15: Support available to individual physiotherapists (2015 results in brackets)

| Type of support | Services |
|---|---:|
| Can consult any member of the Parkinson’s specialist MDT of which they are a member | 44.2% |
| Can consult members of a general neurology/elderly care specialist service of which they are a member | 14.7% |
| Don't work directly in specialist Parkinson’s clinics but access to Parkinson’s specialist MDT/Parkinson’s nurse | 35.8% |
| Don't work directly in a specialist clinic but access to advice from a specialist neurology or elderly care MDT | 3.2% |
| No access to more specialised advice | 2.1% |
| Number: | 95 |

### *Evidence used to inform practice*

The *European physiotherapy guideline for Parkinson’s disease* was used to inform clinical practice in the care of 49.7% of patients (43% in 2015). In five patient cases, no evidence was used. Over the past two years, this European guideline has been highlighted and promoted as evidence-based guidance for physiotherapists working with people with Parkinson’s, so it is disappointing that the percentage of physiotherapists using the guideline has only increased by just under 7%, and that half of all audited physiotherapists are not using them.

Figure 9: Evidence used to inform physiotherapists’ practice and to guide intervention



## Patient audit

### *Referral to physiotherapy*

A referral within two years of diagnosis was reported in 52.0% of patients (49.3% in 2015). This is an encouraging trend, but interestingly, the number of patients referred in the diagnosis phase of Parkinson's was only 16.8%. *The NICE guideline for Parkinson’s disease in adults* (NG71, National Institute for Health and Care Excellence, July 2017) recommends physiotherapy is offered early so that people can be encouraged to exercise and remain active, even when problems arise. There is much evidence to suggest that exercise can have a positive impact on symptoms, and it is important to encourage this from the outset. The Parkinson's exercise framework encourages exercise from diagnosis onwards. (https://www.parkinsons.org.uk/professionals/resources/exercise-framework-professionals)

Table 16: Time between diagnosis and first physiotherapy referral letter (if the person had previous physiotherapy) and first referral letter to this episode (if current physiotherapy episode is the first)

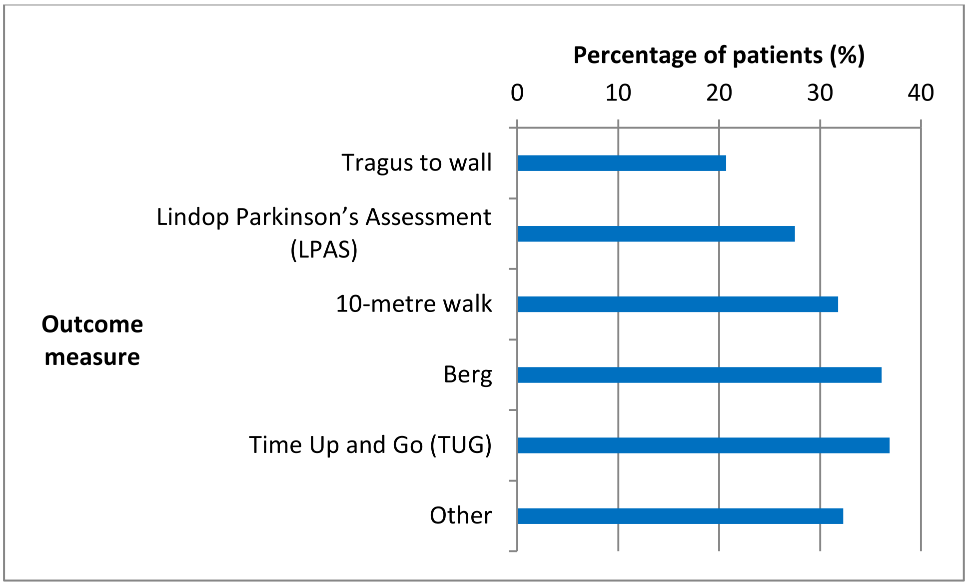
| Time between diagnosis and referral | Patients |
|---|---:|
| Less than 1 year | 29.3% |
| 1–2 years | 28.8% |
| 3–5 years | 18.4% |
| 6–10 years | 14.2% |
| 11–15 years | 6.3% |
| 16–20 years | 2.3% |
| More than 20 years | 0.8% |
| Number: | 1333 |

36.3% of patients included in the audit had previously had physiotherapy for Parkinson’s.

***Use of appropriate outcome measures by physiotherapists***

Outcome measures were reported as being used in 85.2% of patients (84.9% in 2015).

Figure 10: Most frequently used physiotherapy outcome measures



The audit data collection tool included outcome measures recommended in the *European physiotherapy guideline for Parkinson's disease*. For many patients, multiple outcome measures were used and in 32.3% of cases, use of ‘other’ outcome measures not on the suggested list were reported. Some of these were not specific to physiotherapy (a list is included in the reference report) and several others were not recognised outcome measures at all. Unfortunately, for 14.8% of people with Parkinson’s the physiotherapist reported using no outcome measures. This finding is similar to the 2015 audit (15.4%) and reflects the continuing poor practice of some professionals, which has an impact on patient outcomes.

***Physiotherapist Band***

The majority of patients in the audit were assessed by a Band 6 or 7 physiotherapist. 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. It also states that "In some instances, where a clear protocol has been produced or a specific client group in a particular environment, the support worker may have delegated discretion, alongside limited and defined autonomy for some elements of continual assessment. It is essential that the role and specific activities of the support worker are made explicit, in the design of such protocols".

