

2015 UK Parkinson's Audit

Patient and carer report

Introduction

This is a summary of the main findings of the *2015 UK Parkinson's Audit*.

This is the fifth and largest audit of Parkinson's to date. This document outlines the care given to 8,846 people with Parkinson's by 432 services across the UK during the five-month data collection period.

The audit involves:

- elderly care and neurology consultants who offer services for people with movement disorders
- Parkinson's nurses
- occupational therapists
- physiotherapists
- speech and language therapists who care for people with Parkinson's

The audit collects information about how the services work, the patients they see, and then measures these results against approved standards.

For the first time, we recorded the views of patients about their services using a Patient Reported Experience Measure (PREM). A total of 5,834 people with Parkinson's and their carers responded to the PREM questionnaire, giving valuable insights into their experiences as service users.

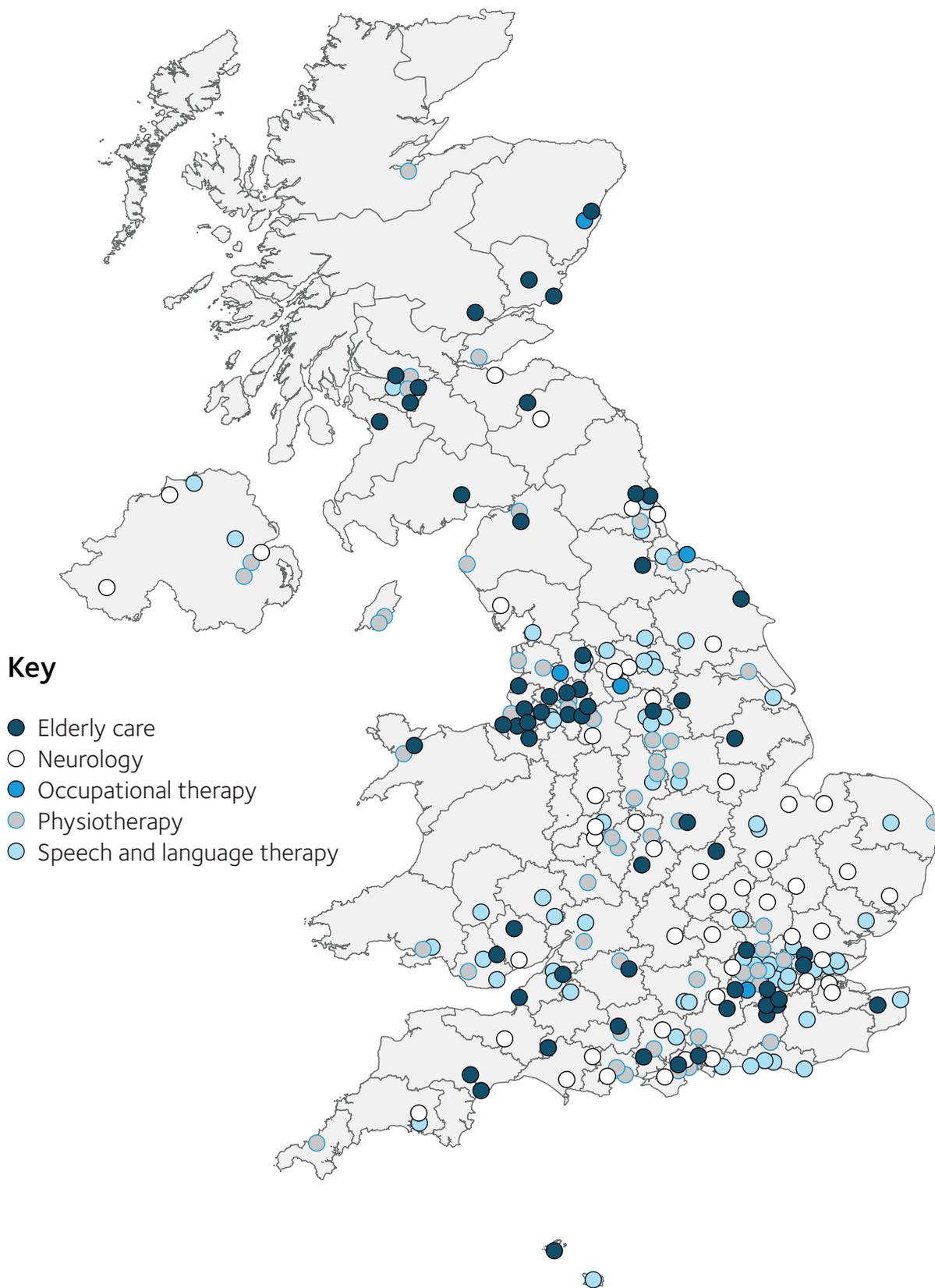
Key findings

We have identified areas of good practice and shortcomings in the services audited. Across all service areas, the audit identified a need for improvements in the following:

- integrated services
- standardised practices
- communication and information sharing
- inpatient management (getting medication on time)
- anticipatory care planning

Parkinson's Audit

Participating services



Note: Some circles overlap so not all services are visible. A complete list of participating services is available in the *Reference Report*.

Elderly care and neurology

A total of 6,202 people with Parkinson's from 239 neurology and elderly care services were involved in the audit. These patients were aged between 39 and 102-years-old with an average age of 74. The majority (60.6%) of patients were male.

Of the 239 participating services, 129 were elderly care (54.0%) and 110 were neurology (46%). The majority (87.6%) of the elderly care services saw patients in a clinic specialising in Parkinson's. For neurology services, this figure was 62.8%.

Evidence of good practice

- **Timely specialist review**

Most patients (98.6%) who attended elderly care and neurology services got a specialist review in the previous 12 months.

- **Clear record of current Parkinson's medications**

Over 90% of people with Parkinson's in the audit had their current prescription of Parkinson's medications checked and recorded at their clinic review.

- **Documentation of advice given about potential side effects of new medication**

