PARKINSON'S
Excellence
Network

2022 UK Parkinson's Audit - Summary Report

Contents

Selected audit findings:

Foreword

We are delighted to present the results of the 2022 UK Parkinson's Audit, the eighth since the audit was launched in 2009. The audit is a fundamental pillar of the Excellence Network: it underpins everything that we do to support improvements to health and care services for people with Parkinson's. It provides rich data about the state of Parkinson's services across the UK, which inform our priorities and help us drive service improvement and measure change.

This audit has identified many areas that have improved since 2019, which is impressive given the immense challenges that staff and services have been facing, including COVID-19 and the worsening NHS staffing crisis. Options for remote consultations, awareness of the importance of activity and exercise, and inductions for new therapists have all improved.

It is particularly pleasing to see such an improvement in the assessment and management of bone health, which was one of the key service improvement priorities identified following the 2019 audit. In response to this, we launched a national multi-centre service improvement project, collaborating with 44 Parkinson's services across the UK. Through this project, over 1000 people with Parkinson's were assessed for bone health and fracture risk and we have worked hard to raise awareness of the importance of bone health among clinicians and people with Parkinson's.

However, unfortunately it is not all good news. The audit has also demonstrated lack of progress, or even deterioration, in other key areas, including early referral to therapy services, waiting times, standardised assessments, and anticipatory care planning. Whilst in most cases this is not surprising - and indeed reflects patterns seen across the entire NHS - it will nevertheless be concerning for people with Parkinson's and their loved ones who are facing enormous challenges and are reliant on Parkinson's services. The social isolation and lack of access to services during the pandemic made both their physical and mental health worse. The rising cost of living in the UK means that some people with Parkinson's are struggling to stay warm and eat well - a further risk to their health and wellbeing.

Meanwhile, NHS staff face the challenge of providing good Parkinson's care in the face of increasing demand, more complex care needs and a shortage of staff. Despite these challenges, we can see from the uptake of this audit that the nurses, therapists, doctors and other health care professionals who make up the multidisciplinary Parkinson's team remain committed to improving care and providing the best service they can to people with Parkinson's.

Thank you so much to everyone who contributed their data and feedback to the audit. Your contribution makes a big difference to care for people with Parkinson’s.

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Introduction

The overall aim of the UK Parkinson's Audit is to provide timely information to clinicians, commissioners, funders, members of the Parkinson's community, and the public on how well Parkinson's care is being delivered so it can be used as a tool to improve the quality of care.

This summary report outlines the most significant findings of the 2022 UK Parkinson's Audit, the eighth to be completed. It is aimed at the services that participated and other similar services across the UK. A separate summary for general audiences, including members of the Parkinson's community, is available on the audit pages of the Parkinson's UK website.[1]

Complete data tables of all the audit results are also available on the website, along with details of the audit's design and methods, the participating services, the dataset and the Patient Reported Experience Measure (PREM) questionnaire.

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 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 continues to face unprecedented challenges coming out of the Covid 19 pandemic, along with other national and international pressures. This makes it more important than ever to look closely at what Parkinson's services are delivering and how teams are being supported to work together through the Parkinson's Excellence Network to share evidence and best practice to improve standards of care.

The design of the audit has 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, 2017 and 2019 audits, with a few exceptions thus allowing direct comparison.

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[1] https://www.parkinsons.org.uk/professionals/uk-parkinsons-audit-transforming-care

In February 2018 the *NICE quality standard for Parkinson's disease* was published[2]. The five quality statements describe high-quality care in priority areas for improvement. This UK-wide audit underpins the NICE quality measure process for these statements and has official recognition from NHS England HQIP

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

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[2] National Institute for Health and Care Excellence (NICE) (2018) *Parkinson's Disease* [QS164]

Executive summary

This UK-wide audit measures the quality of care provided to people living with Parkinson's against a range of evidence-based guidance.

It involves 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 care for people with Parkinson's. The audit engages services within these professions to measure the quality of their practice, within their model of care provision, and to trigger service improvement plans.

The 2022 UK Parkinson's audit reports on the care provided to 9,760 people with Parkinson's during the five month data collection period. It also includes the views of 6,795 people with Parkinson's and their carers, who responded to the Patient Reported Experience Measure (PREM) questionnaire about their experience of the service they attend.

Key themes for improvement

There is still work to be done across all specialties in the following areas:

- specialised multidisciplinary working
- standardised practices
- communication and information sharing
- medicines management
- educating the workforce

Elderly Care and Neurology

Evidence of good practice

- timely specialist review
- adoption of remote consultations
- access to Parkinson's Nurse Specialists or equivalent
- access to therapists with experience in Parkinson's
- monitoring for impulsive compulsive behaviours
- bone health assessment

Areas for Improvement

- early referral to therapy services
- uptake of Parkinson's-specific CPD by clinicians and Parkinson's Nurse Specialists
- advice about Lasting Power of Attorney

- documenting advice on impact of known excessive daytime somnolence on driving
- Anticipatory Care Planning
- access to Clozapine

Occupational therapy

Evidence of good practice

- use of person-centred goal setting and other patient reported outcome measures
- induction and support strategies for new therapists within general competencies framework
- all services seeing patients in person, with phone and video follow-ups offered
- access to Parkinson's-specific CPD at least annually

Areas for improvement

- earlier service referral - during diagnosis stage
- waiting times from referral to first session
- improved awareness of referrers of OT roles
- use of appropriate standardised assessments
- Parkinson's-specific induction for new therapists

Physiotherapy

Evidence of good practice

- exercise advice offered
- physiotherapists are members of a Parkinson's specialist MDT
- individuals being seen by specialised Parkinson's services
- provision of information about non-NHS external services

Areas for improvement

- earlier service referral within 2 years of diagnosis
- use of Parkinson's-specific outcome measures
- use of evidence-based resources to guide practice
- access Parkinson's-specific CPD at least annually
- initial assessments carried out by qualified member of staff
- services offering integrated Parkinson's service (medical and therapy)

Speech and Language therapy

Evidence of good practice

- Parkinson's-specific induction training and support strategies
- increase in specialist SLT provision
- adoption of remote consultations
- swallowing and drooling assessment and management

Areas for improvement

- use of standardised assessments
- access to Lee Silverman Voice Treatment (LSVT)
- access to Expiratory Muscle Strength Training (EMST)
- documentation of on/off status
- Anticipatory Care Planning

PREM

Areas of satisfaction

- service overall felt to be "improving" or "staying the same, already good"
- concerns raised were dealt with, either with onward specialist referral or advice / medication
- advice regarding keeping active / exercise
- information regarding research participation
- access to physiotherapy between scheduled reviews

Areas of concern

- fewer individual service components ranked as excellent or good
- information at diagnosis
- discussions about balance, falls and osteoporosis
- advice regarding contacting the DVLA / car insurance company
- getting medication on time while an inpatient

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	136		129		53		124		64		506	
Patients	3305		3184		627		1837		807		9760	
Patient characteristics												
Age (years)												
Mean (SD) (range)	77.6 (8.0) (28-100)		72.5 (10.0) (19-97)		75.6 (8.9) (29-97)		73.9 (9.4) (22-97)		74.8 (9.2) (41-94)		74.9 (9.1) (19-100)	
Gender												
		%		%		%		%		%		%
Male	2017	61.0	1939	60.9	388	61.9	1131	61.6	568	70.4	6043	61.9
Female	1288	39.0	1245	39.1	239	38.1	705	38.4	239	29.6	3716	38.1
Prefer not to say	0	0	0	0	0	0	1	0.1	0	0	1	0
Duration of Parkinson's (years)												
Mean (SD)	5.9 (5.2)		6.4 (5.5)		5.9 (5.2)		5.6 (5.5)		6.5 (5.9)		6.0 (5.4)	
Median	4		5		4		4		5		4	
(range)	(0–33)		(0–57)		(0–33)		(0–37)		(0–36)		(0-57)	
Phase of Parkinson's												
		%		%		%		%		%		%
Diagnosis	359	10.9	255	8.0	90	14.4	231	12.6	67	8.3	1002	10.3
Maintenance	1543	46.7	1512	47.5	290	46.3	1012	55.1	488	60.5	4845	49.6
Complex	1279	38.7	1298	40.8	224	35.7	576	31.4	228	28.3	3605	36.9
Palliative	124	3.8	119	3.7	23	3.7	18	1	24	3.0	308	3.2

The services taking part are not necessarily the same ones which took part in the last audit in 2019, although many are re-auditing their practice this time.

The PREM questionnaire

In addition to the audit data, 6,795 people with Parkinson's and their carers attending 380 (75.1%) 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.

Elderly Care and Neurology

Aims

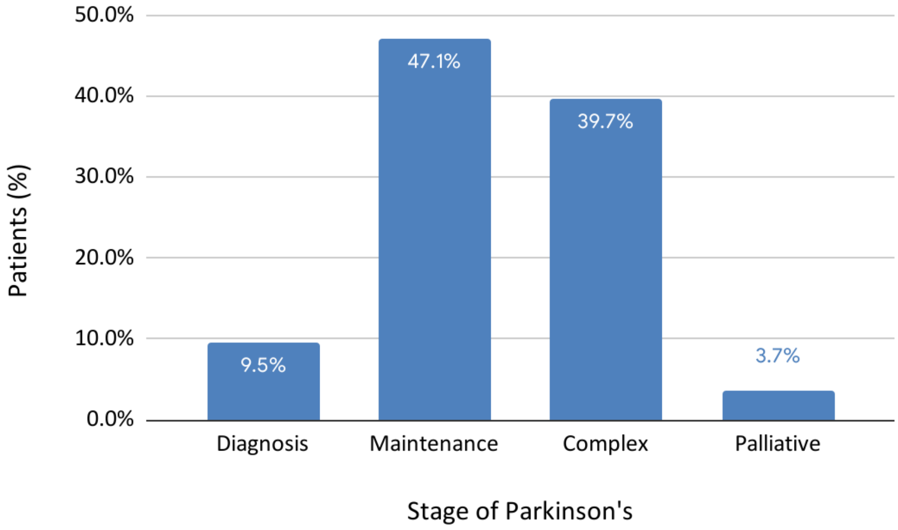
The Elderly Care and Neurology audits are intended to measure the quality of assessment and management of people with Parkinson's attending Elderly Care[3] and Neurology clinics, and also to describe the models of service delivery used. They allow benchmarking of services against standards of good practice and guidance relating to the quality of care for people with Parkinson's. This is particularly pertinent given the current NHS pressures, both staffing and financial, coming out of the pandemic.

Demographics

Elderly Care and Neurology services saw 6,489 people with Parkinson's, who were included in the audit. These patients were aged between 19 and 100 years (mean: 75.1, standard deviation (SD) 9.4 years), and the majority were male (61.0%). Patients seen at Neurology services (mean age: 72.5, SD 10.0 years) tended to be younger than in Elderly Care (mean age: 77.6, SD 8.0 years).

Mean age at diagnosis was 69.0 years (SD 10.8 years) (Elderly Care: 71.7 SD 9.7; Neurology: 66.1 SD 11.1), and patients audited had a mean Parkinson's duration of 6.1 years (SD 5.4, range 0–57 years). The distribution of phase of Parkinson's was very similar across Elderly Care and Neurology audits.

Figure 1: Parkinson's phase in Elderly Care and Neurology



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[3] Elderly Care refers to services provided by a geriatrician.

Service audit

Model of service provision - integrated clinics

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 a multidisciplinary team. This ensures the best quality of life for the person with Parkinson's and their families.

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 available at 17.0% of all clinics (compared to 17.7% of services audited in 2019). This continues to be more common for Elderly Care (22.1%, 21.1% 2019) than Neurology services (11.6%, 13.7% 2019). The most common model of service provision continues to be a joint or parallel doctor and nurse specialist clinic (42.6% of audited services in 2022, 51.1% 2019, 58.7% 2017). A reduced proportion of clinics in both Elderly Care (26.5%, 29.6% 2019) and Neurology (15.5%, 33.1% 2019) are staffed by a doctor alone.

Table 2: Most common model of service provision for medical input in each service

	Elderly Care	Neurology	Elderly Care and Neurology
Doctor alone	26.5%	15.5%	21.1%
Joint/parallel doctor and nurse specialist clinics	43.4%	41.9%	42.6%
Integrated clinics	22.1%	11.6%	17.0%
Community nurse service with consultant input	4.4%	24.0%	14.0%
Nurse-led service	1.5%	5.4%	3.4%
Community nurse service with no consultant input	2.2%	1.6%	1.9%
Number of services:	136	129	265

Adoption of remote consultations

During the Covid-19 pandemic, due to the mandated restrictions, outpatient services supporting people with Parkinson's had to cease or be delivered remotely. Remote consultations have both advantages and challenges for this population. These results show that 93% of audited services offer remote consultations, with neurology offering more in the way of video and telephone than elderly care.

Table 3: Remote consultations offered

	Elderly Care	Neurology	Elderly Care and Neurology
By video	1.5%	0.0%	0.8%
By telephone	48.5%	35.7%	42.3%
By video and telephone	41.2%	59.7%	50.2%
No remote consultations offered	8.8%	4.7%	6.8%
Number of services:	136	129	265

Access to a Parkinson's nurse or equivalent

Statement 1 of the NICE Parkinson's Disease Quality Standard states that adults with Parkinson's disease have a point of contact with specialist services. The audit showed that the majority of people with Parkinson's (97.0%) could access a Parkinson's nurse (95.1%) or equivalent.

Table 4: Access to a Parkinson's nurse or equivalent in Elderly Care and Neurology services

	Elderly Care	Neurology	Elderly Care and Neurology
Yes – Parkinson's Nurse Specialist	94.9%	95.3%	95.1%
Yes – other healthcare professional	0.7%	3.1%	1.9%
No	4.4%	1.6%	3.0%
Number of services:	136	129	265

85.5% of PREM respondents reported that they had access to a Parkinson's nurse (88.7% 2019), with 78.9%% reporting being able to contact them between scheduled reviews (83.7% 2019). 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 complete the PREM. Alternatively it may suggest that some patients were inadequately informed about how to access a Parkinson's nurse.

Access to occupational therapy, physiotherapy and speech and language therapy

Statement 3 of the NICE Parkinson's Disease Quality Standard states that adults with Parkinson's disease are referred to physiotherapy, occupational therapy or speech and language therapy if they have problems with balance, motor function, activities of daily living, communication, swallowing or saliva. The audit demonstrated that almost all (over 95%) services do have access to these specialists. In addition the therapy audits suggest that earlier referral to therapy services by elderly care and neurology consultants should be encouraged.

Table 5: Access to occupational therapy, physiotherapy and speech and language therapy in Elderly Care and Neurology services

	Elderly Care	Neurology	Elderly Care and Neurology
Occupational therapy	96.3%	93.8%	95.1%
Physiotherapy	98.5%	96.9%	97.7%
Speech and language therapy	97.8%	96.9%	97.4%
Number of services:	136	129	265

Mental health

Standardised assessment tools are routinely available in 79.6% of all or most clinics to assess and monitor cognitive function, and in 61.9% to assess anxiety and depression. Of note 20.4% of audited Elderly Care and Neurology services are not able to refer to mental health services that have experience in Parkinson's.

Statement 5 of the NICE Parkinson's Disease Quality Standard states that services for adults with Parkinson's disease provide access to clozapine and patient monitoring for treating hallucinations and delusions. The audit shows that currently 68.3% of services do not have local pathways to provide access to clozapine and for patient monitoring.

Availability of written information

Written information about Parkinson's is routinely available all or most of the time at 82.6% of clinics (86.4% 2019). But written information about Parkinson's is still not routinely available in 7.5% of outpatient clinics. However, providing written information in the clinic may not be enough, as the PREM data suggests that only 59.5% of patients feel they are given enough information at diagnosis (60.7% 2019).

Time critical medications

Statement 4 of the NICE Parkinson's Disease Quality Standard states for adults with Parkinson's disease who are in hospital to take Levodopa within 30 minutes of their individually prescribed administration time. The audit asked "Does your hospital have a local Parkinson's guideline incorporating a recommendation that Levodopa be administered within 30 minutes of prescribed time?", and just over three quarters (75.8%) did (73.3% 2019).

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.

Of note 1 in 5 Consultants had not undertaken any Parkinson's-related CPD in the last 12 months (moreso in neurology).