In 21 of the audit cases (1.4%) a Band 4 carried out the assessment, and in another 27 (1.8%) assessment was carried out by someone ‘other’ than Band 4-8b. It may be that a therapist with a band higher than 8c saw the patient, or that it was a Band 3 or lower. This raises several questions about initial assessments being carried out by unregistered staff, which is not supported by the *NICE guideline*, *NICE quality standards* or the *Chartered Society of Physiotherapy standard.*

Table 17: NHS band of the therapist assessing the patient

| | **Patients** |
|---|---:|
| Band 4 | 1.4% |
| Band 5 | 11.5% |
| Band 6 | 44.3% |
| Band 7 | 38.6% |
| Band 8a | 2.4% |
| Band 8b | 0.1% |
| Band 8c | 0% |
| Other | 1.8% |
| Number: | 1514 |

The majority of physiotherapists had a caseload in which people with Parkinson’s made up less than 40% of total. This reflects the mixed-conditions caseloads that many physiotherapists are required to manage. *The Parkinson's NICE guideline* recommends the following. "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." It is important that the physiotherapist has a good understanding of Parkinson's in order to offer appropriate assessment, advice and any required intervention.

Table 18: Percentage of people seen by the audited physiotherapist in a year who have Parkinson's

| | **Patients** |
|---|---:|
| 0-19% | 24.0 |
| 20-39% | 40.1 |
| 40-59% | 24.6 |
| 60-79% | 2.4 |
| 80-99% | 2.7 |
| 100% | 1.2 |
| Unknown | 5.0 |
| Number: | 1514 |

### Service improvement in physiotherapy services resulting from the 2015 audit

The 2015 audit highlighted shortcomings in the following areas in which services reported implementing service improvement measures:

- Inconsistent use of appropriate standardised assessments for people with Parkinson’s based on best practice.
    - Five services reported moving to the use of appropriate standardised assessments and one, to the development of a new physiotherapy assessment pro-forma to reflect best practice guidance.
- A significant number of physiotherapists are not using outcome measures.
    - Four services reported work on shared resources of relevant outcome measures and three reported individualised goal setting.

The two projects highlighted below aim to demonstrate and produce evidence that physiotherapy is important at all stages of the condition and treatment pathway:

- A project in Newcastle is developing a multidisciplinary team approach to enhanced management. This will provide a consistent access to a physiotherapist as part of the MDT for people who are being considered for deep brain stimulation (DBS) surgery and for post-operative management. Currently physiotherapy assessment is provided unfunded on an ad hoc basis by the academic team, but is not always available. The gait and balance assessments completed by the physiotherapist complement and enhance the current evaluation of the patient. Previous patients with DBS were consulted and overwhelmingly felt that they would have benefitted from access to an in-depth gait and balance assessment, pre-habitation and rehabilitation post DBS. They were also keen for the links to local services to be strengthened to help provide more equitable care for people with Parkinson’s.
- A service in Glasgow is aiming to show that having dedicated support in an integrated team will improve access from the point of diagnosis. This project will establish the role of an advanced physiotherapy practitioner within the Parkinson’s and movement disorder service within the Department of Medicine for the Elderly, South Sector of Greater Glasgow & Clyde, and evaluate the impact of that role within the service.

## Speech and language therapy

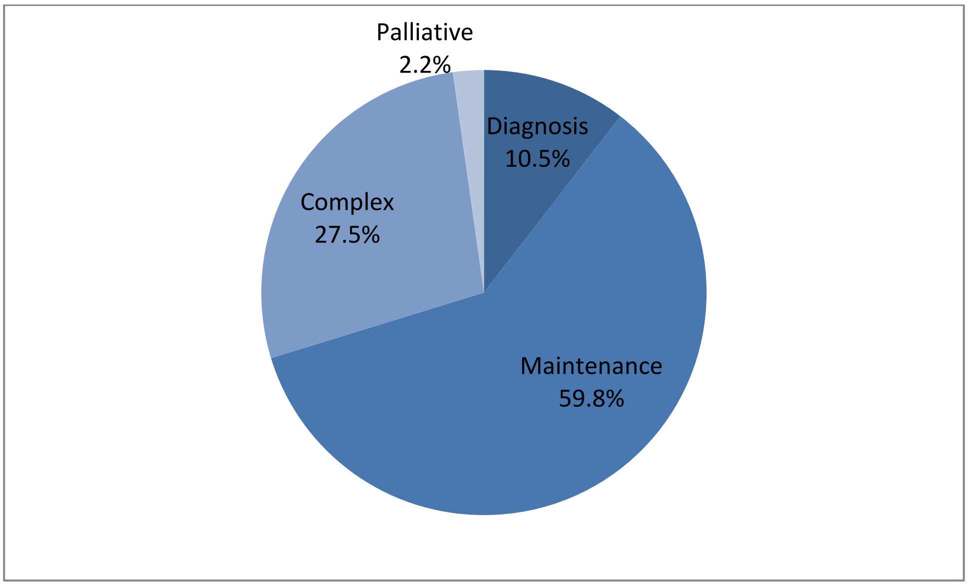
### Aims

The speech and language therapy audit intended to examine the models of service delivery including timings and source of referral, nature of concerns patients are seen for, the types of assessment and interventions used, information giving and support and whether practice adheres to national guidelines. It also examined the seniority of staff, their experience and their ongoing professional development in Parkinson's.

### Demographics

Speech and language therapists in 64 services registered for the audit reported on 810 people with Parkinson's. Patients were aged between 22 and 96 years (mean: 73.8 years) and the majority were male (71.5%) and living in their own home (90.6%). Audited patients had a mean Parkinson's duration of 6.0 years (range 0–37 years). While the NICE guideline recommends referring patients to speech and language therapy services in the early phase of the condition for assessment for education and advice, the majority of patients continue to be seen in the maintenance phase (59.8%). This is consistent with the 2015 audit (57.9%).