Advice was given to 83.3% of people with Parkinson's who were started on new medication. Interestingly, however, the PREM data suggests that only 62.8% of patients felt they had enough information about new medication.

Shortcomings

- **Lack of integrated care**

Integrated care is a way of organising the service so that specialist doctors, Parkinson's nurses, occupational therapists, physiotherapists, and speech and language therapists work as a multidisciplinary team and provide support for patients and carers. Despite being generally regarded as best practice, integrated care services are not widely available.



Sometimes the service doesn't feel joined up. There is no automatic referral to other services – it feels as if you have to find out for yourself and ask to be referred. In emergencies it is hard to get hold of the consultant. The nurse is often extremely useful in their place, but she is very busy.

Table 1: Most common model of service provision in each service

	Elderly care	Neurology	Overall
Doctor only	26.4%	30.9%	28.5%
Joint or parallel doctor and nurse specialist clinics	55%	63.6%	59%
Integrated care	18.6%	5.5%	12.6%

- Failure to record discussions of excessive daytime sleepiness and its relevance to driving**
 Questioning about excessive daytime sleepiness was recorded in only 30.9% of cases. Where excessive daytime sleepiness was recorded in people with Parkinson’s, its impact on driving was documented in only about half of cases.
- Potential impulse control disorders poorly documented in people taking a dopamine agonist**
 Since the last audit, there has been an improvement in the number of elderly care and neurology services recording enquiries about compulsive behaviours (for example gambling, overeating, hypersexuality, excessive shopping) in patients taking dopamine agonists such as Ropinirole or Pramipexole. However, 22.5% of patients still appear to have not been given a warning about potential compulsive behaviours related to their medication.
- Blood pressure poorly recorded in neurology clinics. Pain and saliva generally poorly recorded**
 Neurology clinics scored poorly (54.6%) compared with elderly care clinics (81.5%) in documenting blood pressure. However, assessments of pain and saliva problems were poorly documented in both services.
- Lack of anticipatory care planning**
 Anticipatory care planning is a process designed to support people living with a chronic long-term condition to help them plan for an expected change at some time in the future.