Table 6: Services where all Consultants and Parkinson's Nurse Specialists* have attended movement-disorder-specific CPD in the last 12 months

	Elderly Care		Neurology		Elderly Care and Neurology	
	2019	2022	2019	2022	2019	2022
Consultants	91.5%	90.2%	62.9%	68.6%	78.2%	80.3%
Parkinson's Nurse Specialists	97.8%	93.0%	93.4%	89.5%	95.7%	91.3%

* excluding services with no named Consultant or Parkinson's Nurse Specialist or equivalent

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. 96.7% of patients audited in Elderly Care and Neurology services had received a specialist review in the preceding 12 months. The PREM data however suggests that 17.6% of respondents, with access to a Consultant, felt their needs were not met, and this figure was 13.0% for specialist nurses.

Medicines management and monitoring for compulsive behaviours

There was evidence of information being provided about potential side effects of new medication for 87.7% of patients in the audit (84.0% 2019). Of note, the PREM data suggests that 70.5% of patients feel they are given enough information when prescribed new medication (68.7% 2019).

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

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	86.4%	89.0%	87.7%
No	13.6%	11.0%	12.3%
Number of patients:	2050	2161	4211

Statement 2 of the NICE Parkinson's Disease Quality Standard states that adults with Parkinson's disease taking dopaminergic therapy are given information about the risk of impulse control disorders, when starting treatment and at least annually.

The 2022 audit results demonstrate that 76.9% of patients on dopaminergic therapy have had a recorded discussion about compulsive behaviours in the preceding year (79.0% in neurology and 74.8% in elderly care). This is an upward trend up from 68.9% in 2019, 67.4% in 2017 and 64.2% in the 2015 cycle.

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	74.8%	79.0%	76.9%
No	25.2%	21.0%	23.1%
Number of patients:	2498	2636	5134

Driving and excessive daytime sleepiness

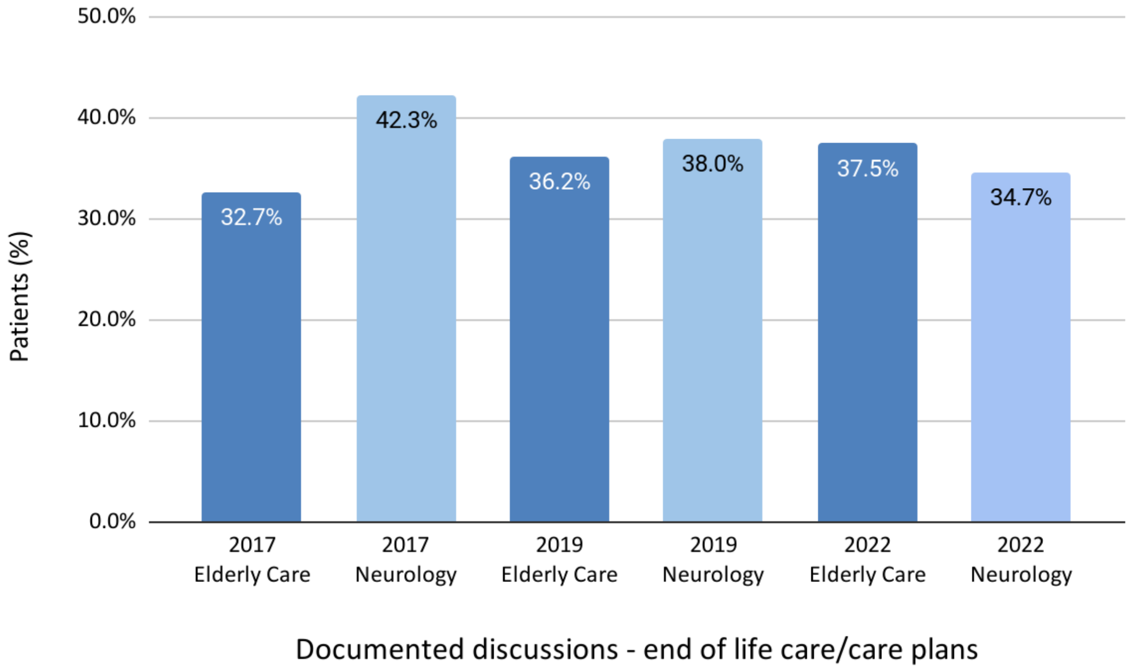
When excessive daytime sleepiness was recorded, its impact on driving was documented in 75.3% of drivers. This is an increase from 67.2% in 2019 (62.8% 2017, 56.6% 2015). This does however mean that one quarter of drivers with documented excessive daytime somnolence do not have documentation about the effect this may have on driving. This is in addition to those drivers who are not asked at all about this important issue.

Table 9: 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	73.8%	76.6%	75.3%
No	26.2%	23.4%	24.7%
Number of patients:	730	813	1543

Anticipatory Care Planning

Figure 2: Percentage of patients with markers of advanced disease with documented discussions regarding end of life care issues/care plans within the last 12 months

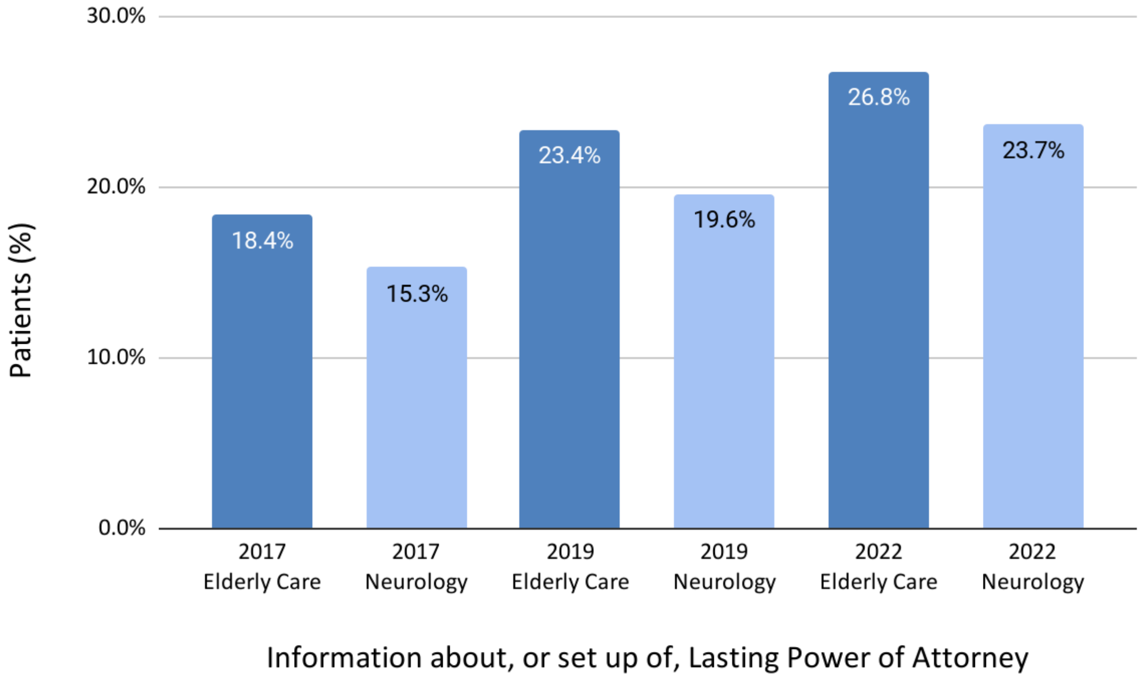


Of those people who had markers of advanced disease (25.5%), discussions regarding end-of-life care issues were recorded in 36.3% (36.9% 2019, 36.8% 2017).

Power of Attorney

The percentage of patients and/or carers (at all phases of Parkinson's) having been offered information about, or having set up, a Lasting Power of Attorney (Power of Attorney in Scotland) improved to 25.3% overall (Elderly Care 28.6%, Neurology 23.7%), meaning 75% still have no documented evidence.

Figure 3: Percentage of patients and/or carers offered information about, or having set up, a Lasting Power of Attorney (Power of Attorney in Scotland)



In the 2015 audit only those with markers of advanced Parkinson's were included in 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 discussions taking place earlier.

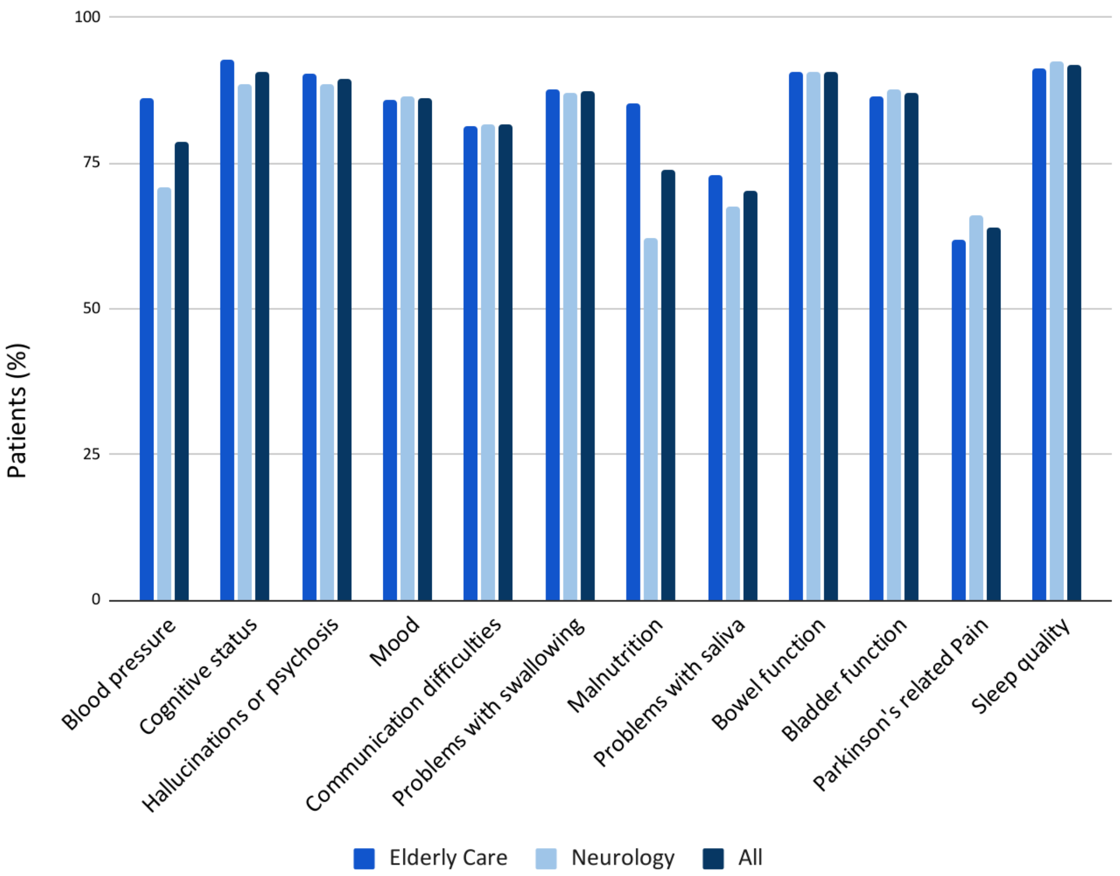
Of note, however, 67.1% of patients in the palliative phase had been offered information about, or had set up, a Lasting Power of Attorney (59.8% 2019, 56.1% 2017 and 49.5% 2015).

Domain scores

The audit recorded whether services completed assessments in three domains during the previous 12 months: (i) non-motor symptoms, (ii) assessment of bone health and Activities of Daily Living and (iii) multidisciplinary involvement.

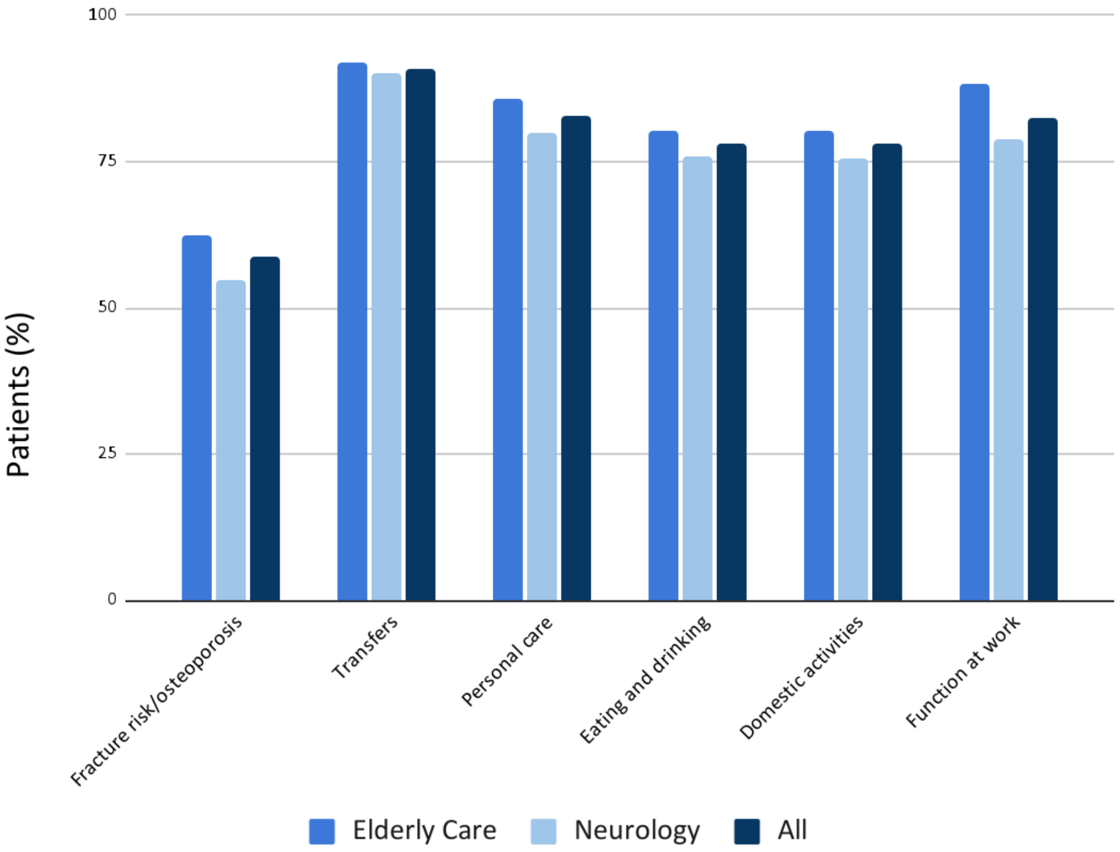
For each element within a domain, total scores were calculated by summing passes (a score of 1) and fails (a score of 0) for each patient. A pass was achieved if the assessment was done. However, a pass was also achieved if an assessment was not done but was considered and not felt to be indicated or appropriate. A fail indicates when an assessment was not done and not considered. Patients were excluded if not specifically relevant to the question being asked, for example omitting those not in employment when asking about function at work.Total domain scores were then calculated for each domain.

Figure 4: Domain 1 – Non-motor assessments during the previous year



Blood pressure assessment is documented in 86.2% of audited Elderly Care clinics, and in 70.9% of Neurology. Elderly Care services screen 85.4% of their patients for malnutrition, and Neurology services screen 62.1%. Assessments of pain and saliva problems were poorly documented by both specialties in 2015, 2017 and 2019. The services audited in 2022 show no significant improvement in pain assessment at 63.9%, but a small improvement in saliva assessment at 70.4%. Mental health however continues to be documented well with 90.8% having evidence of enquiry/assessment re: cognitive status, and 89.4% and 86.2% of patients respectively have been asked about hallucinations/psychosis and mood.