Figure 11: Phase of Parkinson's on referral to speech and language therapy



### Service audit

#### *Model of service provision*

The majority of speech and language therapy input (75.0% 2017; 76.3% in 2015) was offered to people with Parkinson's within general adult acquired speech and language disorder services. Only three speech and language therapy services saw people with Parkinson's in a specialist Parkinson's clinic. (4.7% 2017; 7.9% 2015). As with 2015, for the majority of services (60.3% 2017; 61.9% 2015) Parkinson's constitutes less than 20% of referrals.

However, 71.9% of these services specialise in neurological conditions (76.2% in 2015), with 50.0% specialising in the treatment of Parkinson’s within their service provision (47.6% in 2015).

People with Parkinson’s were mostly seen in either outpatient/community clinics (66.8%; 64.6% in 2015) or their homes (26.1%; 28.4% in 2015).

Most patients were being treated by therapists for whom Parkinson’s is only a part of a mixed caseload and not a specialised service.

Table 19: Percentage of individuals referred to a service annually with a diagnosis of Parkinson’s

| | **Services** |
|---|---:|
| 0-19% | 59.4% |
| 20-39% | 23.4% |
| 40-59% | 7.8% |
| 60-79% | 1.6% |
| 80-100% | 6.3% |
| Total | 98.4% |
| Missing | 1.6% |
| Number: | 64 |

### *Accessing Parkinson’s-related Continuing Professional Development (CPD)*

Of the audit services, 81.3% reported having opportunities to undertake Parkinson’s-related CPD at least yearly (79.4% in 2015). This remains stable.

Specific induction and support strategies for working with people with Parkinson’s was given to new staff in 17.2% of speech and language therapy services, a slight increase on the 14.3% reported in 2015. 62.5% of responding services included Parkinson’s within their general competencies (50.8% in 2015). While this reflects a slight improvement on 2015 this is an area for further development. Services should consider how new staff are inducted into working with people with Parkinson’s to ensure consistency of service between therapists. This is especially true where therapists are only seeing people with Parkinson’s as part of a generalist caseload.

### *Access to services*

The majority of speech and language services offered a full service for communication changes (93.8% 2017; 90.5% in 2015), for swallowing (93.8%) and drooling (90.6%).

The Lee Silverman Voice Treatment (LSVT) programme was offered in full by 43.8% of services, an increase on 34.9% in 2015. It was not available to all potentially eligible people with Parkinson’s in 7.8% of services (17.5% in 2015). A similar alternative programme to

LSVT was offered by 28.1% of services. These findings show LSVT is increasingly available to people with Parkinson's and services can offer it to more people. But still less than half of patients in the audit had access to the full LSVT programme.

### *Review policy*

Only 14.1% (12.7% 2015) of speech and language therapy services offered regular 6-12 month reviews.

## Patient audit

### *Referral to speech and language therapy*

The majority of patients were seen in a timely manner (86.8%). Patients were referred for specific opinion on an aspect of their communication and/or swallowing (77.5% 2017; 79.0% 2015). 60.3% of all patients audited received a full communication assessment and 57.5% of all patients audited received a full swallow assessment. There is an overlap in these percentages as a number of patients will have required both a communication and swallowing assessment.

### *Content of assessment*

For patients referred for communication assessments, the assessment mainly focussed on speaking (96.6% 2017; 97.9% 2015). The majority of assessments occurred within a one to one context (87.1%). In less than half of patients all speech subsystems were assessed across stimulated and unstimulated conditions (38.6%). As in 2015, the main focus for assessment was loudness (92.2% 2017; 94.1% 2015).

Table 20: Assessment results available for all speech subsystems in initial assessment and all review appointments (in individuals not seen for swallow only)

| | **Patients** |
|---|---:|
| Subsystems assessed in both stimulated and unstimulated conditions | 38.6% |
| Restricted range of subsystems and/or conditions assessed, justification documented | 24.6% |
| Restricted range of subsystems and/or conditions assessed, no justification documented | 21.1% |
| No assessments documented, but with justification documented | 9.5% |
| No assessments and with no justification documented | 6.2% |
| Number: | 634 |

85.0% of people with Parkinson's were assessed on communication participation (83.7% 2015) and 88.0% (84.9% 2015) on how Parkinson's impacted on communication participation (excluding those seen for swallowing issues only). These are key outcome measures so it is positive that they continue to be assessed consistently.

The area of assessment that continues to show no change is the standardised assessment of intelligibility (10.3% 2017; 10.5% 2015). Intelligibility assessment is a key part of the perceptual assessment of motor speech disorders as it usually forms one of the key outcome measures for treatment. Therefore, a robust baseline pre and post treatment is essential and recommended in the RCSLT clinical guidelines (2005). While there has been no change in people with Parkinson's receiving a standardised assessment, there is an increase in measurement of intelligibility overall (67.7% 2017; 53.7% 2015). This is positive, but standardised or evidence-based measures of intelligibility should be considered as a key outcome measure for treatment.

Table 21: Intelligibility assessed (in individuals not seen for swallow only; 2015 results in brackets)

| Evaluation of intelligibility | Patients |
|---|---:|
| Standardised diagnostic intelligibility test completed and score given | 10.3% |
| Informal assessment, non-standardised tool/subsection of other test completed and score given | 33.3% |
| Informal assessment (e.g. rating scale) completed | 34.4% |
| No assessment/results documented but justification given | 10.4% |
| No assessment documented and no justification given | 11.7% |
| Number: | 634 |

The full details of test scores and their interpretations regarding communication strengths and needs were documented in just under two thirds of patients audited (59.9% 2017; 53.5% 2015).

### *Care planning*

Although full test scores and their interpretations are not always fully documented, there was a plan of management detailed in the notes of 90.4% (89.9% 2015) of patients. This remains a consistent area of strength but would be enhanced by full analysis of test results on which to base planning and outcome measurement.