Of those people with Parkinson’s who had signs of advanced symptoms (such as dementia, increasing frailty, impaired swallowing, nursing home level of care) discussions about end of life care issues and advice about lasting power of attorney was recorded in only around 28% and 26% of cases, respectively.
- Poor management of bone health in elderly care and neurology**
 Where there were concerns about falls and/or balance, fracture risk and osteoporosis (thinning of the bones) was considered in only 36.4% of people with Parkinson’s.
- Underuse of Parkinson’s local advisers (previously called information and support workers)**
 The results show that signposting to a Parkinson’s local adviser is poor for people with Parkinson’s and/ or their carers. This is only considered in 36.1% of elderly care and 47.8% of neurology patients.

Occupational therapy

An occupational therapist is a healthcare professional who can help with new ways of doing things such as bathing, dressing, eating, working and learning, and give advice on adapting the home or workplace.

A total of 561 people with Parkinson's from 47 occupational therapy (OT) services were included in the audit.

Evidence of good practice

- **Appropriate timing of referral to occupational therapy in the majority of people referred**
The majority of referrals were judged to have been made at the appropriate time for that person.
- **Availability of information essential for occupational therapy assessment and intervention**
Over three quarters of referrals got most of the information they needed for assessment and intervention.
- **Use of evidence to inform clinical practice**
Since the 2012 audit, there has been a significant increase, up to 78.8%, in the number of services using the *Occupational Therapy for People with Parkinson's: Best Practice Guidelines*.

Shortcomings

- **Inconsistent use of appropriate standardised assessments for people with Parkinson's based on best practice**
Just over half (55.3%) of the OT services used standardised assessments for people with Parkinson's.
- **Lack of integrated services**
Fewer than 13% of OT services reported working in an integrated clinic. The majority of OT services (65.9%) were based in the community, within rehabilitation, reablement or day hospital teams. Only 25.6% of OT services reported being members of a Parkinson's specialist multidisciplinary team, while another 25.6% reported being members of an elderly care or neurology specialist service.

Physiotherapy

A physiotherapist is a healthcare professional who helps keep people moving and functioning as much as possible when they are affected by injury, illness or a long-term condition such as Parkinson's.

Included in the audit were 83 physiotherapy services reporting on 1,263 people with Parkinson's receiving physiotherapy. Assessment from a multidisciplinary team was offered in 52 services (62.7%).

Evidence of good practice

- **Use of good quality resources to guide clinical practice**
The European Physiotherapy Guideline for Parkinson's Disease was used to inform clinical practice in the care of 43% of patients. Other guidelines used included the older physiotherapy-specific guideline, *The Royal Dutch Society for Physical Therapy in Patients with Parkinson's Disease* (31.6%) and *The UK Quick Reference Cards* from the Dutch guidelines (28.3%).

- **Reduced waiting time between diagnosis and initial physiotherapy referral**

The time between diagnosis and referral to physiotherapy ranged from under a year to over 20 years. A referral within two years of diagnosis was reported in 49.3% of patients. Of the patients receiving physiotherapy, 40.5% had not previously been offered physiotherapy.



Experience of physiotherapy and voice therapy has been excellent. Occupational therapy has also been very helpful.

Table 2: Time between diagnosis and referral to physiotherapy

Duration of disease	Patients
Less than 1 year	27%
1–2 years	22.3%
3–5 years	20.2%
6–10 years	17.3%
11–15 years	7.7%
16–20 years	3.8%
More than 20 years	1.7%

Shortcomings

- **Inconsistent use of appropriate standardised assessments (outcome measures) for people with Parkinson’s**

An outcome measure is the result of a test that is used to determine the baseline function of a patient at the beginning of treatment. During and after treatment, the same test can be used to measure progress. For many patients in the audit, multiple outcome measures were used. In 32.3% of cases, other non-recommended outcome measures were used, some of which were not specific to physiotherapy.