Figure 5: Domain 2 – Assessment of bone health and Activities of Daily Living (ADL) during the previous year

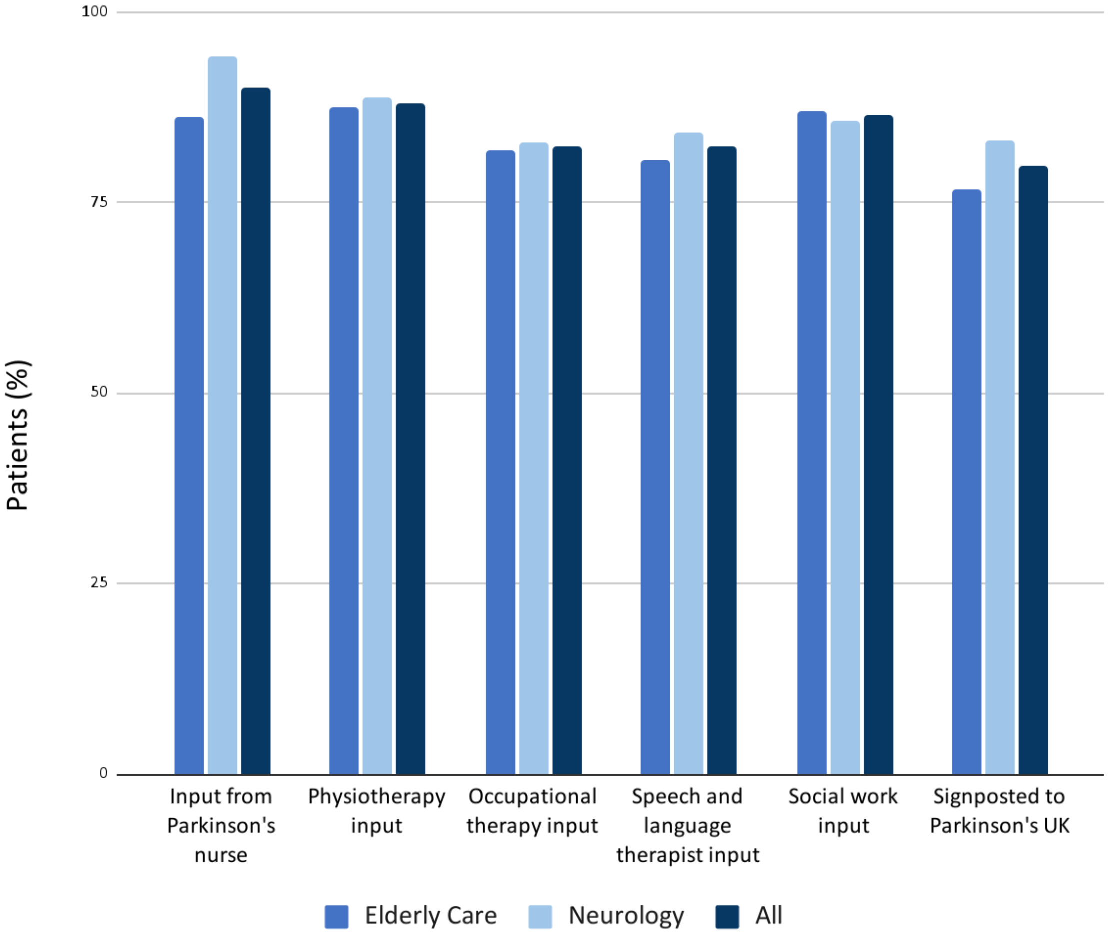


Assessment of bone health has significantly improved from 40% in 2019 to 60% in this audit cycle, possibly reflecting the raised profile of this important aspect of Parkinson's care. Sub group analysis demonstrated that those services that had actively participated in the first phase of the national Bone Health service improvement project assessed bone health in 74.8% of their audited patients. A second phase of the project is planned in 2023 with supporting resources on the Parkinson's UK website.

Assessment of ADLs are all above 75%. All have improved from 2019.

Of those audited people with Parkinson's who are in employment (20.1% of the total, n=1307), 17.6% (n=230) had no evidence of enquiry regarding problems with function at work. This is approximately one in six.

Figure 6: Domain 3 – Multidisciplinary involvement during the previous year



The results show that 79.8% of patients and/or carers had been signposted to Parkinson’s UK in the last year, or had been previously signposted. Consideration for multidisciplinary input continues to be high despite reconfiguration of many AHP services post pandemic. It is not clear if this picture represents all services across the UK, or just those audited.

Occupational therapy

Aims

The Occupational therapy audit aims to establish the quality of occupational therapy services for people with Parkinson’s, examining the models of service delivery and therapy provision taking into account recommendations made in evidence-based guidelines. This is the sixth round that occupational therapists have participated in the audit, allowing for benchmarking of local services against UK wide standards of good practice and identifying areas for service improvement projects.

Demographics

Occupational therapy services reported on 627 people with Parkinson’s. Patients were aged between 29 and 97 (mean age 75.6 years), living in their own homes (94.4%) with a mean disease duration of 5.9 years (range 0-33 years). Of the audited patients the majority were white (92.1%), living in England (85.3%) with 61.9% male.

While the NICE guideline recommends referring people with Parkinson's to occupational therapy in the early stages of the condition for assessment, education and advice with an emphasis on 'staying well', as in previous years most patients continue to be seen in the maintenance phase (46.3%, 48.6% 2019, 46% 2017). Of the patients audited, 14.4% were in the diagnosis phase. Where this was not the first episode of occupational therapy for the patient, 22.5% had first been referred at diagnosis, almost on par with first referrals in the complex phase (19.1%)

Service audit

Occupational therapists in 53 services participated in the audit, down by 35% from 2019, which is disappointing after an upward trend in each previous audit cycle, but likely due to demands on services from the ongoing effects of the pandemic.

Model of service provision

69.9% of services specialise in neurological conditions generally, with 75.5% specialising specifically in Parkinson's. This is an increase since 2019 when 59.8% were specialist Parkinson's services. Fewer generic occupational therapy services participated in the audit this year. 18.9% of therapists reported working in an integrated Parkinson clinic (14.6% 2019) and typically occupational therapists are community based and provide interventions to people in their own homes (67.9%). There has been no significant change since the last audit and the pandemic has not limited where occupational therapists can carry out their interventions.

The number of services who have an annual referral rate of over 40% for people with Parkinson's has increased to 43.4% (28.1% 2019), with 56.6% having a referral rate of less than 40% (72.0% 2019). This likely reflects an increase in Parkinson’s- specific therapists participating in the audit; however it still shows that therapists working in neurological rehabilitation (69.8%) continue to have a caseload of mixed conditions and therefore may not routinely be assessing and treating people with Parkinson's.

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

86.8% of the audited occupational therapists report being able to access Parkinson's-related CPD at least annually (90.2% 2019) and 54.7% are able to consult a member of the specialist Parkinson’s MDT for advice when needed. Thankfully, this year no therapists reported that ‘no support' is available.

Induction and support strategies for new occupational therapists

Availability of Parkinson’s-specific induction for new therapists remains largely unchanged (39.6%, 40.2% 2019). The number of audited services offering no formal induction has fallen from 26.8% in 2019 to 13.2%.

In the previous two audits 'provision of induction' (2019) and 'specialist induction' (2017) for new therapists working with people with Parkinson’s have been hightled as areas for improvement. There has been an upward trend in the number of new occupational therapists being offered induction within a general competencies framework (47.2%, 32.9% 2019). However, the content of this is not specified and may not include Parkinson’s education.

Clinical practice

Due to the pandemic, a new audit question explored how patients are seen. All services offer face to face appointments, with video conferencing used by 32.1% and telephone by 62.3%. The patient audit highlights a significant increase in referrals to address mental wellbeing, cognition, emotional and/or neuro-psychiatric problems.

Outcome measures

Outcome measures were used by 79.2% of services. The RCOT *Occupational Therapy for People with Parkinson's*[4] highlights Parkinson’s-specific quality of life or severity scale measures, and suggests the use of the Canadian Occupational Performance Measure (COPM), Assessment of Motor and process skills (AMPS) and or Fatigue Impact Scale (FIS).

Although the specific measures were not explored, a range of measurement types are being utilised by occupational therapists, with 83.3% of services using patient reported outcome measures (PROMS). Of note 33.3% of services used outcome measures for the reporting of service data which may include number of referrals and duration of treatment episode - these do not necessarily reflect the quality of therapy interventions. Whilst the value of using outcome measures is recognised, it is necessary for the measure to be utilised pre and post intervention which may not fit services who provide assessment only or very short episodes of input.

Patient audit

Referral to occupational therapy

32.1% of patients were referred to occupational therapy within the first two years of diagnosis, with 25.5% of those referred being 3-5 years and 6-10 years since diagnosis and 16.9% with a diagnosis of Parkinson's for more than 11 years. This remains unchanged from the 2019 results.

Sources of referral also remain unchanged, with the highest rate coming from a Parkinson’s nurse (30.3%), neurologist or geriatrician (27.7%) and reported to have been triggered by a medical review in 60.0% of cases, with GP and self-referrals making up a relatively low percentage (10.0% and 4.9%).

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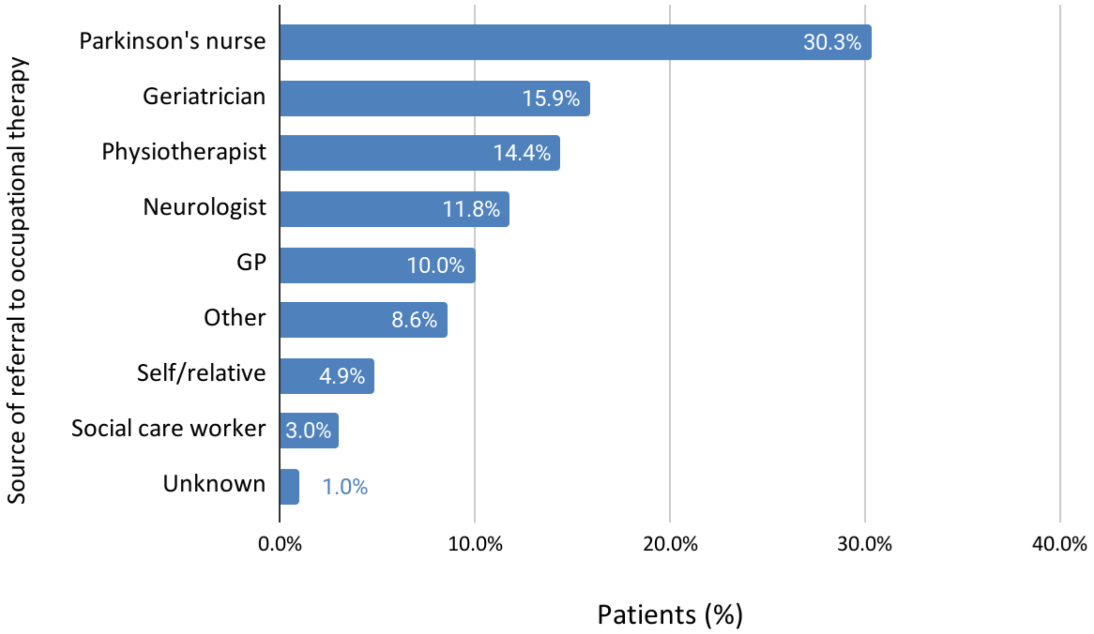
[4] Occupational Therapy for People with Parkinson’s, Ana Aragon and Jill Kings, Royal College of Occupational Therapists, 2018

Figure 7: Source of referral to occupational therapy services



Just under half of patients were seen by an occupational therapist within 4 weeks of referral, with 12.0% breaching the NHS 'referral to treatment (RTT)' target of waiting no more than 18 weeks. The time frames were amended for this audit round to reflect the waiting times statistics commonly reported in NHS services; however it is positive that there is comparatively little change from the 2019 results, given the pressures on services over the last three years.

Table 10: Time between the date of the referral and the date of the initial appointment for this episode of care

	Patients
1 to 4 weeks	48.5%
5 to 8 weeks	21.5%
9 to 12 weeks	11.2%
13 to 18 weeks	6.9%
More than 18 weeks	12.0%
Number of patients:	627

Reason for referral

Reasons for referral are generally similar to 2019, with almost 80% of patients referred due to transfers and mobility, followed by environmental issues to improve safety and function (58.5%) and personal care activities (54.9%), with fewer referred for fatigue, family roles and work. There is a substantial increase (34.0% up from 26.9% in 2019) in referrals to address mental wellbeing, cognition, emotional and/or neuro-psychiatric problems.

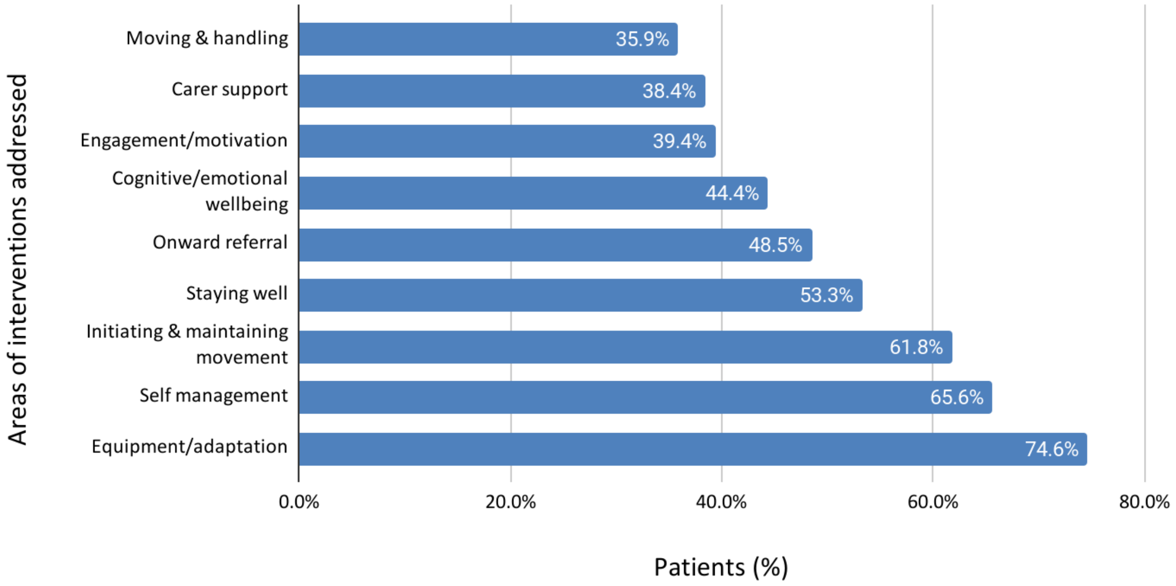
Assessment and goal setting

Standardised assessments were reported to be completed by occupational therapists in only 38.3% of the audited cases. More positively, goals were reported to have been set collaboratively with 87.7% of patients and/or carers, which is a key principle of best practice for occupational therapists working with people living with Parkinson's.

Interventions and onward referrals

Occupational therapists reported use of a wide range of interventions related to self-care, physical function, cognitive and emotional wellbeing, participation and the needs of carers, with onward referrals and support being made for 48.5% of patients.

Figure 8: Areas of intervention addressed in occupational therapy



Evidence base used to inform practice or guide intervention

In addition to clinical experience, occupational therapists used a diverse range of information sources, particularly the RCOT *Occupational Therapy for People with Parkinson's* (68.3%), advice from a colleague or supervisor (55.2%), the NICE guidance (55.5%), information from Parkinson's UK's website (54.1%) and training courses (52.8%) - all increases since 2019.

Physiotherapy

Aims

The Physiotherapy audit establishes whether physiotherapy services are currently providing quality services and interventions for people with Parkinson's (taking into account recommendations from evidence-based guidelines and using standardised assessments). It allows for 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 124 services participated in the audit, and reported on 1,837 people with Parkinson's receiving physiotherapy, with an increase of patients seen in England, Northern Ireland and the Channel Islands but a reduction in the other devolved nations.

The majority of patients seen were White (90.2%, 88.4% 2019) with a reduced percentage of Asian (5.2% from 5.9%) and Black (1.3% from 2.1%) patients seen. Patients were aged between 22 and 97 years (mean age 73.9 years). The highest percentage of individuals were aged over 70 and each of the over 70 age groups saw an increase since 2019 (45.6% 70-79, 25.4% 80-89%, 2.5% over 90). 95.0% of patients live in their own homes, suggesting that those in care homes and other settings may be underserved.

Service audit

How assessments are offered

The high percentage of services offering video (55.6%) and telephone consultations (27.4%) represents a shift in service post-pandemic to a more accessible approach. 100% offer face-to-face assessments. In the patient audit, the vast majority (97.2%) were seen face to face with 16.5% by telephone and only 1.7% by video.