### *Content of therapy*

Direct therapy for communication focused mainly on vocal loudness (62.9%) and strategies to improve intelligibility (58%) supported by patient education and advice (80.2%). There was less emphasis on the non-direct aspects of treatment, such as generalisation of skills, participation and carer support. These are key aspects of intervention to ensure that therapy outcomes have a direct benefit to the person with Parkinson's in their daily lives.

Table 22: Percentage of patients with interventions targeting features outside of direct speech/voice work

| | Patients |
|---|---:|
| Patient education/advice | 80.2% |
| Managing patient participation | 46.3% |
| Managing patient impact | 42.1% |
| Managing generalisation outside clinic | 47.5% |
| Carer education/advice | 46.2% |
| Managing career impact | 11.1% |

### *Information giving*

For both communication and swallowing, results and the rationale for resulting actions (e.g. review period, intervention plans) were explained to the patient and/or carer in 91.1% of cases. The therapist provided education and advice to 92.6% of patients to help them make informed decisions about their future care and treatment. Intervention was also prophylactic and anticipatory in three quarters of cases. This appears to be a strength in speech and language therapy service delivery, where anticipatory planning is important (particularly in management of swallowing).

### *Speech and Language therapist Band*

The majority of patients are seeing therapists who see less than 20% of people with Parkinson's a year (42.1% 2015) and are Band 6 or 7. This is consistent with working with a varied caseload and a team with a mixed skillset. The NICE guideline requires that patients are assessed by a therapist experienced in working with Parkinson's. This means that even working within a mixed caseload clinicians need access to training and supervision to ensure that they have the knowledge and skills to provide high quality, evidence-based assessment and treatment to people with Parkinson's. This should include opportunities to keep up to date and regular supervision.

Table 23: NHS Band of the therapist assessing the patient

| | Patients |
|---|---:|
| Band 5 | 18.5% |
| Band 6 | 36.2% |
| Band 7 | 34.3% |
| Band 8a | 9.0% |
| Band 8b | 2.0% |
| Number: | 810 |

## Service improvement in speech and language therapy services resulting from the 2015 audit

The 2015 audit highlighted shortcomings in the following areas in which services reported implementing service improvement measures:

- Inconsistent use of appropriate standardised assessments for people with Parkinson’s based on best practice.
    - Services report moving to the use of appropriate outcome measures and standardised assessments.
- Failure to fully document test results on which management plans or reports are based.
    - Services report the development of a new assessment pro-forma to reflect best practice guidance and capture test results.

Access to speech and language therapy and standardised assessment at the point of diagnosis is important but is usually managed by therapists who are not seeing people with Parkinson’s routinely. The project below is already showing clear evidence that having access to a specialist is not only reducing the waiting times for assessments, but is providing a much more holistic assessment that goes beyond simple communication difficulties:

- The Royal Berkshire Hospital has introduced a specialist and dedicated speech and language therapy service for patients with Parkinson's. This will enable people to have timely access to highly specialist speech and language therapy and to assess and manage their communication and swallowing difficulties. There are two specific remits of the post. One is to support the multidisciplinary team and provide them with training and support around communication and swallowing difficulties in patients with Parkinson’s. The other is to improve patient care, and to empower patients with Parkinson’s to manage their communication and swallowing difficulties independently, through the provision of highly specialist speech and language therapy across community and acute care settings.

## Patient Reported Experience Measure (PREM) questionnaire

### Aims

The PREM questionnaire gathered views from people with Parkinson’s and their carers about their Parkinson’s service. Of the 477 services that submitted clinical data to the audit, 56.4% also took part in the PREM. This provided responses from 6,446 people with Parkinson’s and their carers.

### Demographics

The majority of PREM questionnaires (75.6%) were completed by a person with Parkinson’s rather than a carer. The majority of respondents were male (60.8%) and white (92.6%). Only 3.1% of respondents lived in a care home, and 19.2% lived alone. The duration of Parkinson’s ranged from less than a year to over 20 years.

The demographics of the respondents to the PREM questionnaire were comparable to those seen in the audit data.

### Findings

#### *Frequency of review by consultant or Parkinson’s nurse*

The majority of respondents (82.5%) felt that the number of reviews carried out by their consultant met their needs, while 81.6% felt this was true for their Parkinson’s nurse. Some respondents felt that they weren’t reviewed enough by either their consultant (14.1%) or Parkinson’s nurse (11.8%).