- **Significant number of physiotherapists are not using outcome measures**

For 15.4% of people with Parkinson’s, the physiotherapist reported using no outcome measures.

- **Low number of people with Parkinson’s referred to physiotherapy within a year of diagnosis**

The minority (27%) of patients were referred to physiotherapy within a year of diagnosis. Ideally, all patients should be offered a referral to a physiotherapist at diagnosis.

Speech and language therapy

A speech and language therapist is a healthcare professional who specialises in providing treatment and advice for improved communication, swallowing and saliva control.

A total of 63 speech and language therapy (SLT) services, reporting on 821 people with Parkinson's receiving speech and language therapy, were included in the audit. Most people with Parkinson's received SLT within general adult speech and language disorders services (76.3%). Only five services saw people with Parkinson's in a specialist Parkinson's clinic.

Evidence of good practice

- **Availability of services for both communication and swallowing difficulties**
The majority of SLT services offered a full service for communication changes (90.5%) and for swallowing or drooling (93.7%).
- **Time taken from referral to receiving an appointment**
The majority (85.4%) of patients were seen within the target time from referral to first SLT appointment.
- **Completeness of assessment on first referral**
On first referral for communication, 92.8% of patients received a full assessment (if a full assessment was not made the reasons for these were documented). The equivalent figure for swallowing assessments was 93.4%.

Shortcomings

- **Inconsistent use of appropriate standardised assessments for people with Parkinson's based on best practice**
The main aspects of speech and language are routinely evaluated, while other areas of functioning (reading, writing, language, participation) are less well addressed in terms of routine assessment and use of standardised measures. Assessment of the key area of intelligibility is done, but only 10.5% use a standardised intelligibility assessment. 53.7% rely on less-accurate and less-sensitive evaluations.
- **Failure to fully document test results on which management plans or reports are based**
Full results of assessment and patients' strengths and needs were often not documented. However, the majority of people with Parkinson's did have a clear management plan documented. A more complete breakdown of what details were or were not documented in clinical notes is available in the *Reference Report*.
- **Proportion of people referred who have progressed beyond the initial stages of their Parkinson's**
The majority of people with Parkinson's referred to SLT are not at the diagnosis stage. This may reflect the increased need for SLT input as the condition progresses.

Table 3: Stage of Parkinson’s at first referral to SLT

Parkinson’s stage	Patients
Diagnosis	14.1%
Maintenance	57.9%
Complex	18.3%
Palliative	1.7%
Not Known	7.9%
Number	820

- **Variability in review policies**

Only eight SLT services (12.7%) operated a recommended regular review policy within 6–12 months.

Patient Reported Experience Measure (PREM)

The PREM questionnaire gathered views from people with Parkinson’s and their carers about their Parkinson’s service. Of the 432 services that submitted clinical data to the audit, 52.1% also took part in the PREM. A total of 5,834 questionnaires were completed by people with Parkinson’s and their carers. Many who did this survey did not or could not answer all the questions. We have adjusted the way we present these results and have not counted unanswered questions in most cases. The exception is the answers to questions about receiving information, where we counted lack of answer as a negative. No question received fewer than 2,000 countable answers.

Over 1,800 open comments were also collected from the PREM questionnaires, covering a wide range of issues for people with Parkinson’s and their carers. Over 70% of those responding reported a high level of satisfaction with their service, with many saying that a high value is placed on multidisciplinary input. However, not all comments were positive. Roughly 7% said they had significant concerns regarding timing and delays within services, and a further 7% felt there was a lack of information and communication regarding Parkinson’s. The reliance of people with Parkinson’s on their Parkinson’s nurse was clear. This was mostly highlighted by very appreciative comments, but many people commented on the difficulties faced if a Parkinson’s nurse was not available.

Who completed the questionnaires?