Type of service

More services report being specialist neurological services (75.8%, 70.6% 2019) or specialising in the treatment of individuals with Parkinson's (66.1%, 60.8% 2019). Of note, 24.2% do not specialise in the treatment of individuals with neurological conditions. There is also an increase in the percentage of services who have more than 40% of people with Parkinson's referred to their service annually. 21.0% of services have an annual caseload of 40-59% compared to 19.6% in 2019 and 11.3% have an annual caseload of 80-100% compared to 8.5% in 2019.

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

In 91.1% of services physiotherapists could access CPD at least annually, similar to 2019. Of note in the patient audit 42.5% of therapists reported that they had received post-graduate Parkinson's-relevant training within the last 2 years. This raises questions as to whether physiotherapists may have been unable to take up CPD training due to pandemic and post-pandemic workload pressures.

Induction and support strategies for new physiotherapists

In 2019, 57.5% of services reported that they had induction and support strategies for new physiotherapists working with individuals with Parkinson's.

For this audit the question was refined, with 32.5% of services having Parkinson's- specific induction and support strategies for new physiotherapists, and 46.0% as part of more general competencies. This raises questions about the Parkinson's-related content of such "general competencies". The percentage of services with no support strategies for new starters decreased from 47.5% in 2019 to 21.8% this year.

Accessing support/advice

There was an increase in the percentage of respondents who reported that they could access help and support from the specialist MDT of which they were a member (40.3%, 30.1% 2019), and a further 44.4% reported they were able to access support from a Parkinson's MDT of which they were not a member or from a Parkinson's specialist nurse. This leaves 7.3% being only able to access help from a general medical team and one service reported that it had no support available from any source.

Clinical practice

Fewer services are offering an integrated (medical and therapy) model of service (5.6%, 13.7% 2019) and there was a decline in those offering an MDT assessment (58.1%, 62.1% 2019). An integrated multidisciplinary approach is recognised by NHS Rightcare 2019 as the optimal model to ensure people with Parkinson's receive the highest standard of care.[5]

Most services reported that patients were seen individually or individually and in groups. It is encouraging to see that for those who offered groups, an increased percentage were offering education or exercise within these groups. Education was offered by 81.0% (68.6% 2019) and exercise by 96.9% (75.8% 2019).

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[5] NHS RightCare Progressive Neurological Conditions Toolkit | Parkinson's UK (parkinsons.org.uk)

All services reported that they provided information about non-NHS/external services (e.g. Parkinson's UK, leisure centre classes) which is encouraging as this supports promotion of self-management for individuals and may relieve pressure on over-burdened NHS services.

Patient audit

Parkinson’s phase on this referral

There was a marked increase in the number of individuals referred in the complex phase (31.4%, 26.9% 2019). This may be due to the effect of the pandemic and longer waiting lists for therapy.

Time since diagnosis and stage of Parkinson’s/previous physiotherapy

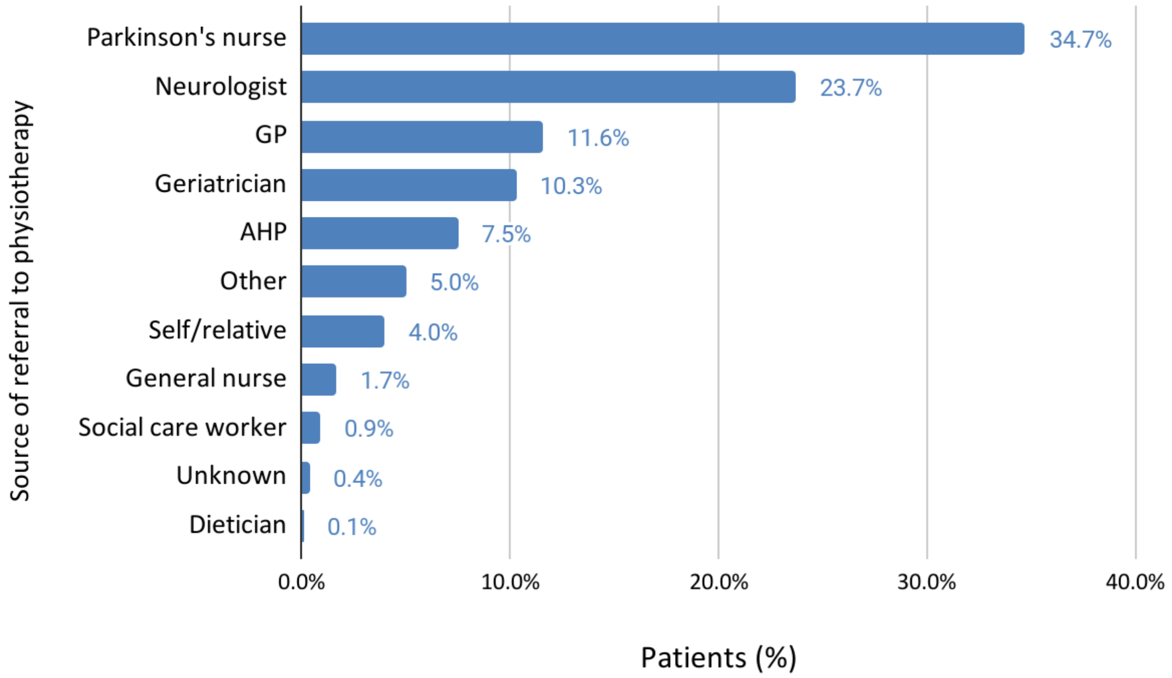
More people were being referred for initial physiotherapy assessment at later stages of Parkinson’s. There was a reduction in the number of people in the patient audit who had been diagnosed under 3 years (35.4%, 40.7% 2019). In cases where the date of diagnosis was known, only 25.3% of people were first referred to physiotherapy in the diagnosis stage, with most referred in the maintenance stage (51.7%). This does not comply with NICE guidance which recommends referral to physiotherapy early for assessment and advice on activity and exercise.

Since 2019 there has been a shift to patients being seen in the maintenance and complex phase of the condition. This may represent the triage requirements of the pandemic with newly diagnosed patients and those in the palliative phase not being considered an urgent priority.

Referral to physiotherapy

Most referrals were made by Parkinson’s nurse specialists (34.7%), with 23.7% by neurologists. 10.3% were from elderly care consultants – fewer than GP referrals (11.6%). This is an area that needs to be addressed to encourage earlier referral by consultants.

Figure 9: Source of referral to physiotherapy services



There has been an increase in the number of urgent versus routine referrals (16.2% 2022 and 9.3% 2019). This may reflect the impact of the pandemic on individuals – symptoms may have progressed more rapidly with the need for physiotherapy intervention more urgent.

Waiting times for the initial physiotherapy appointment for this episode of care

Physiotherapy waiting times have increased with more patients waiting 13 weeks or more for their initial appointment.

Table 11: Time between the date of the referral letter and the date of the initial appointment for this episode of care

Time between referral letter and initial appointment in this episode	**Patients**	
	2019	**2022**
1 to 4 weeks	41.0%	38.8%
5 to 8 weeks	29.1%	23.2%
9 to 12 weeks	15.0%	13.0%
13 to 18 weeks	7.3%	11.8%
More than 18 weeks	7.6%	13.1%
Number of patients:	2099	1835

Outcome measures

Overall use of Parkinson's-specific outcome measures was unchanged from 2019. The outcome measures included in the audit options list were all evidence-based for use in Parkinson's, and there was a reduction in the percentage of patients with whom 'other' measures were used (from 40.5% to 23.0%) which may be an improvement. The totals for "other" are slightly skewed by two therapists who then reported that they had used listed Parkinson's-specific outcome measures.

Of the 'other' measures some were:

- Parkinson's-specific but not physiotherapy-specific (e.g. anxiety and depression scales)
- not Parkinson's-specific (e.g. Rivermead or Trunk impairment Scale - a stroke outcome measure)
- not evidence-based outcome measures (e.g. 'physical assessment', 'challenge' or the use of photographs or video)
- adapted versions of Parkinson's-specific measures (e.g. ten times sit to stand rather than the evidence-based Five Times Sit to Stand)
- not outcome measures (e.g. Hoehn & Yahr scale is a stage of Parkinson's scale)

There has been no improvement in the percentage where 'no outcome measures' were used (20.3%, 21.5% 2019). Some of the reasons given were justifiable and included 'telephone or video consultation' (16 cases; although outcome measures are available that are suitable for virtual assessment and should be encouraged), or 'patient was too fatigued or unwell'. Of note other reasons were:

- no time
- qualified therapist or student not being aware of or unfamiliar with outcome measures
- assessment carried out by an assistant
- the clinician lacked Parkinson's-specific experience
- outcome measures not deemed necessary as 'function-based approach' or the patient was 'too complex'
- the patient had come for a different problem (other than Parkinson's (e.g. musculoskeletal)

Some therapists reported they were focusing on postural control (balance) and therefore did not use outcome measures.This is a core area for assessment and intervention by physiotherapists and several evidence-based, Parkinson's appropriate balance outcome measures are available.

Table 12: Most frequently used Parkinson's-specific outcome measures

	Patients
Timed Get Up and Go	43.8%
Berg Balance Scale	35.9%
10 metre walk	29.2%
Five Times Sit to Stand	22.3%
Lindop Parkinson's Assessment Scale (LPAS)	20.9%
History of Falls Questionnaire	20.8%

Exercise advice/intervention

Although most patients were offered advice or intervention on exercise, the percentage was lower (93.3% compared to 97.2%) than in 2019.

Exercise programmes based on balance, strength and flexibility as well as function-based exercise were the most commonly offered. PD Warrior was offered to 25.9% of patients and aerobic exercise to 22.6%. Alexander Technique was the least commonly offered (0.5%, 1.6% in 2019). Of the 'other' options, not all were 'exercise-based' interventions, but referrals to gyms and local exercise groups as well as exercise prescriptions and advice about the importance of exercise were included by several responders. Walking football, boules and swimming were also reported.

Table 13: Exercise, activity advice and interventions offered

	Patients
Aerobic exercise	22.6%
Alexander technique	0.5%
Boxing	2.7%
Cycling	3.7%
Dance	1.8%
Exercise programme focused on balance	62.1%
Exercise programme focused on flexibility	49.2%
Exercise programme focused on strength	63.8%
Function-based exercise (e.g. stair practice)	38.6%
High Intensity Interval Training	3.7%
LSVT-BIG	3.5%
Nordic walking	1.8%
PD Warrior	25.9%
Pilates	4.1%
PWR!Moves	1.1%
Tai Chi	2.6%
Treadmill training	1.3%
Yoga	1.6%
Other	14.0%

Band of therapist carrying out initial assessment

CSP Guidance states that initial assessment should be carried out by a qualified physiotherapist (i.e. Band 5 or above).[6] An increased percentage of patients had an initial assessment by a Band 5 physiotherapist (9.4%, 6.7% 2019), and more were seen by Band 7 or 8 compared to 2019.

Of note, there was an increase in the percentage initially assessed by a Band 4 (unqualified) therapist – 3.8% compared to 2.7% in 2019. For some patients, the reason given for no outcome measures being used was that an assistant had carried out the assessment. In light of patients being more complex at the point of initial assessment this fails to acknowledge the complexity of the condition and symptoms requiring specialist assessment. This is against best practice and clinical guidelines.

Percentage of caseload seen by the audited physiotherapist with Parkinson's

Compared to 2019, a greater proportion of patients were seen by therapists who saw a higher percentage (40-59% and 80-99%) of people with Parkinson's in a year.

Table 14: Approximate percentage of people seen by the audited therapist in a year who have Parkinson's

	Patients	
	2019	**2022**
0-19%	30.3%	22.2%
20-39%	41.9%	33.7%
40-59%	16.4%	24.8%
60-79%	3.7%	2.6%
80-99%	4.3%	11.4%
100%	0.9%	1.8%
Unknown	2.5%	3.6%
Number of patients:	2099	1837

Evidence base used to inform practice or guide intervention

There was a reduction in the percentage of physiotherapists reporting the use of Parkinson's evidence-based guidelines to inform their practice. The vast majority reported using clinical experience (94.9%, 98.8% 2019). The use of evidence-based resources or Parkinson's-relevant post-graduate training is reduced. NICE Guidance was used by 58.7%,

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[6] Chartered Society of Physiotherapy Supervision, Accountability & Delegation – PD126 (April 2017)

and only 45.1% used the European Guideline (51.5% 2019). Only 21.2% used peer-reviewed journals.

Of note 42.5% had received post-graduate Parkinson’s-relevant training within the last 2 years, despite the service audit data showing 91.1% of services could access Parkinson’s-related CPD annually.

This indicates that there is a lack of additional specialist education and training uptake within the physiotherapy field with many respondents reporting their training is from clinical experience (94.9%) or a colleague (39.4%).

Table 15: What the audited therapist used to inform clinical practice or guide intervention

	Patients
Advice from colleague or supervisor	39.4%
Allied Health Professionals’ competency framework for progressive neurological conditions	31.6%
Clinical experience	94.4%
European Physiotherapy Guideline for Parkinson’s Disease (2013)	45.1%
Information from Parkinson’s UK website	47.1%
NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017)	58.7%
Postgraduate training (e.g. attending courses/lectures specific to Parkinson’s) within last 24 months	42.5%
Published evidence in a peer reviewed journal (read within last 12 months)	21.2%
Other	2.1%
None	0.0%

Speech and language therapy

Aims

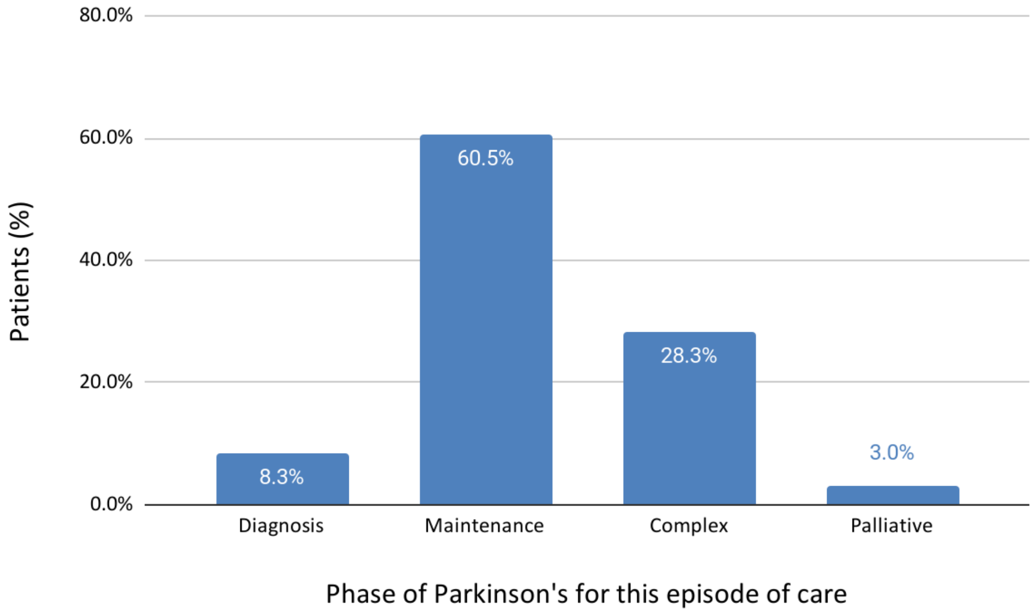
The Speech and language therapy audit aims to evaluate the structure and quality of service provision for people with Parkinson’s. It examines the models of service delivery, assessment and interventions, seniority and experience of staff and the ability to access continuing professional development.

Demographics

Speech and language therapists from 64 services (79 in 2019) participated in the audit, reporting on 807 people with Parkinson’s (1,022 in 2019). Patients were aged between 41 and 94 years (mean 74.8 years), the majority were male (70.4%) and living in their own home (89.3%). Audited patients had a mean Parkinson’s duration of 6.6 years (range 3-10 years).

While the NICE guideline recommends referring patients to speech and language therapy in the early phase of the condition for assessment, education and advice; most patients continue to be seen in the maintenance phase (60.5%, 61.5% 2019). Figure 10 shows low percentages of audited patients in the diagnosis stage (8.3%, 7.3% 2019), complex stage (28.3%, the same as 2019) and palliative phase (3.0%, 2.8% 2019, 1.2% 2017). For initial referral to speech therapy, diagnosis stage referrals increased to 16.5%, with 56.6% in the maintenance stage, 15.5% in the complex and 0.9% in the palliative stage.