#### *Quality of services provided within a Parkinson’s service*

Figure 12: Quality of service offered by consultant/doctor

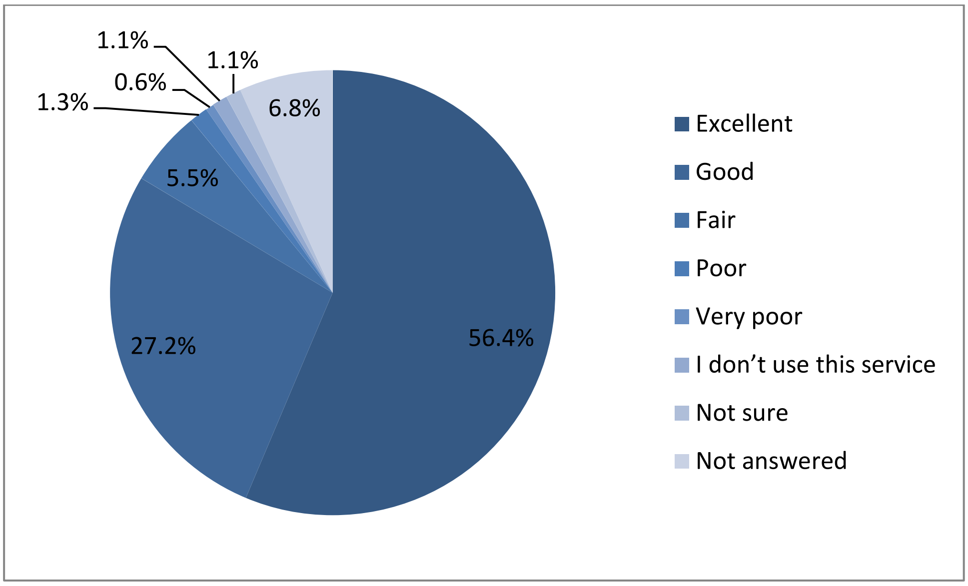


Figure 13: Quality of service offered by Parkinson’s nurse

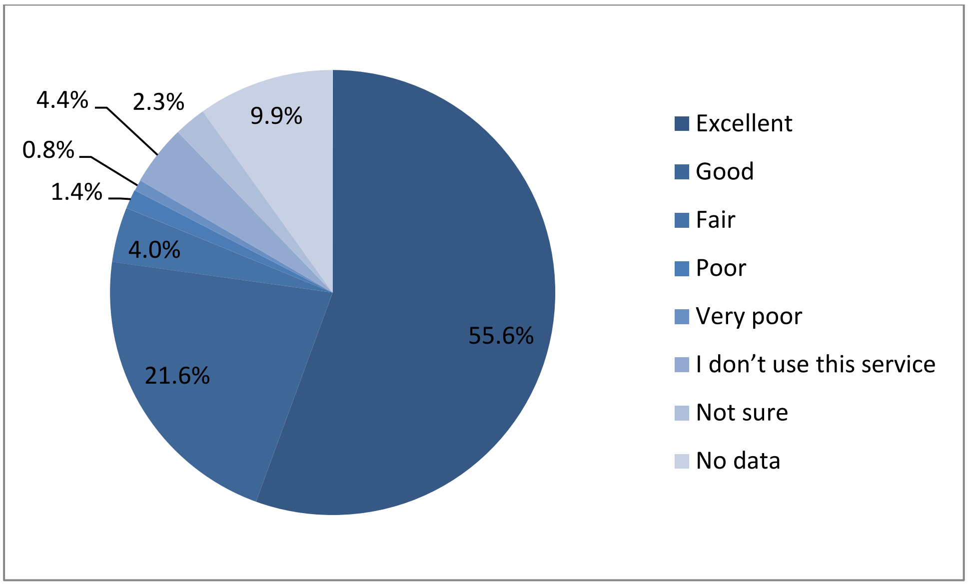


Figure 14: Quality of service offered by occupational therapists

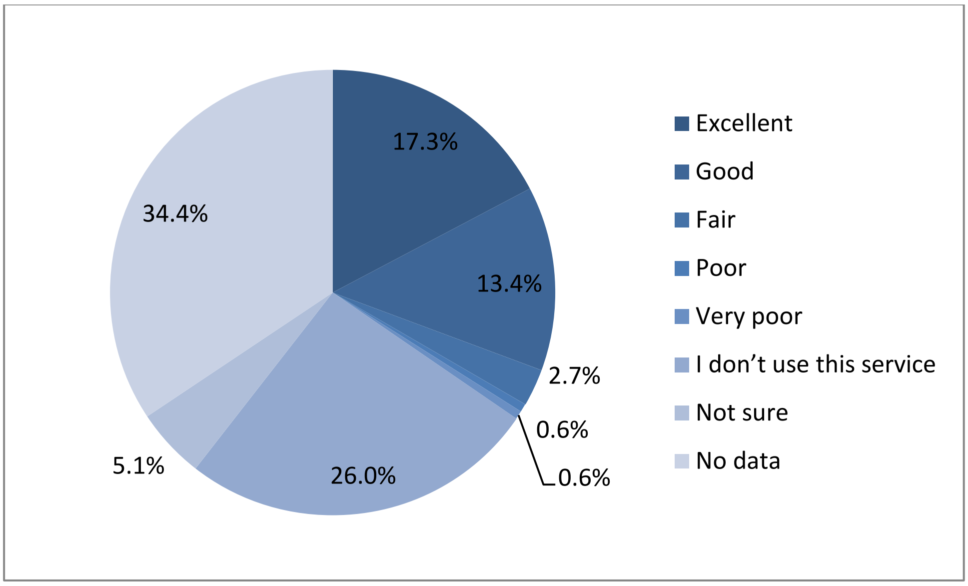


Figure 15: Quality of service offered by physiotherapists

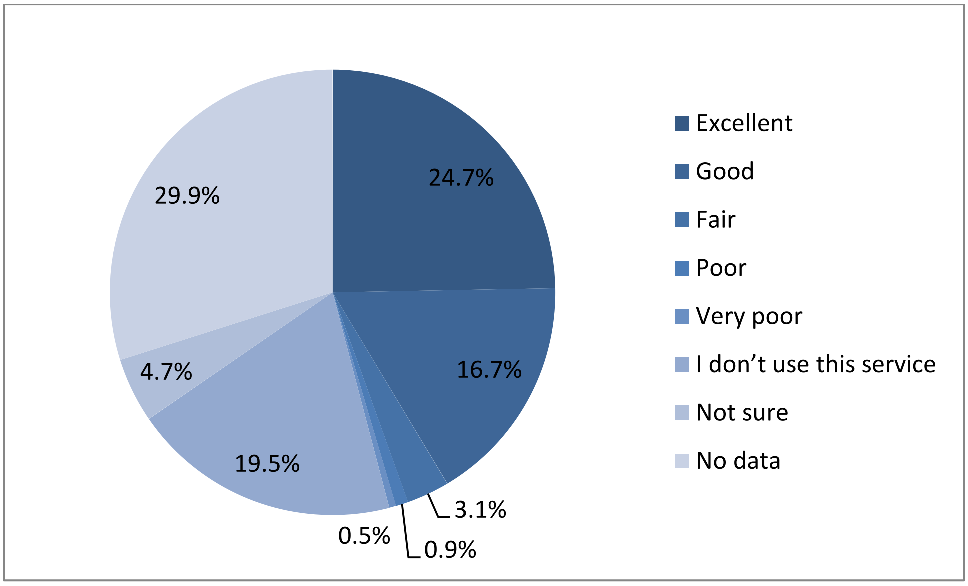
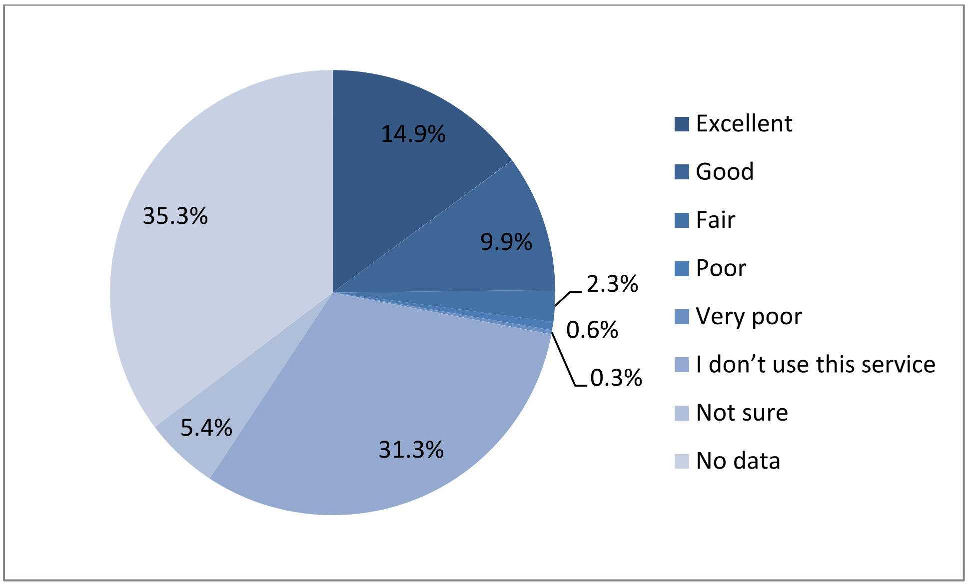


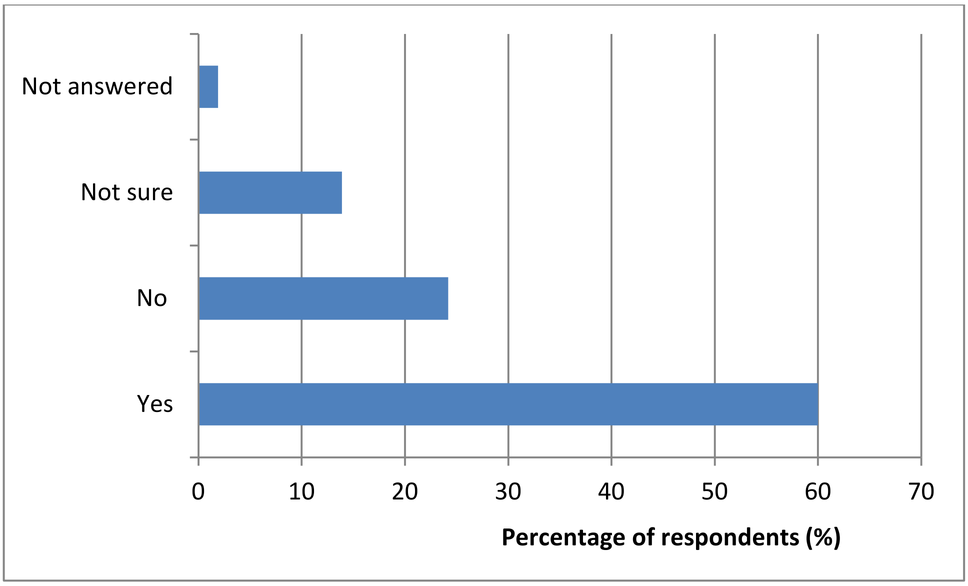
Figure 16: Quality of service offered by speech and language therapists



***Provision of information***

Although the majority of respondents (61.1% of those who answered) said they had received enough information about Parkinson’s at diagnosis, there was still a significant number who had not received enough information or were not sure if they had.

Figure 17: Percentage of people with Parkinson’s who received enough information about Parkinson’s at diagnosis



38.1% felt that they were not given enough information, or were not sure if they had been given enough information. This included information about potential side effects, when starting new medications.