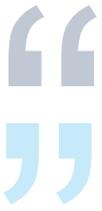
Most of the PREM questionnaires, the majority (72.4%) were completed by a person with Parkinson’s and the rest by a carer on their behalf.

Areas of satisfaction

- **Most people with Parkinson’s or carers were satisfied with the frequency of review by medical staff and their Parkinson’s nurse**

The majority of respondents (73.3%) felt that the number of reviews carried out by their consultant met their needs. While fewer (67.5%) felt this was true for their Parkinson’s nurse. Some respondents felt that they were reviewed less than was needed by either their consultant (13.2%) or Parkinson’s nurse (10.2%).

- **Over three quarters rated the service received from medical staff and their Parkinson’s nurse as excellent or good**



The Parkinson's service has always been first rate. The consultant and his staff have always responded promptly to my needs, and consequently my condition has remained as stable as possible. I am forever grateful for the quality of their service.

Figure 2: Quality of service offered by consultant or doctor

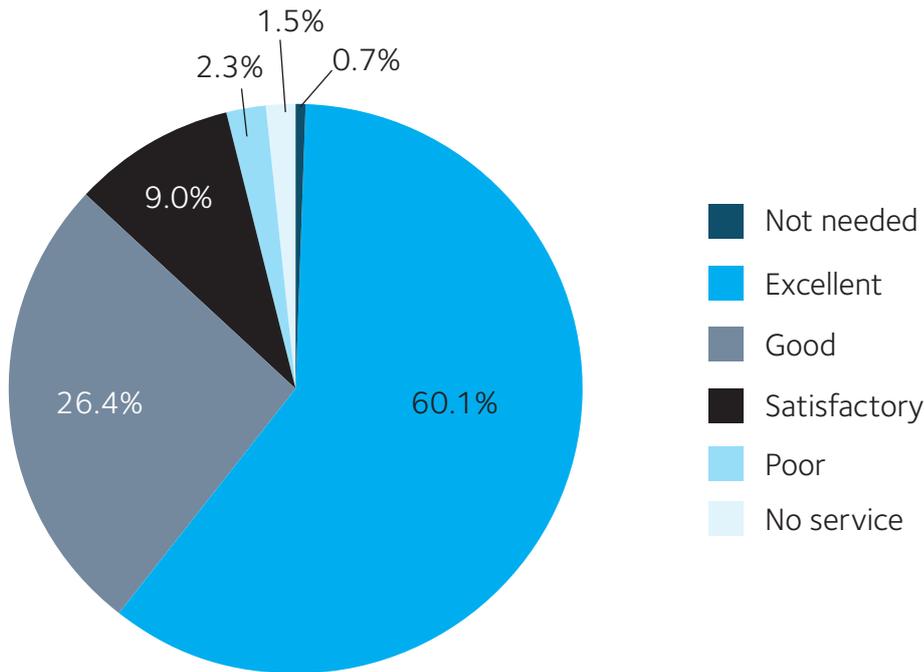
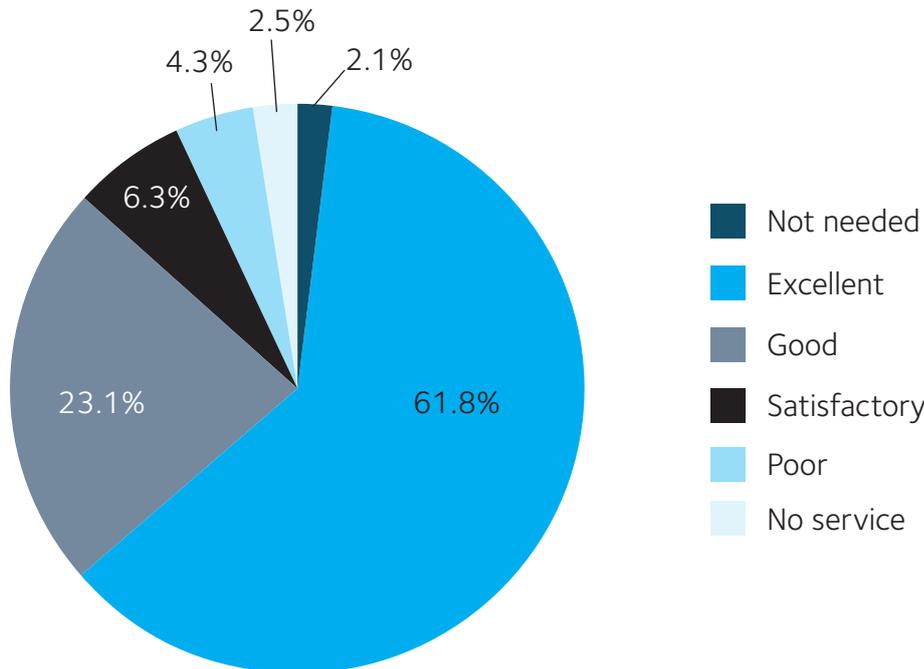