Figure 10: Parkinson's phase for the audited episode of care



The audit revealed that the majority of patients were treated 3-10 years post diagnosis, with a significant downtrend after this.

Service audit

Most respondents were specialist therapists who see Parkinson's patients alongside other neurological conditions (48.4%). This compares to responses from speech therapy service managers (28.1%), Parkinson's Specialist SLTs (10.9%) and generalist SLTs (12.5%).

Model of service provision

81.1% of respondents have a low percentage of Parkinson's patients referred to their service annually (0-39%).

Table 16: Percentage of individuals referred to a service annually with a diagnosis of Parkinson's

Individuals referred annually with a diagnosis of Parkinson's	Services	
	2019	**2022**
0-19%	57.0%	48.4%
20-39%	24.1%	32.8%
40-59%	10.1%	9.4%
60-79%	1.3%	1.6%
80-100%	7.6%	7.8%
Number of services:	79	64

Services offer the majority of consultations in the client's home (37.5%) compared to outpatients (26.6%) or a community rehabilitation service (26.6%), with only 3.1% (2 services) offering an integrated MDT clinic. 84.4% of services specialise in neurological conditions but only 54.7% specialise in Parkinson's; this figure has not changed since the 2019 audit.

The pandemic has allowed many services to offer different ways of accessing therapeutic consultations. Therefore a new question was added to the audit for 2022 which identified that all contributors offer appointments face to face, 78.1% video consultations and 68.7% provide telephone appointments.

Accessing Parkinson's-related induction and Continuing Professional Development (CPD)

There has been an increase in services offering Parkinson's-specific induction for new therapists to 40.6% (19% 2019, 17.2% 2017). The number of services with no induction or support strategies for new therapists to Parkinson's (10.9%) also improved (30.4% 2019). Access to Parkinson's-specific CPD has remained high at 87.5%.

Access to services

The majority of services (95.3%) are offering assessment of communication needs with a small number experiencing service restrictions. Referrals are accepted for all people referred for a swallowing assessment. However, there was a reduction in access to specialist advice on saliva management from 93.7% in 2019 to 85.9% in 2022. This may be due to prioritisation decisions following the pandemic, as before Covid there were very few areas that did not offer this in all cases (6.4%).

The NICE guideline highlighted the need to offer people with Parkinson's 'attention to effort' therapies like Lee Silverman Voice Therapy (LSVT) and Expiratory Muscle Strength Training (EMST). Of the 64 services, 34.4% offer LSVT to all eligible candidates. A further 26.6% offer a limited service and 23.4% offer 'attention to effort' based therapy. A small number of services have no LSVT service (6, 9.4%) or cannot offer it due to a lack of staff training (4, 6.3%).

Despite the strong evidence base for EMST and its reference in the NICE guidelines, it was only offered to 3.0% of patients seen for swallowing issues in this audit.

Patient audit

Referral to speech and language therapy

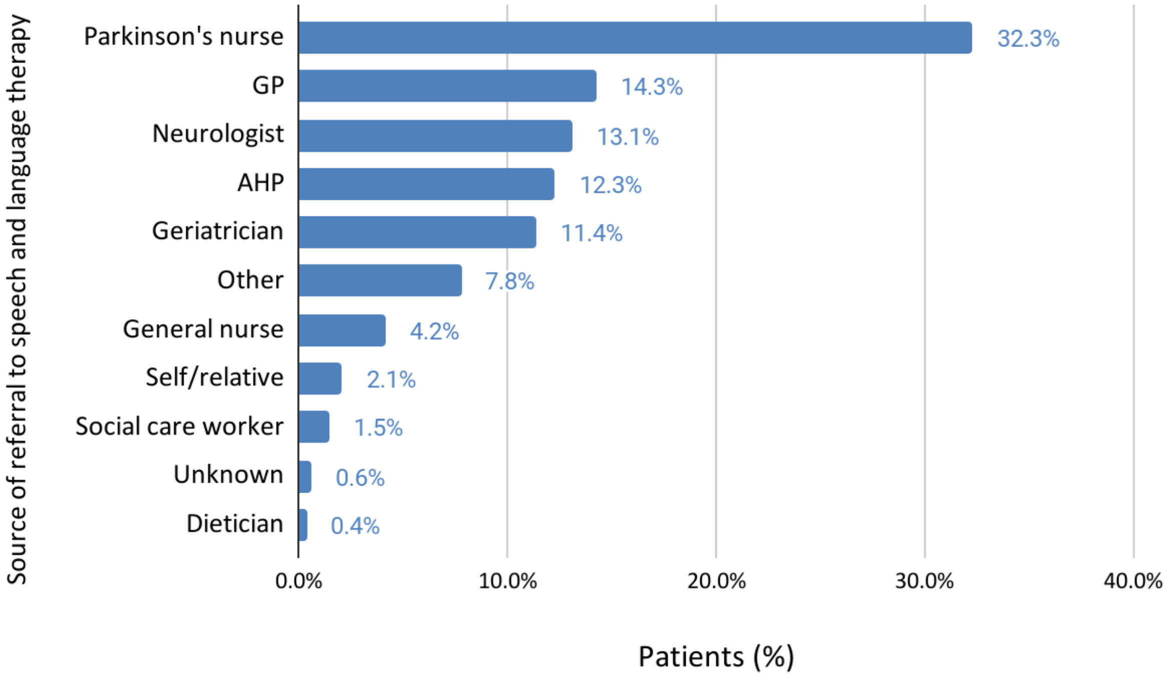
The majority of referrals are being processed in a timely manner with 63.4% seen within 8 weeks. 19.6% of individuals waited over 3 months for an initial assessment. A third of cases were offered assessment and review (33.1%), with individual treatment offered for 37.9% of patients and group treatment 3.7% (with individual and group treatment offered to 6.4%).

Table 17: Time between date of referral and date of initial appointment for this episode of care

	Patients
1 to 4 weeks	34.7%
5 to 8 weeks	28.7%
9 to 12 weeks	17.0%
13 to 18 weeks	7.3%
More than 18 weeks	12.3%
Number of patients:	806

The primary source of referrals are the Parkinson's Nurse Specialist (32.3%), with a relatively low number of referrals from AHP colleagues (12.3%), Neurologists (13.1%) and Elderly Care (11.4%, a slight increase from 4.3% in 2019).

Figure 11: Source of referral to speech and language therapy services



Content of assessment

There has been limited progress in the use of assessment measures by services across a number of areas. There are still low numbers documenting an 'on' or 'off' phase of the medication cycle (36.7%, 31.2% 2019). This is a recommendation in the the Dutch guidelines[7] and is crucial to making an accurate assessment of communication and swallowing, reflecting performance differences and how these can impact on assessment findings.

The majority of patients did have documentation of their intelligibility but only 5.0% by standard diagnostic test. The most popular means of assessment was using an informal assessment such as a rating scale (48.8%). In 21.1% of cases intelligibility was not documented in the care report, 10.8% with a justification provided. 8.0% of patients had an initial audio/visual recording included in the record and available. Nearly half of all eligible cases (47.3%) had no documentation that word finding was discussed or assessed.

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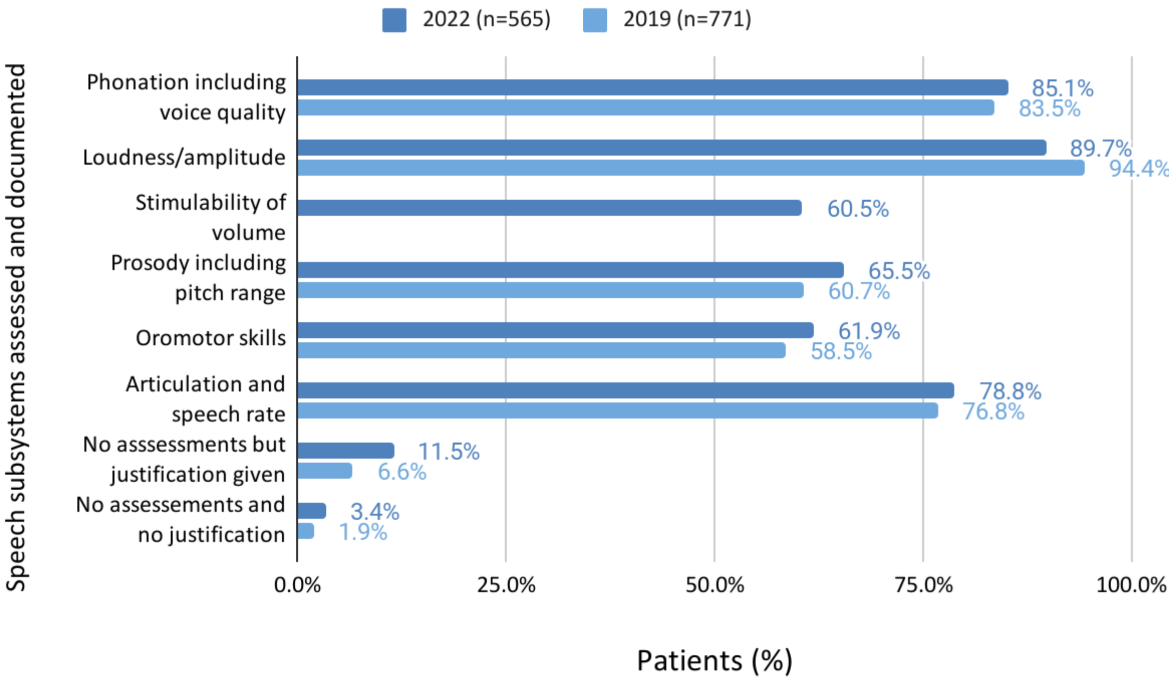
[7] ParkinsonNet *Guideline for speech-language therapy in Parkinson's disease* (2011), Kalf J G, de Swart B J M, Bonnier M

Saliva management was assessed in approximately 60% of cases, but in only 1.7% cases was a formal published assessment used. Evaluation is primarily via clinical observations (20.0%) or patient report (24.8%).

There was no screening question for dysphagia in 8.5% of cases referred for communication assessment only. This has improved since 2019 when 11.4% were not screened, but reflects the lack of use of a standard assessment protocol.

Speech assessment usually included volume although there was a small but concerning reduction in the assessment and documentation of loudness levels (89.7%, 94.4% 2019). Of note stimulability of volume (a new question for 2022) was assessed for only 60.5% of patients, yet this is crucial in establishing whether an individual is capable of producing increased volume during therapy. Conversely, there were small improvements across the board in other subsystems. Phonation and voice quality were consistently assessed (85.1%, 83.5% 2019), articulation and speech rate to a lesser degree (78.8%, 76.8% 2019), prosody (65.5%, 60.7% 2019) and oro-motor skills less frequently (61.9%, 58.5% 2019) but all showing small gains.

Figure 12: Speech subsystems assessed and documented



* no 2019 data for 'Stimulability of volume''

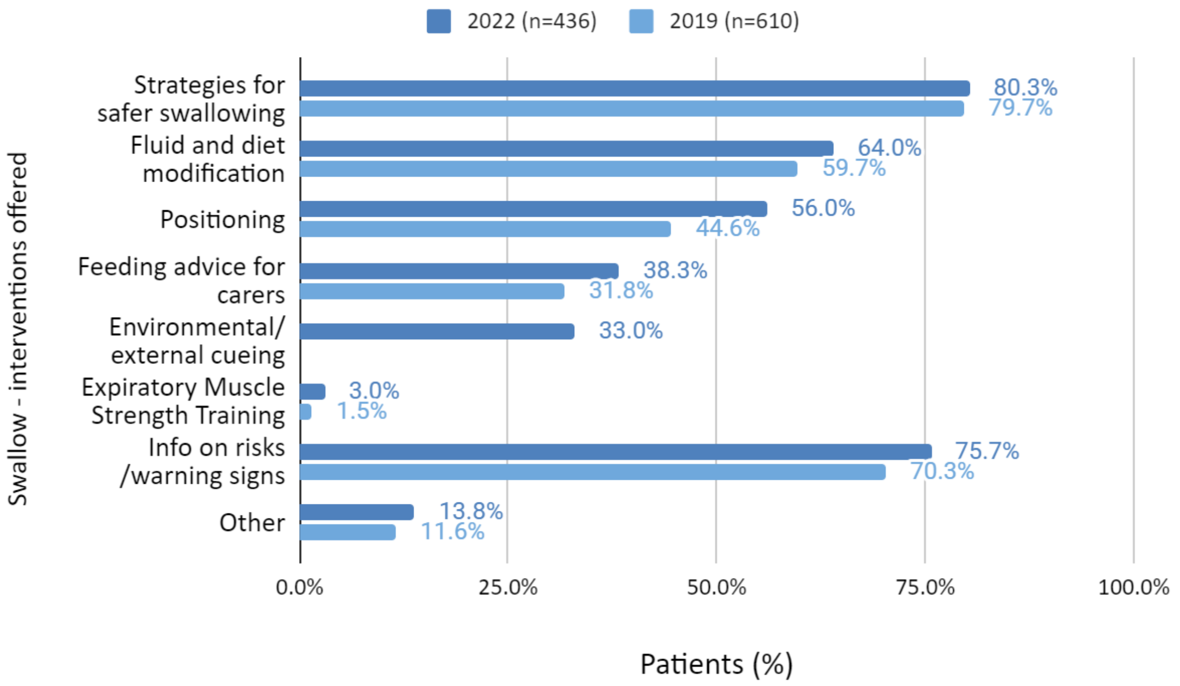
There were small increases in the number of patients where communication participation (87.1%, 83.9% 2019), the impact of Parkinson's on communication (88.3%, 87.4% 2019) and the impact of communication change on partners/carers (68.1%, 61.6% 2019) were considered.

Interventions

The primary focus of communication therapy continues to be on vocal loudness albeit with a small decrease since the last audit (75.2%, 83.4% 2019). Additional communication intervention targets were strategies to optimise intelligibility (71.1%, 77.0% 2019) further supporting the need for adequate assessment of intelligibility. There was a small increase in the provision of interventions for word finding difficulties and language change (20.5%, 14.7% 2019). There were small decreases in the provision of education and advice, support for the impact of communication change and participation and in managing generalisation outside the clinic setting (57.2%, 64.9% 2019). This may reflect service pressures but there needs to be continued focus on these areas outside of the direct work in order for there to be functional and quality of life gains.

Swallowing interventions have all improved apart from provision of EMST which has stayed relatively static and extremely low (3.0%, 1.5% 2019). This is recommended in the NICE guidelines and shows measurable positive outcomes. It is possible that the pandemic has impacted on service developments including provision of EMST.

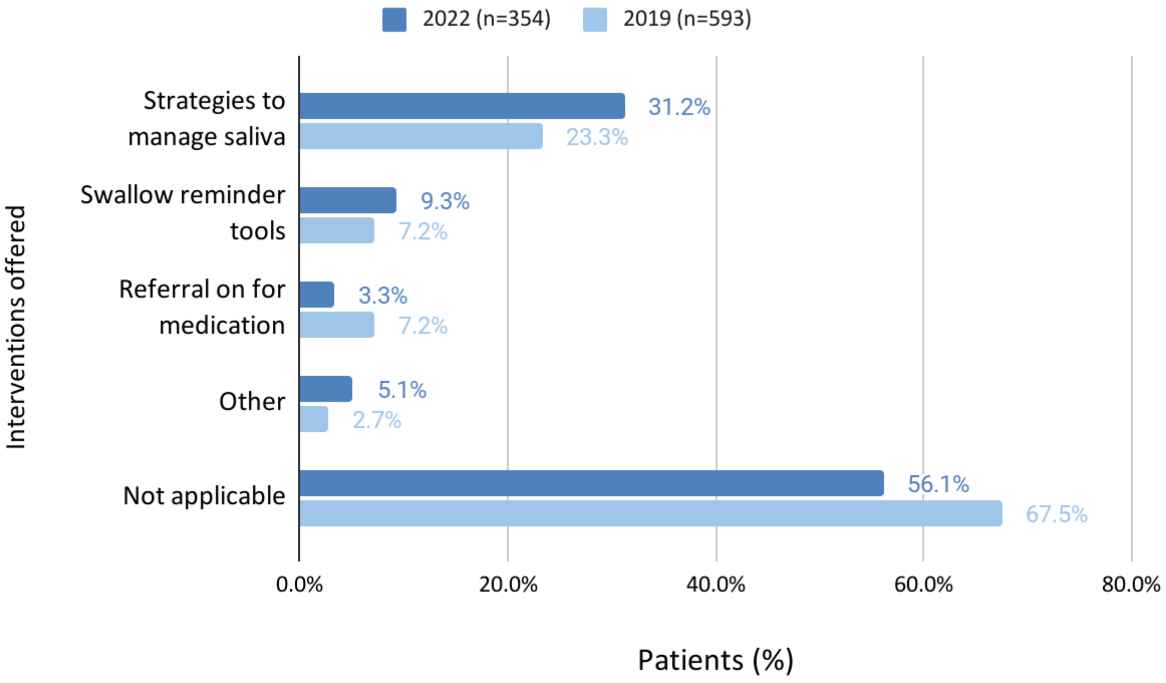
Figure 13: Interventions offered for swallow (excluding patients seen for communication/ drooling only)



* no 2019 data for ‘Environmental/external cueing’

Sialorrhea interventions were fairly low, with strategies to manage saliva at 31.2% but there is improved provision compared to the 2019 audit (23.3%). There is also evidence of increased use of swallow reminder tools, although again very small numbers. The use of a standardised SLT assessment would give us confidence to know if there were genuinely no sialorrhea concerns as therapists primarily documented that saliva management intervention was not relevant as the patient was referred for another reason.