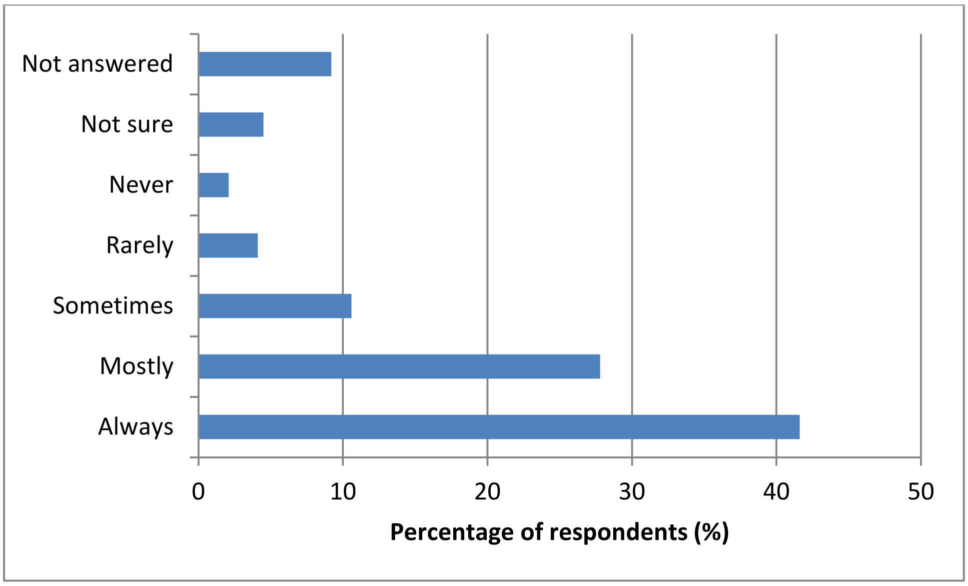
### ***Advice given to drivers about contacting the DVLA and their car insurance company***

Of people with Parkinson's who were drivers and who answered this question, 16.1% had either not been given information about contacting the DVLA or their insurance company, or were not sure whether they had. This is an improvement on the 26.5% who responded this way in 2015.

### ***Medicines management in hospital***

In the last year, 22.9% of respondents had been admitted to hospital. Getting medication on time can be a problem when a person with Parkinson's goes to hospital. When someone with Parkinson's doesn't get their medication at the time prescribed for them their symptoms become uncontrolled. This increases their care needs considerably. Not receiving medication on time contributes to a 73% increase in the length of hospital stay for a person with Parkinson's compared with people of similar age without Parkinson's. It may also lead to further health problems.

Figure 18: Percentage of people with Parkinson’s who received their Parkinson’s medication on time while in hospital



Of those who did not always receive their medication on time, 43.7% said this had a negative or significantly negative effect, 33.7% were unsure if it had any effect, 19.1% said it had no effect and 3.5% said it had a positive effect.

In some cases, hospitals will allow a patient to self-medicate, which ensures they take their medication on time, every time. 58.5% of our respondents wanted to manage and take their own medication, which they had brought from home and 34.5% were able to. However, 50.8% were unable to self-medicate and 14.7% were not sure if they were able to.

### ***Enquiry into balance and falls***

75.8% of people who responded to this question reported raising concerns about balance and falls, or being asked if they had any concerns about them. This is encouraging.

### ***Accessing Parkinson’s UK support services***

25.8% reported that their service had not given them information on how to access Parkinson’s UK support services, or they were not sure if they had.

***Overall service quality***

Figure 19: Percentage of people with Parkinson's who feel listened to by their Parkinson's service

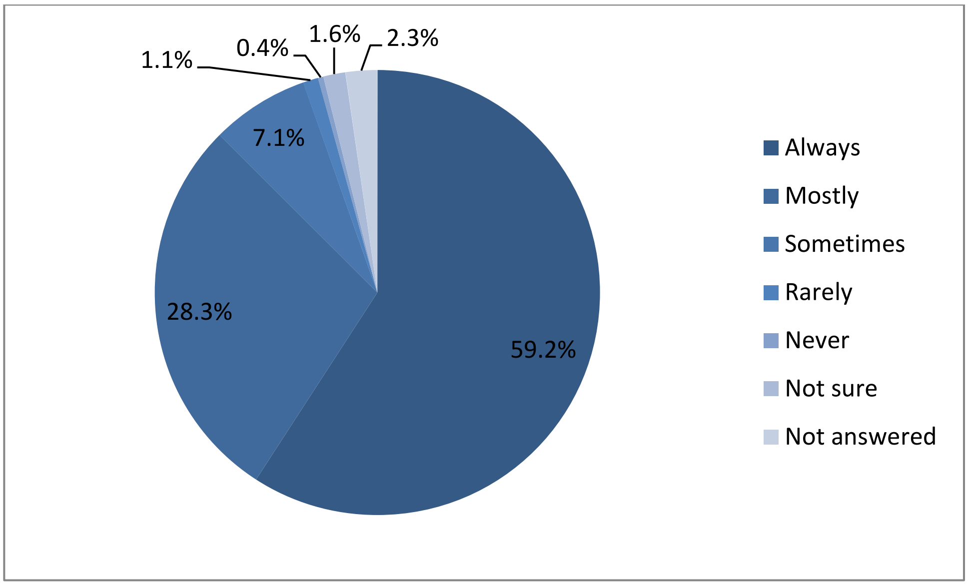
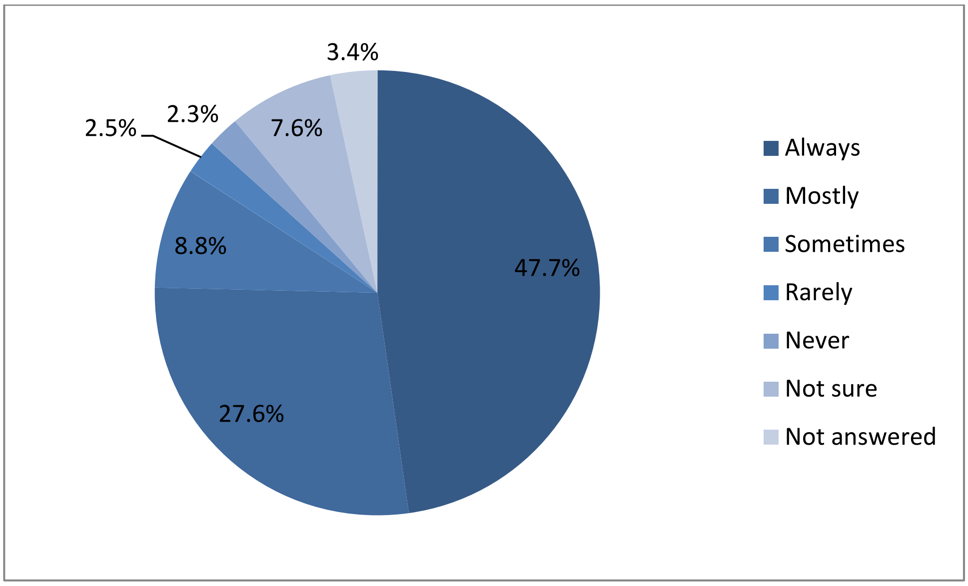