Figure 3: Quality of service offered by Parkinson's nurse



- **Most people with Parkinson’s felt listened to all or most of the time**



My Parkinson’s service treats me as a whole person and not just a number or a set of symptoms. My family feel totally supported and included.

Table 4: Percentage of people with Parkinson’s who feel listened to by their Parkinson’s service

Feel listened to	
Always	62.5%
Mostly	25.4%
Sometimes	9.6%
Rarely	1.6%
Never	0.9%

Areas of concern

- **Only two thirds felt they received enough information about Parkinson’s at diagnosis**
Although the majority of respondents (64.9%) said they had received enough information about Parkinson’s at diagnosis, there was still a significant number who had not or were not sure.



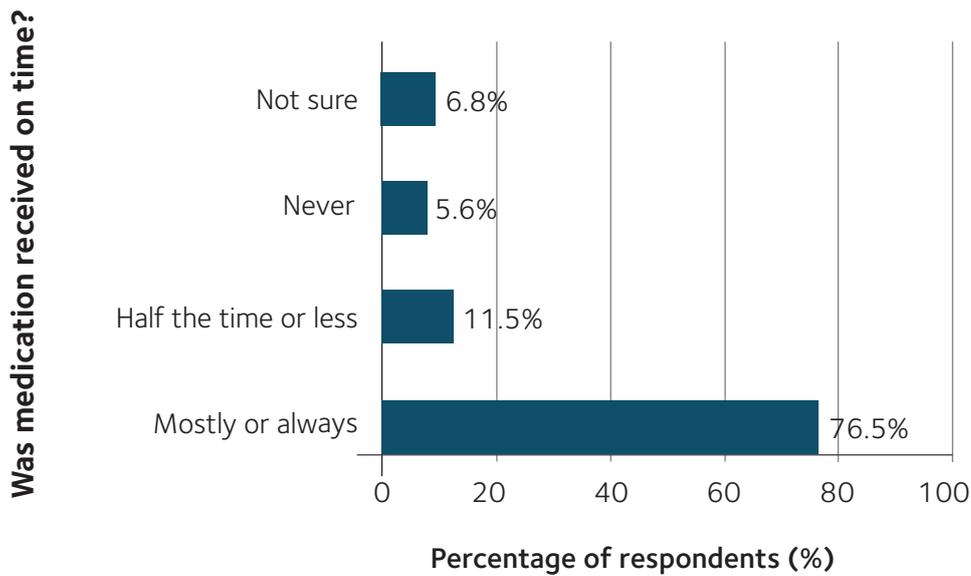
When I was told I had Parkinson’s by the specialist, I was given no information about the condition or any advice. I had to find out all about it by myself. The local Parkinson’s group, which I discovered in town on an information stall, helped me find out about the Parkinson’s nurse, who has been a great help.