Figure 14: Interventions offered for drooling



* Where 'not applicable' was selected, the patient was seen for communication or swallow only.

Information giving

Assessment results and management plans were discussed with patient and partner/carer in most cases (96.8%, 98.2% 2019) and information about communication and/or swallowing was provided to the patient the majority of the time (93.1%).

Speech and language therapist Band

The NICE guideline requires that patients are assessed by a therapist experienced in working with Parkinson's. 44.6% of therapists who treated patients were a Band 6 grade, and 33.0% Band 7.

Table 18: NHS Band of the therapist assessing the patient

Band of therapist assessing patient	Patients
Band 4	0.6%
Band 5	16.7%
Band 6	44.6%
Band 7	33.0%
Band 8a	5.0%
Band 8b	0.1%
Number of patients:	807

The percentage of people with Parkinson’s seen by the audited therapist was between 0-39% in nearly 60% of cases. This demonstrates that most therapists are managing a general adult neurology caseload, not specifically Parkinson’s. There was a similar finding in 2019.

Patient Reported Experience Measure (PREM)

Aims

The PREM is included as part of the audit to understand the experience of people with Parkinson's and their carers of their Parkinson's service. 6795 people and their carers completed a questionnaire. Of the 506 services that submitted clinical data 380 (75.1%) also took part in the PREM.

Demographics

The majority of PREM questionnaires (77.4%) were completed by a person with Parkinson's rather than a carer. The majority of respondents were male (61.7%) and white (93.0%), although there was increased representation from ethnic minorities than in the previous cycle (7.0% as compared with 5.4%). Of note 2.5% of respondents lived in a care home and 19.6% lived alone. 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 (80.3%) felt that the amount of contact that they had with their Parkinson's nurse met their needs. This was similar to the percentage who felt this was true for their Parkinson's specialist doctor at 78.7%. This compares commensurately with 80.3% and 79.4% respectively in 2019.

Access to services

Respondents who felt they required access to services reported a decreased ability to access Parkinson's nurses, occupational therapy, physiotherapy and speech and language therapy services compared with 2019 data. This could reflect pandemic pressures and ongoing remobilisation of services. In addition 899 respondents were able to access mental health services, but 255, who felt this was required, were not able to.

Figure 15: Are you able to access a Parkinson’s nurse?

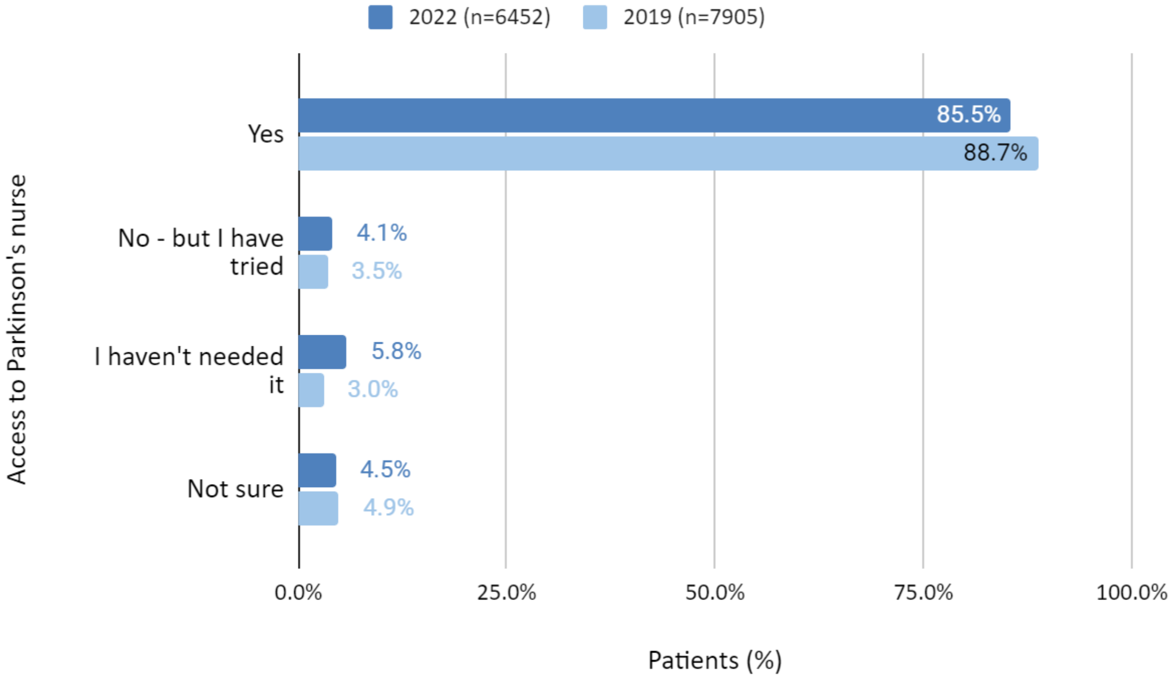


Figure 16: Are you able to access an occupational therapist?

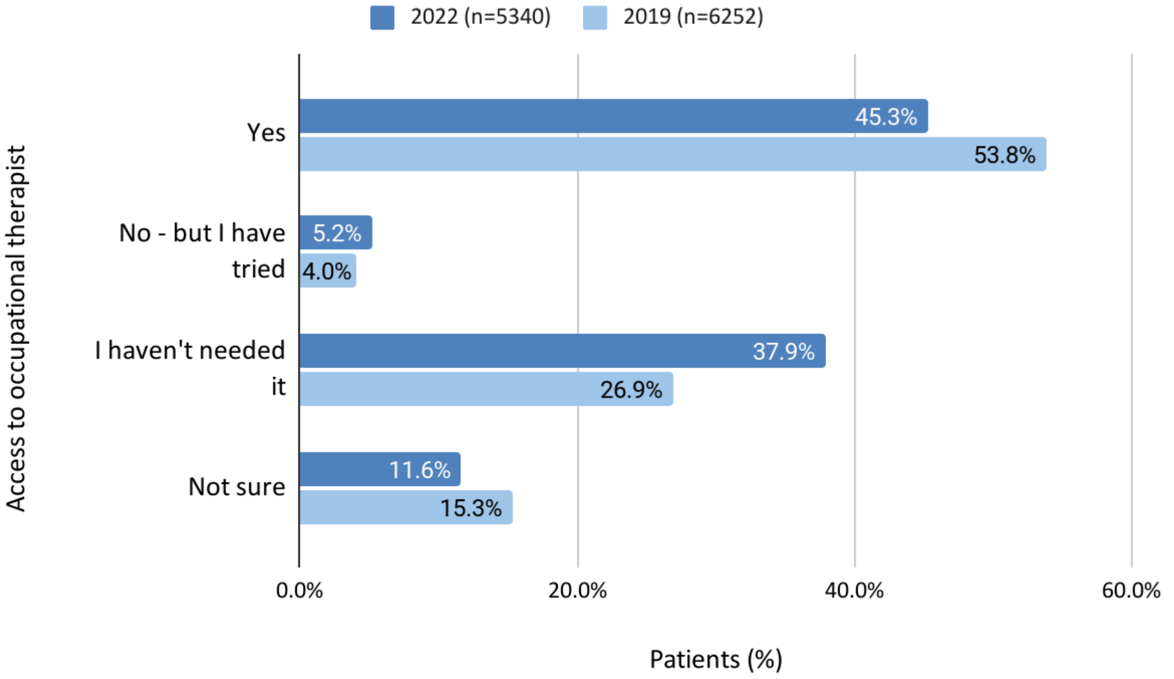


Figure 17: Are you able to access a physiotherapist?

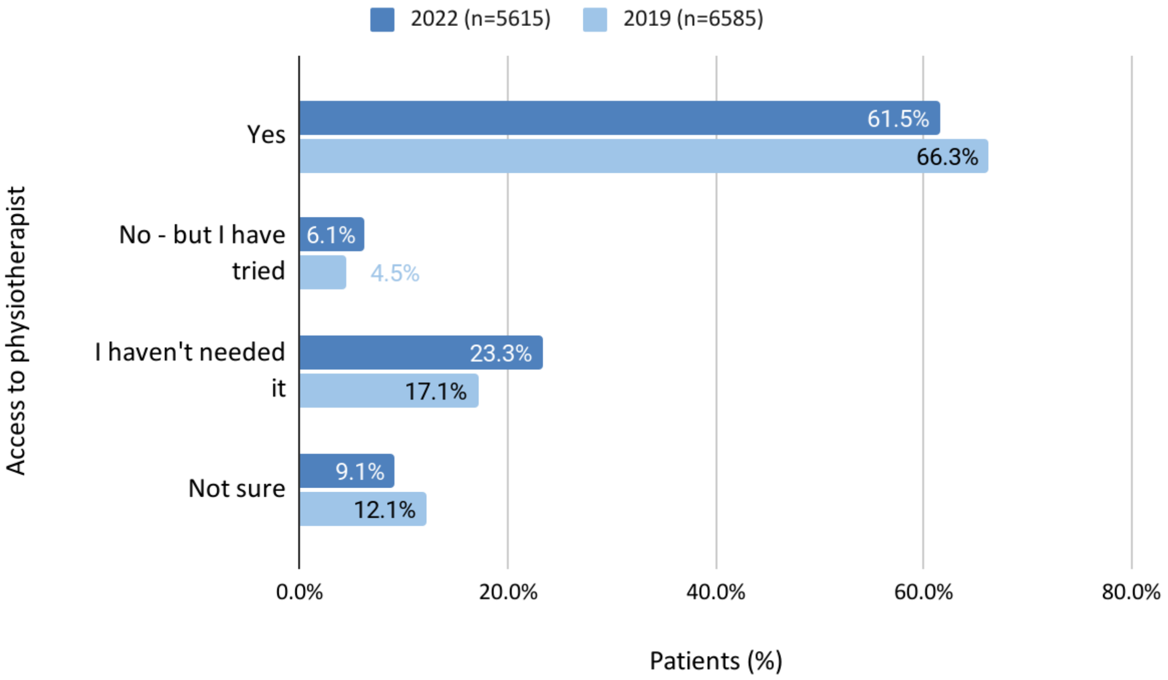


Figure 18: Are you able to access a speech and language therapist?

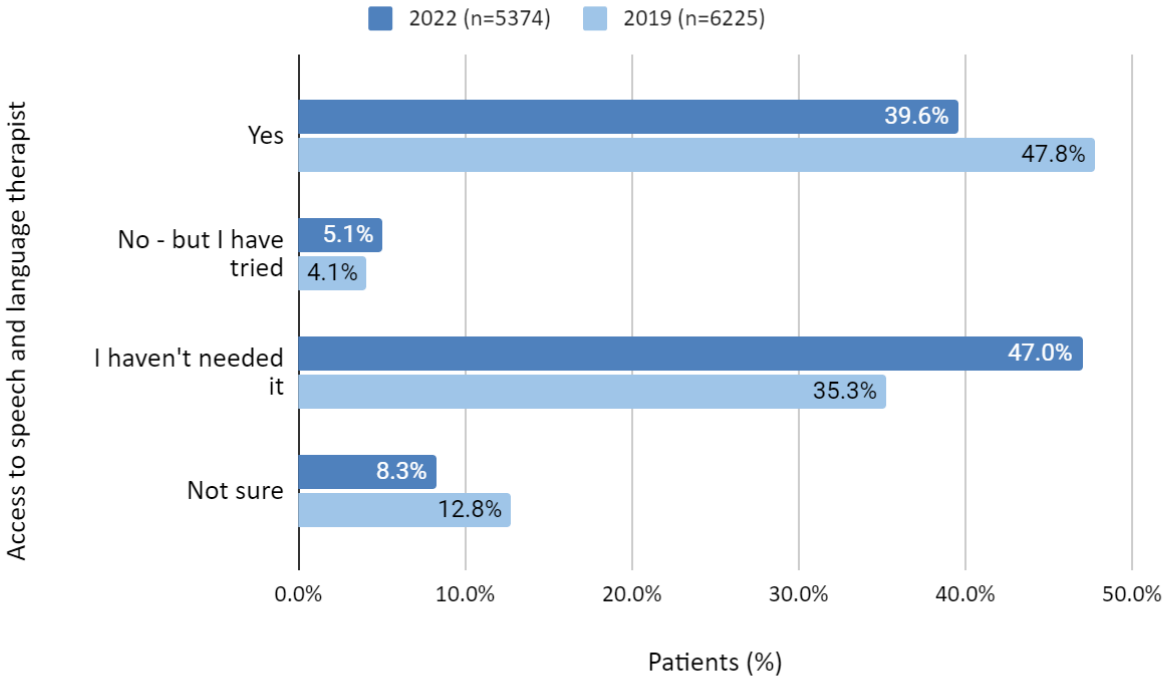
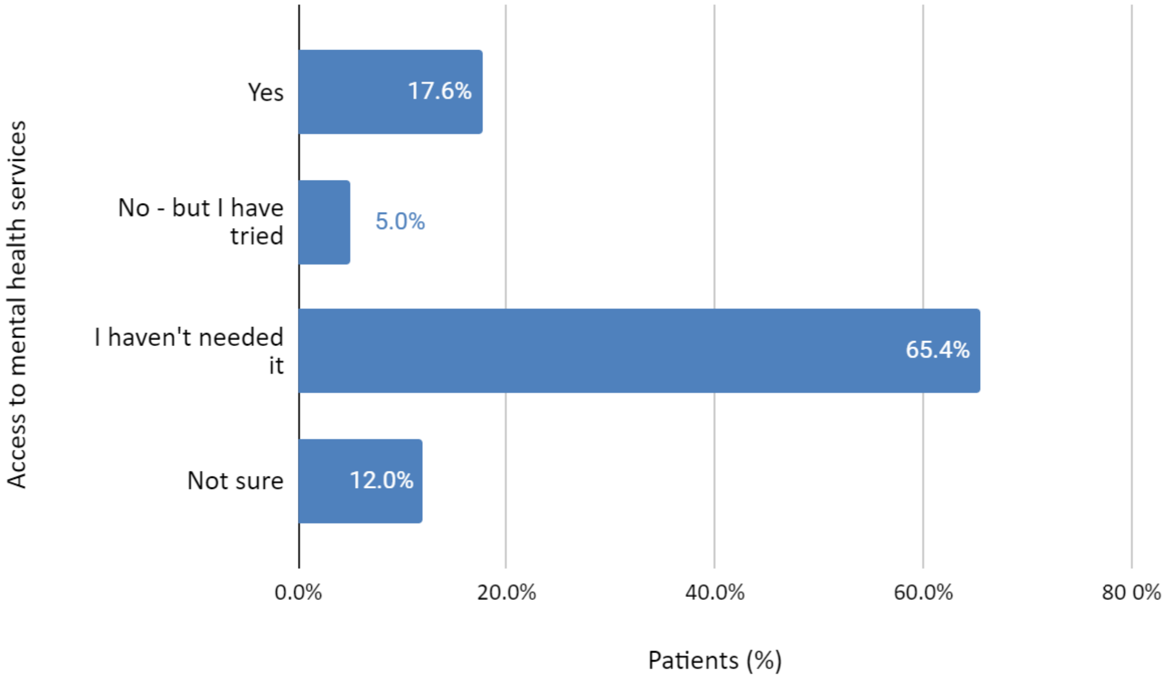


Figure 19: Are you able to access mental health services (psychology/psychiatry)? (new question for 2022; n=5100)



Access to services between scheduled reviews also dropped compared to 2019, apart from physiotherapy where this went up from 53.7% to 61.5%.