Figure 20: Percentage of people with Parkinson's who feel their Parkinson's service involved them in decisions about their care



The majority of respondents reported that their service was already good (61.5%) with another 26.5% saying their service was improving. 10.6% felt that their service needed to improve but was staying the same, and 1.4% reported that their service was getting worse.

**Service improvement resulting from the 2015 PREM**

Services reported implementing improvement measures such as:

- In Northern Ireland, the *Parkinson's Anticipatory Next Dose Approach* ('PANDA') project aims to empower people living with Parkinson's to take control and lead on the timely, independent self-administration of their Parkinson's medicines, while in hospital. It is hoped that this project will anticipate and accommodate the variation in the administration and timing of Parkinson's medicines outside the traditional ward rounds, and simplify the self-administration process. This will provide a model of care which integrates seamlessly into the challenges of a 'real world' acute hospital setting.

- Leeds Quality Improvement Parkinson's Collaborative is a hospital based multidisciplinary quality improvement team at Leeds Teaching Hospital NHS Trust. It is focusing on improving the quality of inpatient care, specifically ensuring that people with Parkinson's get medication on time. They have launched an 'intervention bundle' and a rolling education programme, which has seen a decrease in missed and omitted doses.

- The Ayrshire Parkinson's Service, along with their hospital managers and the three Ayrshire health and social care partnerships propose improving their service, through better access to a multi-disciplinary team. This would take place at Biggart Hospital, Prestwick and Ayrshire Central Hospital and Irvine one morning every week. If successful, this model will be rolled out in similar a setting within East Ayrshire. This pilot will test out and produce evidence to demonstrate that multidisciplinary working has better outcomes for people with Parkinson's.

## Actions indicated by the audit findings

It is very encouraging to note the significant progress that has been made to improve the quality of care delivered to people with Parkinson's and their carers. There is still work to be done across all specialisms in the following areas:

### *Specialised multidisciplinary working*

It is suggested that service provision moves away from non-specialised or 'doctor only' clinics to an integrated multidisciplinary clinic or joint/parallel doctor and nurse specialist clinics. It is also recommended that earlier referral to physiotherapy, occupational therapy and speech and language therapy is considered as recommended by the NICE guideline.

Attendance at specialist meetings about Parkinson's and movement disorders is desirable as part of the portfolio of CPD for movement disorder specialists, occupational therapists, physiotherapists and speech and language therapists.

### *Standardised practices*

In clinics, recording of non-motor symptoms continues to be poor. This could be improved through use of, for example, the non-motor symptoms questionnaire. Bone health assessment could be rapidly assessed using a bone health app available on clinic desktops. Drivers should be identified at every review, and they should reaffirm that they are aware of their legal responsibility to notify the DVLA and their insurance company. They should also assess their ongoing driving ability. Many clinics have, as standardised practice, a clinic nurse who checks weight and an erect and supine blood pressure. This means they are assessing for malnutrition as well as orthostatic hypotension.

Use of standardised guidance, assessments and outcome measures rather than reliance on clinical experience and peer support in occupational therapy, physiotherapy and speech and language therapy should be the norm. For example, health professionals should use the *Best practice guideline for occupational therapy and Parkinson's* and the *European physiotherapy guideline for Parkinson's*. There should be clear evidence of goal setting as a result of the assessments and full documentation of test results.

All patients should be able to access the Lee Silverman Voice Treatment.

Specialist induction programmes and ongoing support should be available for new therapists. Online learning and training modules could be considered.

### *Communication and information sharing*

Information regarding diagnosis and new medication should be available at all clinics. Information regarding Parkinson's UK support and services should also be readily available.

### *Medicines management*

Inpatient medicines management is poorly done according to the PREM results, with only two out of five patients consistently getting their medication on time. It is suggested that services may wish to audit their own practice and initiate quality improvement projects if shortcomings are highlighted. At outpatient clinics, patients should be asked about the development of any side effects pertaining to their medication including impulse control disorders and day time somnolence associated with driving. These things should also be documented.

### *Anticipatory care planning*

The audit illustrates that medical staff are poorly documenting end-of-life care issues for those in the palliative phases. It is however, very encouraging that the speech and language therapy audit finds that those patients are consistently given information and support with anticipatory care planning. This supports specialised multidisciplinary working, communication and information sharing.

## Conclusion

The results of the 2017 audit demonstrate real progress in improving the overall quality of Parkinson's services since 2015 and are a tribute to the hard work and dedication of the professionals involved. The developments in practice and services achieved through their improvement plans offer learning and inspiration for others taking their next step in the improvement cycle.

It's crucial we continue to work to close the gaps in services identified as priorities in the 2015 audit. In many cases simple adjustments will enable more standardised, evidence based care that can improve life for people affected by the condition. And a whole range of support, tools, data and training are available through the UK Parkinson's Excellence Network to help professionals deliver the change that's needed.

Together we can continue to drive up standards of care and make sure that everyone affected by Parkinson's can get the consistent high quality services they deserve.

**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**

UK PARKINSON'S
Excellence
Network