- **Of those who responded, a quarter had either not been given information regarding contacting the DVLA (or DVA) or their insurance company, or they were unsure whether they had**
There is a legal requirement for drivers with Parkinson’s to inform the DVLA (or DVA) and their car insurance company of their diagnosis of Parkinson’s.
- **Just under half of patients admitted to hospital in the last year always received their medication on time**
In the last year, 22.7% of respondents had been in hospital. When someone with Parkinson’s doesn’t get their medication at the time prescribed for them their symptoms may become worse – increasing their care needs considerably.



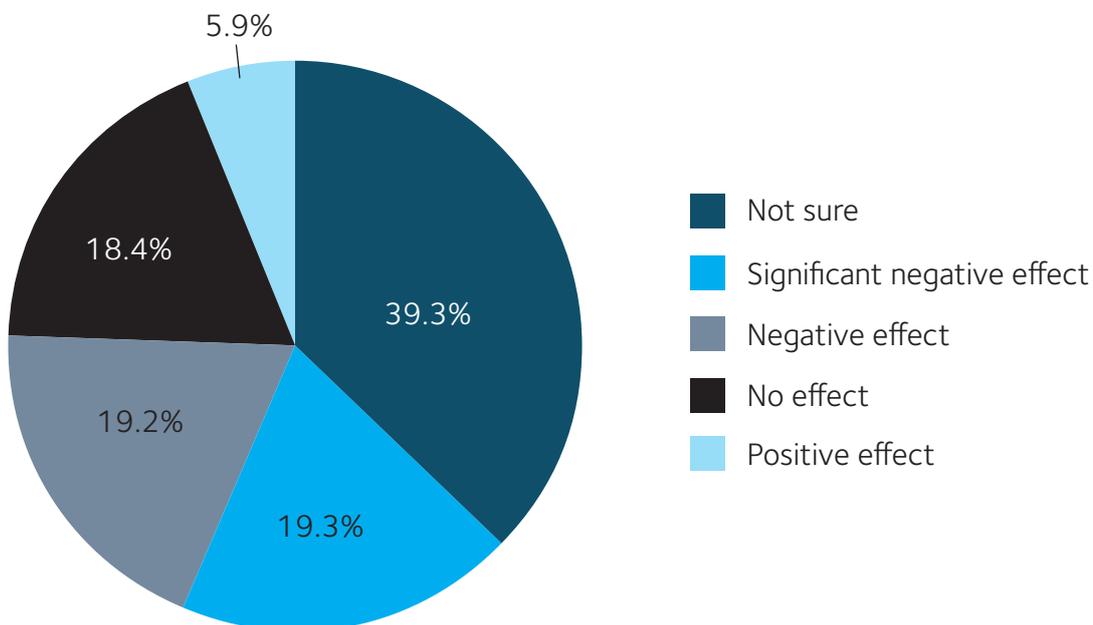
My experience in hospital was awful. There was seemingly no understanding of Parkinson's and I was seen as a nuisance patient asking for my pills on time. No access to a Parkinson's nurse on the ward. Huge need for education as staff didn't know anything about Parkinson's.

Figure 4: Percentage of people with Parkinson's who received their Parkinson's medication on time while in hospital



38.5% felt worse as a result of the late medication and half of these felt significantly worse.

Figure 5: Effect of late Parkinson's medication in hospital



In some cases, hospitals will allow a patient to self-medicate so they can take control of getting their medication on time every time. The majority (53%) of people with Parkinson's were able to do this.

How the audit findings will be used

The findings of the audit are being used by participating services to shape their quality improvement plans. They are also being used at a UK level to prioritise the activities of Parkinson's UK and the UK Parkinson's Excellence Network in working towards quality Parkinson's services for all. Another audit will take place in 2017 to track improvements and inform further plans.

For more detail on these key findings, and the recommended actions, please see the audit *Summary Report*. For details of the audit design and methods, participating services, the audit and PREM questions, and the comments submitted as part of the PREM please see the *Reference Report*.

parkinsons.org.uk/audit