Quality of services provided within a Parkinson’s service

There has been a small reduction in the percentage of respondents who felt that the service components were excellent or good across all components compared to 2019 as could be expected given the pressures the NHS has been under. It is also noteworthy that fewer patients are using the various service components compared with 2019.

Figure 20: Quality of service offered by Parkinson’s specialist doctor

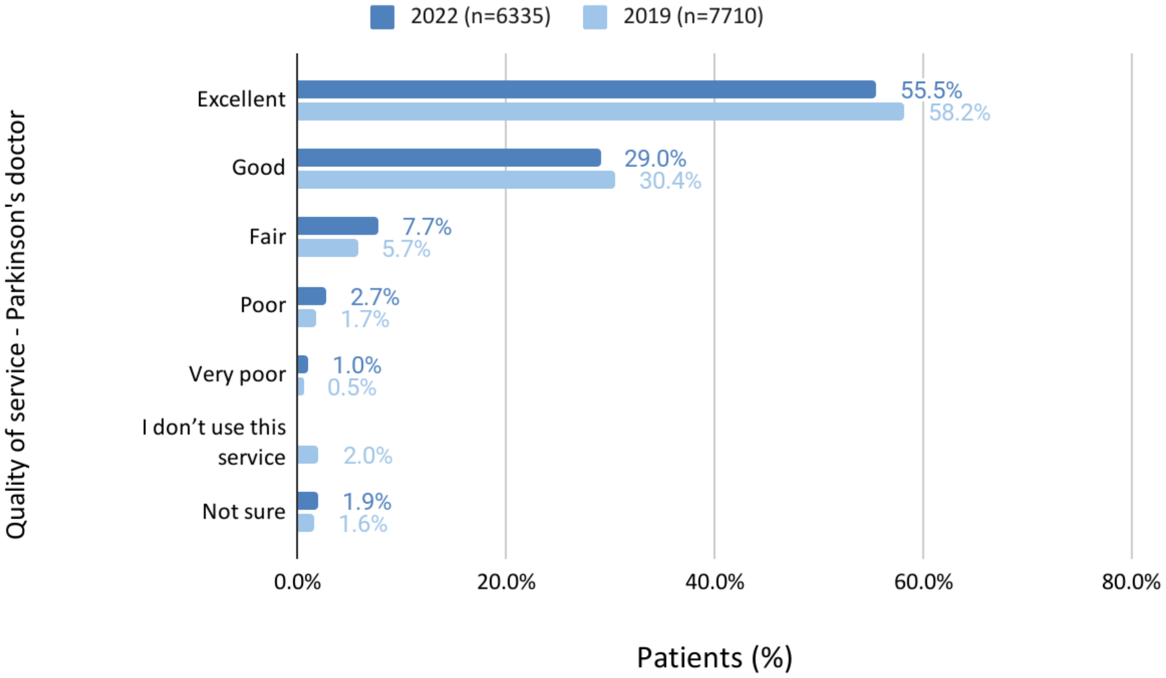


Figure 21: Quality of service offered by Parkinson’s nurse

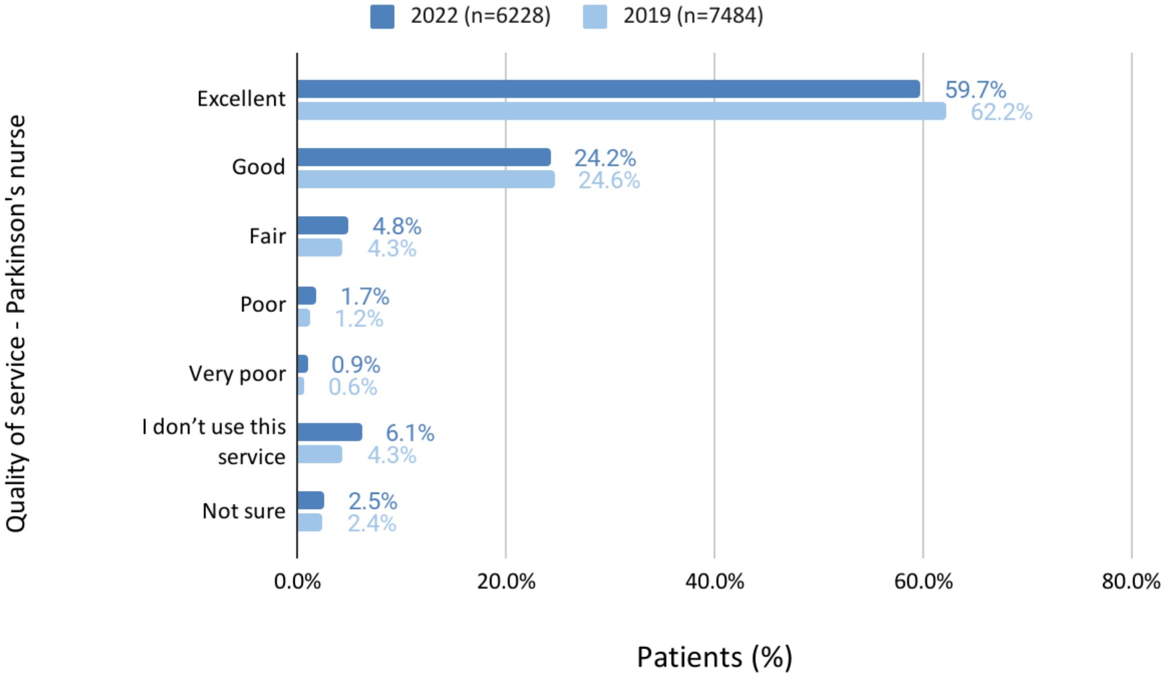


Figure 22: Quality of service offered by occupational therapists

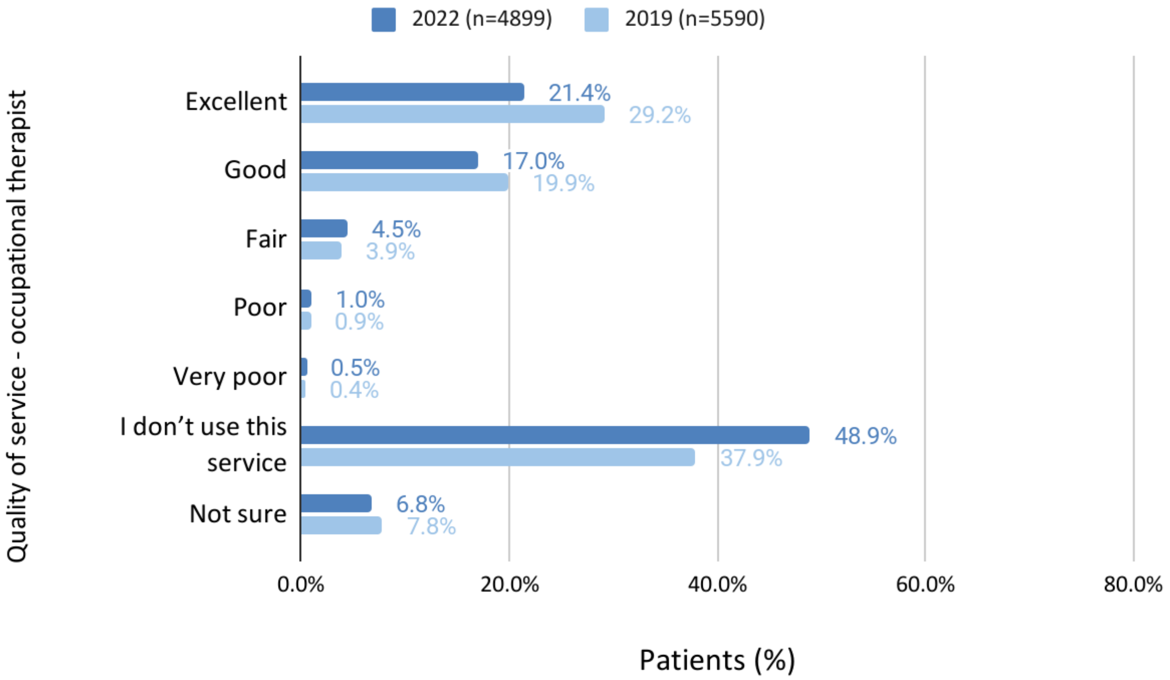


Figure 23: Quality of service offered by physiotherapists

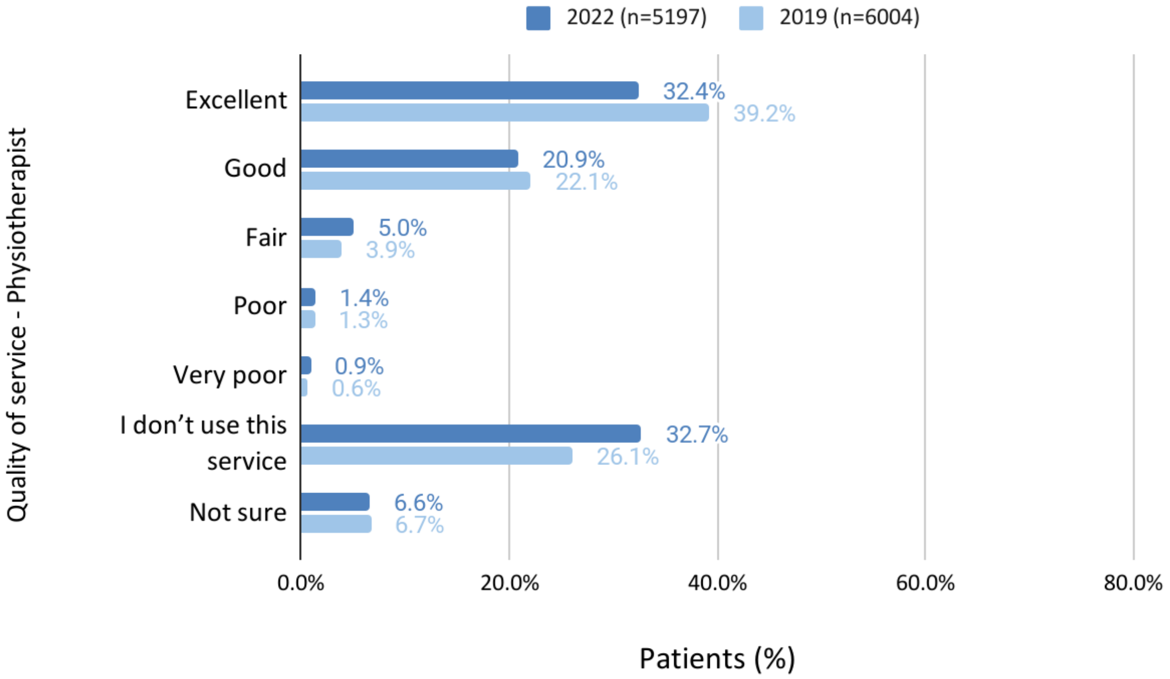


Figure 24: Quality of service offered by speech and language therapists

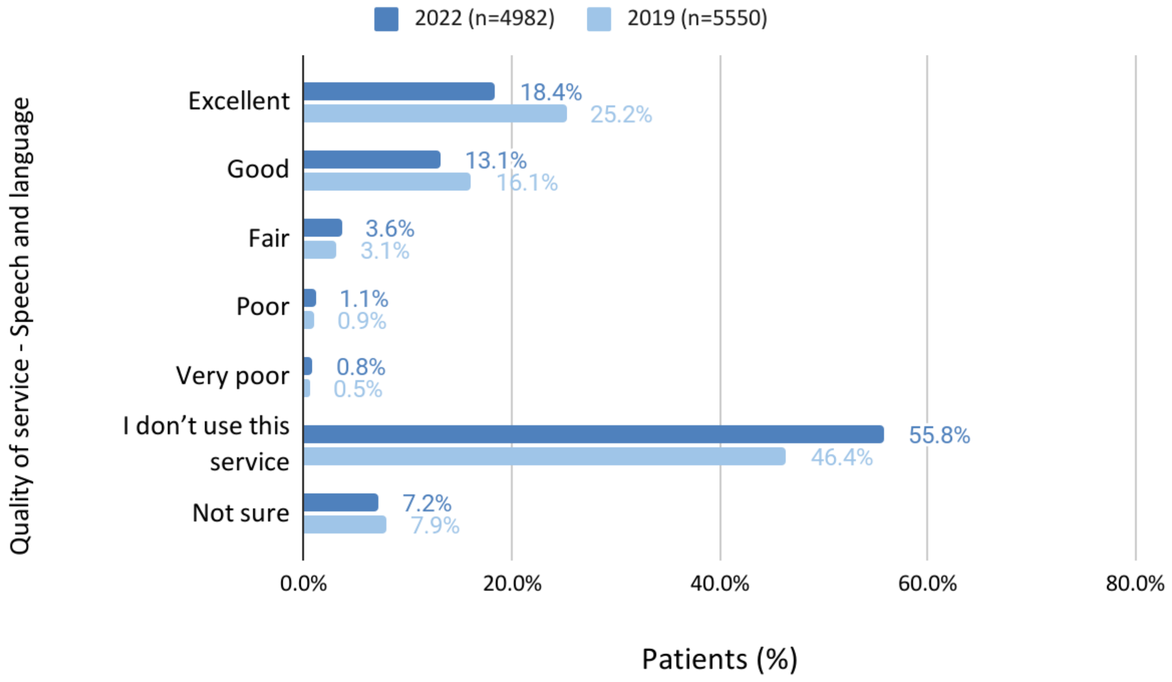
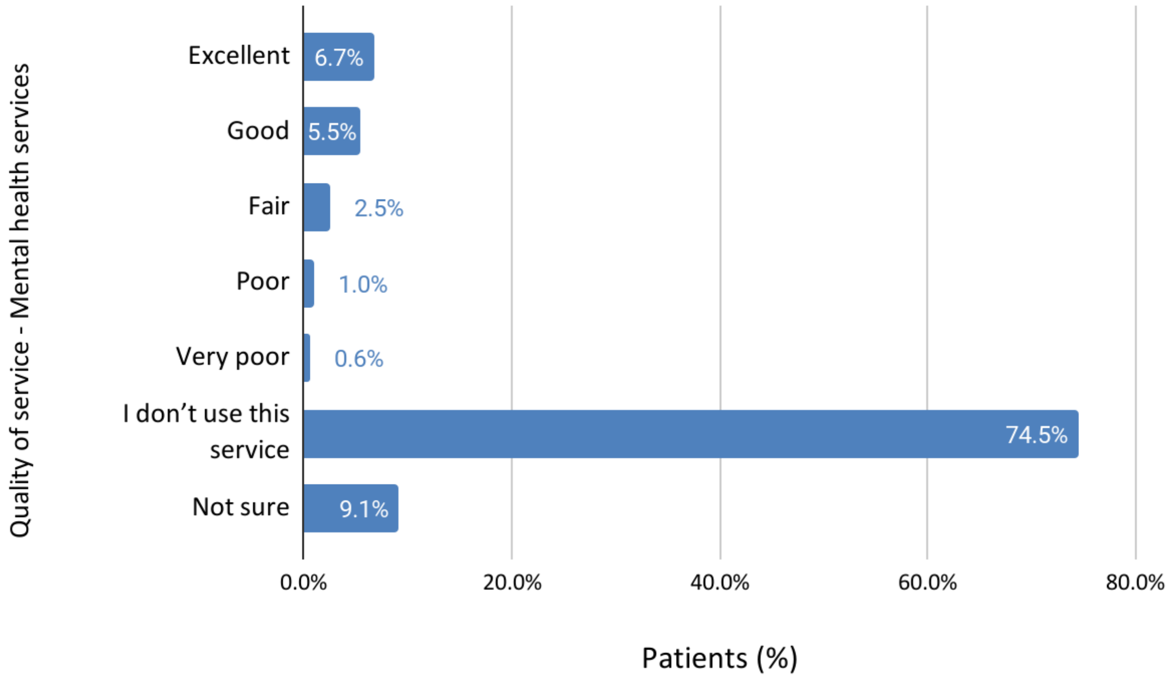


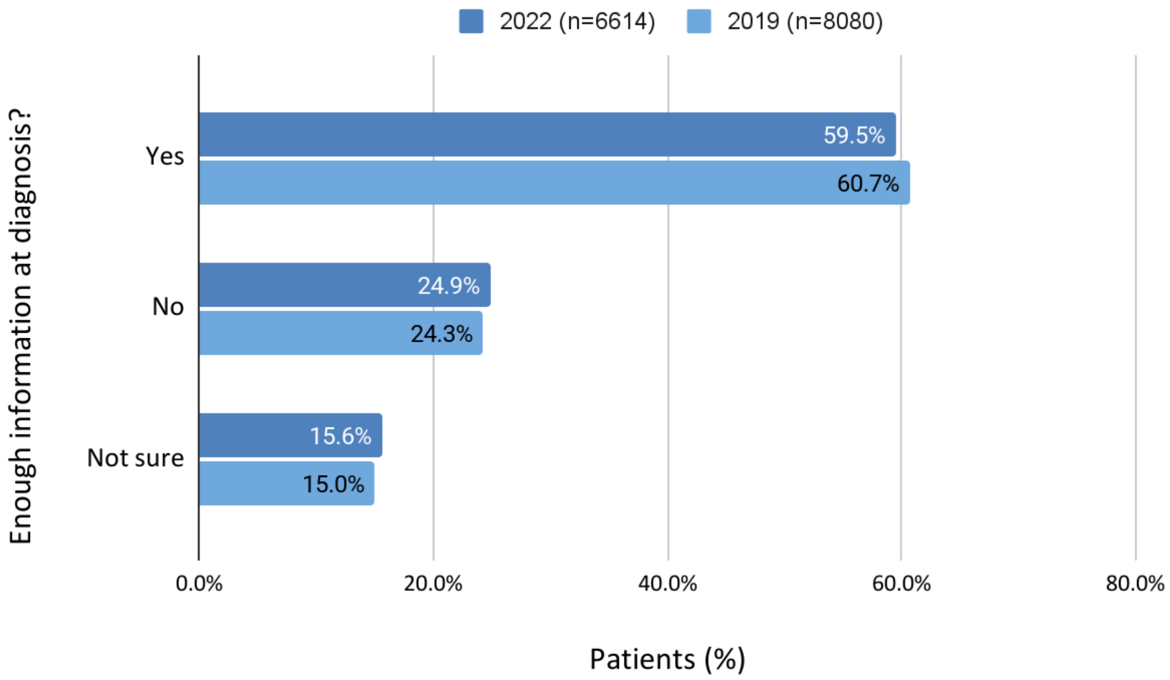
Figure 25: Quality of service offered by mental health services (psychology/ psychiatry) (new question for 2022; n=4705)



Provision of information about Parkinson's at diagnosis

Although the majority of respondents (59.5% of those who answered) said they had received enough information about Parkinson's at diagnosis, there was still a substantial number, as in 2019, who had not received enough information or were not sure if they had.

Figure 26: Percentage of people with Parkinson's who received enough information about Parkinson's at diagnosis



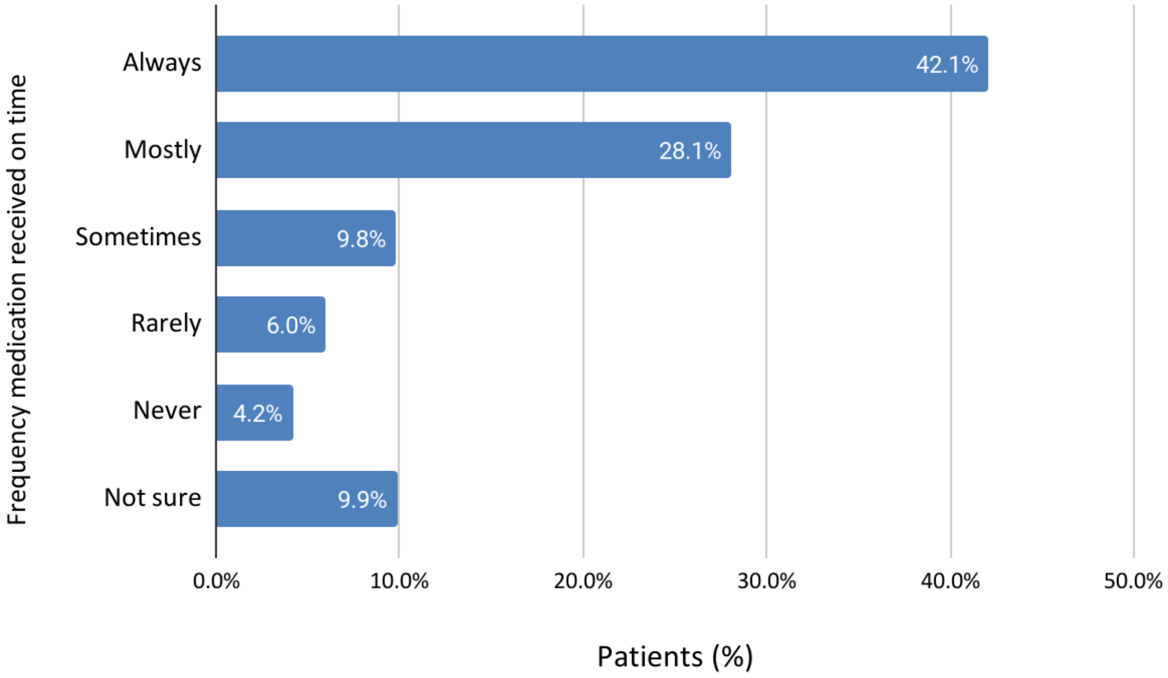
Advice given to drivers about contacting the DVLA and their car insurance company

Of the people with Parkinson's who were drivers and answered this question, 79.5% had been given information about contacting the DVLA and their insurance company. This is similar to the 82.0% in 2019 and 83.9% in 2017, but still means that 1 in 5 has not been given advice, or were not sure if they have been given advice, which is of concern.

Medicines management in hospital

In the last year 21.2% of respondents had been admitted to hospital. Getting medication on time can be a problem when a person with Parkinson's goes into hospital. When someone with Parkinson's and motor fluctuations doesn't get their medication at the time prescribed for them their symptoms can 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.[8]

Figure 27: Percentage of people with Parkinson's who received their Parkinson's medication on time while in hospital (n=1293)



Of those who did not always receive their medication on time, 39.6% said this had a negative or significantly negative effect, 39.4% were unsure if it had any effect, 14.6% said it had no effect and 6.4% 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. 48.0% of our respondents wanted to manage and take their own medication, which they had brought from home.

Enquiry into balance, falls and osteoporosis

People with Parkinson's are more likely to fall and have osteoporosis than age matched controls.[9] Evidence-based guidance is available for assessing bone health.[10]

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[8] Parkinsonism and Related Disorders, Measuring the burden and mortality of hospitalisation in Parkinson's disease: A cross-sectional analysis of the English Hospital Episodes Statistics database 2009-2013. (2015 May;21(5):449-54), Low V, Ben-Shlomo Y, Coward E, Fletcher S, Walker R, Clarke CE

[9] Henderson EJ, Lyell V, Bhimjiyani A, Amin J, Kobylecki C, Gregson CL. Management of fracture risk in Parkinson's: A revised algorithm and focused review of treatments. Parkinsonism Relat Disord. 2019 Jul;64:181-187. doi: 10.1016/j.parkreldis.2019.03.021. Epub 2019 Apr 8. PMID: 30992234

[10] https://frax.shef.ac.uk/frax/ and https://www.nogg.org.uk/full-guideline

60.2% of respondents raised concerns or recalled having been asked if they had any concerns, regarding balance and falls, compared with 76.3% in the 2019 audit cycle, and 18.5% stated that osteoporosis and fracture risk had been discussed with them. This very important part of Parkinson's care is currently being addressed in a PUK national quality improvement project, and will form an integral part of the next audit cycle.

Actioning concerns raised

The majority of respondents felt that concerns raised were dealt with, either with onward specialist referral or advice/medication.

Enquiry into information given regarding keeping active / role of exercise

74% of respondents had been given information about keeping active and physical exercise.

Information regarding research

The percentage of respondents who had been given information about Parkinson's- related research increased from 27.6% to 32.9% despite the research restrictions during the pandemic.

Accessing Parkinson's UK support Services

A third 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

The majority still felt that their service was "improving" or "staying the same,already good" despite known pandemic pressures. These figures (83.1%) are slightly down compared with 2019 (87.2%). 2.4% felt their service was getting worse and 14.5% that their service needed to improve but was staying the same compared with 1.6% and 11.2% respectively in 2019. Overall these figures are very encouraging and reassuring given the known service restraints and ongoing remobilisation and reconfiguring of services.

Actions indicated by the audit findings

It is encouraging to note the progress that has been made to improve the quality of care delivered to people with Parkinson's and their carers despite the pandemic and other pressures on the NHS. There is still work to be done however across all specialities in the following areas:

Specialised multidisciplinary working

Statement 3 of the NICE Parkinson's disease quality standard states that adults with Parkinson's are referred to physiotherapy,occupational therapy and speech and language therapy if they have problems with balance, motor function, ADLs, communication swallowing or saliva. The audit finds that the majority of services have access to these therapies, but that patients are not consistently being referred and / or not early enough.

Standardised practices

The recording of non-motor symptoms in clinics could be improved through use of, for example, the non-motor questionnaire. Many clinics have, as standard practice, a clinic nurse who checks weight and an erect and supine blood pressure, ensuring patients are regularly assessed for malnutrition and orthostatic hypotension.

Use of up to date 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 care professionals should use the RCOT best practice guide, the European physiotherapy guideline for Parkinson's, and the Dutch guidelines for speech-language therapy in Parkinson's disease. In addition the NICE guidelines highlighted the need to offer people with Parkinson's 'attention to effort' therapies like Lee Silverman Voice Therapy (LSVT) and Expiratory Muscle Strength Training (EMST).

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 available, as should information regarding lasting power of attorney and DVLA notifications. Anticipatory care planning should be considered and documented by all members of the multidisciplinary team.

Medicines management

In response to statement 4 of the NICE Parkinson's disease quality standard it is advised that all hospitals consider having a local Parkinson's guideline incorporating a recommendation that levodopa be administered within 30 minutes of the prescribed time. The PREM results indicated that less than half of audited inpatients consistently received their medication on time. Time critical Parkinson's medication is a priority programme for the Parkinson's Excellence Network with online resources being developed to better support healthcare professionals.[11]

At outpatient clinics patients should be asked about the development of any side effects pertaining to their medication including impulse control disorders (NICE quality statement 2) and excessive daytime somnolence in association with driving. These should be clearly documented.

All appropriate patients should have access to Clozapine (NICE quality statement 5) for treating hallucinations and delusions.

Educating the workforce

Attendance at specialist meetings about Parkinson's is desirable as part of the portfolio of CPD for movement disorder specialists, occupational therapists, physiotherapists and speech and language therapists. This is to enhance delivery of good quality care based on the most up to date evidence based practice. Meetings also allow for staff to improve their performance across other areas of their professional work such as networking, research opportunities and support. Increased promotion of existing CPD resources and training opportunities should be considered by the appropriate bodies.

These 5 areas are not mutually exclusive, but rather encompass the key themed areas for improvement work with the aim of driving up the quality of care delivered to people with Parkinson's and their carers

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[11] https://www.parkinsons.org.uk/professionals/excellence-network-national-priority-programmes

Service Improvement as a result of the 2019 audit

Two highly-successful national quality improvement projects were supported by Parkinson's UK through the Parkinson's Excellence Network.

Bone Health

This national project was developed by a multidisciplinary team with input from national experts in bone health and Parkinson's. The aim was to increase knowledge among Parkinson's healthcare professionals about how to assess bone health in Parkinson's, and to improve rates of assessing and treating bone health in specialist services (Elderly Care and Neurology).

In the project, 1131 people with Parkinson's were assessed for bone health and fracture risk, by a total of 80 healthcare professionals from 44 specialist services.

In these cases there was a 10% absolute increase in the proportion of patients managed with anti-resorptive treatment. This was a relative increase of around 67% from pre-project levels. An estimate of effectiveness suggests that the new treatments introduced to patients, in this project alone, would be expected to prevent around 3 vertebral fractures and 2 non-vertebral fractures (including the prevention of 1 hip fracture).

We are so encouraged by the results of this project that we would like to involve more people with Parkinson's, in even more clinical centres, in 2023. We will open this new (and simplified) project in the first quarter of 2023. This invitation will include all centres that took part in the 2022 project, to involve even more people with Parkinson's at these sites, as well as new centres.[12]

Therapist induction

This national project was developed by a multidisciplinary team with input from national experts in the Therapies and Parkinson's. This was in response to data from the 2019 Audit highlighting the lack of services offering documented induction programmes for therapists new to the field.

The inaugural Therapists Induction Course was held in June 2022, and offered 4 weeks of pre-recorded online sessions and a weekly live Q&A. Each week focused on a different stage of Parkinson's and was taught by multidisciplinary teams of therapists with expertise in Parkinson's.

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[12] https://www.parkinsons.org.uk/professionals/uk-parkinsons-audit-transforming-care

There were 148 participants in the programme, and 99% said they would recommend the course. In each of the 4 weeks, there are between 3 and 3.5 hours of material available, that is largely ‘on demand’ so that participants can access at a time that suits. This course is free to all therapists, and another is planned for the latter half of 2023.

Conclusion

These results, from the only national Parkinson's audit in the UK, demonstrate ongoing delivery of excellent Parkinson's care. There continues to be almost ubiquitous access to specialist nurses or equivalent, and also to therapists. There have been significant improvements in many areas such as options for remote consultations, awareness of the importance of activity and exercise, bone health, and inductions for new therapists.

The areas for improvement vary across the different service types but some key themes have emerged, including early referral to therapy services, waiting times, standardised assessments, anticipatory care planning and advice about driving.

The Parkinson’s Excellence Network continues to support services looking to take their next step in the improvement cycle. We have a range of funding opportunities for services and individual health and social care professionals and students. We provide education programmes, for all levels of staff from all professional backgrounds, to improve care for people with Parkinson’s. And we provide the latest updates and create opportunities for health and social care professionals to share best practice, network and collaborate, and receive support from peers.

Over the coming months, we will be working with members of the Parkinson’s community and clinicians to agree the priorities for our next national service improvement project(s).

Better support, better services, better care. Every day.
Together, we are transforming Parkinson’s care.

Acknowledgements

The work of the following groups and individuals was central to the successful running of the 2022 UK Parkinson’s Audit

Governance Board

Dr Anne-Louise Cunnington – Clinical Lead
Dr Donald Grosset – Clinical Director, Parkinson’s Excellence Network (to June 2022); Service Improvement Lead, Parkinson’s Excellence Network
Prof Richard Walker - Joint Clinical Director, Parkinson’s Excellence Network (from September 2022); Clinical Lead: Medicine, Parkinson’s Excellence Network;
Prof Camille Carroll - Joint Clinical Director, Parkinson’s Excellence Network; Neurology lead (from September 2022)
Fiona Lindop – Clinical Steering Group representative
Lisa Brown, Alison Leake, Annette Hand – Parkinson’s nurse representatives
Dr Rowan Wathes - Associate Director, Parkinson's Excellence Network, Parkinson’s UK
Katherine Crawford - Director of Services, Parkinson’s UK (to September 2022)
Juliet Tizzard - Director of External Relations, Parkinson’s UK
Emma Cooper - England Country Director, Parkinson’s UK
Katherine French - Service Improvement Programme Manager, Parkinson’s UK
Cathal Doyle – Head of Strategic Intelligence, Parkinson’s UK
Kim Davis – Audit Manager, Parkinson’s UK
Elaine Evans – Person with Parkinson’s

Reporting Group

Membership as per Governance Board with the addition of:

Ana Aragon and Laura Hartley - occupational therapy
Caroline Bartliff and Debra Borsley - speech and language therapy
Sophia Hulbert - physiotherapy

The Parkinson's UK 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

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