

2022 UK Parkinson's Audit: complete data tables

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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)	77.6 (8.0)		72.5 (10.0)		75.6 (8.9)		73.9 (9.4)		74.8 (9.2)		74.9 (9.1)	
(range)	(28-100)		(19-97)		(29-97)		(22-97)		(41-94)		(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

Elderly Care and Neurology

Demographics

Table 2: Gender of Elderly Care and Neurology patients

Gender	Elderly Care	Neurology	Elderly Care and Neurology
Male	61.0%	60.9%	61.0%
Female	39.0%	39.1%	39.0%
Other/prefers not to say	0	0	0
Number:	3305	3184	6489

Table 3: Patients in each Parkinson's phase

Parkinson's phase	Elderly Care	Neurology	Elderly Care and Neurology
Diagnosis	10.9%	8.0%	9.5%
Maintenance	46.7%	47.5%	47.1%
Complex	38.7%	40.8%	39.7%
Palliative	3.8%	3.7%	3.7%
Number:	3305	3184	6489

Table 4: Ethnicity of Elderly Care and Neurology patients

Ethnicity	Elderly Care	Neurology	Elderly Care and Neurology
White	93.0%	86.7%	90.0%
Asian/Asian British	2.9%	6.0%	4.4%
Black/African/Caribbean/Black British	0.6%	2.4%	1.5%
Mixed/multiple ethnic groups	0.2%	0.5%	0.3%
Other ethnic group or prefer not to say	3.3%	4.4%	3.8%
Number:	3305	3184	6489

Table 5: Elderly Care and Neurology patients living alone

Patient lives alone	Elderly Care	Neurology	Elderly Care and Neurology
Yes	26.1%	22.1%	24.2%
No	65.5%	72.0%	68.7%
No, at residential home	3.4%	2.9%	3.2%
No, at nursing home	4.9%	3.0%	3.9%
Number:	3305	3184	6489

Service audit

Table 6: What is the 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 input from/contact with consultant(s)	4.4%	24.0%	14.0%
Nurse-led service (patients with no named consultant)	1.5%	5.4%	3.4%
Community nurse service with no input from/contact with patients' named consultant(s)	2.2%	1.6%	1.9%
Number:	136	129	265

Table 7: Are remote consultations offered?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes - by video	1.5%	0	0.8%
Yes - by telephone	48.5%	35.7%	42.3%
Yes - by video and telephone	41.2%	59.7%	50.2%
No	8.8%	4.7%	6.8%
Number:	136	129	265

Table 8: Are patients routinely provided with information regarding Parkinson's, either written or by referral to Parkinson's Connect?

	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	58.1%	43.4%	50.9%
Most clinics (>75%)	26.5%	37.2%	31.7%
Some clinics	6.6%	13.2%	9.8%
Not routinely available	8.8%	6.2%	7.5%
Number:	136	129	265

Table 9: Can your service refer to the following specialties with experience in Parkinson's?

Access to specialties	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%
Psychiatry/mental health	85.3%	73.6%	79.6%
Number:	136	129	265

Table 10: Does your service have local pathways to provide access to clozapine and for patient monitoring?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	31.6%	31.8%	31.7%
No	68.4%	68.2%	68.3%
Number:	136	129	265

Table 11: Does your hospital have a local Parkinson's guideline incorporating a recommendation that Levodopa must be administered within 30 minutes of prescribed time?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	80.1%	71.3%	75.8%
No	19.9%	28.7%	24.2%
Number:	136	129	265

Assessments

Table 12: Is a standardised assessment tool routinely available in clinic venues to assess and monitor cognitive function?

Standardised assessment for cognition available	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	64.0%	55.8%	60.0%
Most clinics (>75%)	17.6%	21.7%	19.6%
Some clinics	8.8%	11.6%	10.2%
Not routinely available	9.6%	10.9%	10.2%
Number:	136	129	265

Table 13: Is a standardised assessment tool routinely available in clinic venues to assess mood (anxiety and depression)?

Standardised assessment of mood available	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	46.3%	41.9%	44.2%
Most clinics (>75%)	12.5%	23.3%	17.7%
Some clinics	16.9%	10.9%	14.0%
Not routinely available	24.3%	24.0%	24.2%
Number:	136	129	265

Consultants

Table 14: Have all consultants providing medical input to this service attended Movement Disorder specific external CME in the last 12 months?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	90.2%	68.6%	80.3%
No	9.8%	31.4%	19.7%
Number:	122	102	224

Parkinson's Nurse Specialists

Table 15: Can patients in this service access a Parkinson's Nurse Specialist or equivalent?

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

Table 16: Have all Parkinson's Nurse Specialists associated with the service attended Parkinson's specific external CME in the last 12 months?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	88.2%	86.0%	87.2%
No	6.6%	10.1%	8.3%
No Parkinson's nurse	5.1%	3.9%	4.5%
Number:	136	129	265

Table 17: What is the main arrangement for contact between Consultants and Parkinson's Nurse Specialists?

Type of contact	Elderly Care	Neurology	Elderly Care and Neurology
Regular contact in multidisciplinary meeting, joint or parallel clinic	44.9%	36.4%	40.8%
Regular face-to-face contact outside clinic	15.4%	14.7%	15.1%
Regular telephone/email contact with occasional face-to-face contact	21.3%	34.9%	27.9%
Telephone/email contact only	14.7%	11.6%	13.2%
No or rare contact	0.7%	1.6%	1.1%
No Parkinson's Nurse Specialist	2.9%	0.8%	1.9%
Number:	136	129	265

Patient audit

Specialist review

Table 18: How have consultations with this patient taken place in the last 12 months?

	Elderly Care	Neurology	Elderly Care and Neurology
In person	94.7%	93.0%	93.9%
Virtually - by video	2.1%	3.3%	2.7%
Virtually - by telephone	27.4%	30.1%	28.7%

*Some patients received more than one type of consultation

Table 19: Time since most recent medical review (by doctor or nurse specialist)

Time since medical review	Elderly Care	Neurology	Elderly Care and Neurology
Less than 6 months	77.3%	73.5%	75.4%
6-12 months	19.6%	23.1%	21.3%
More than 1 year	1.5%	2.5%	2.0%
More than 2 years	0.5%	0.3%	0.4%
Never	1.1%	0.6%	0.8%
Number:	3305	3184	6489

New/recent Parkinson's medication

Table 20: Is there documented evidence of a conversation with the patient/carer and/or provision of written information regarding potential adverse side effects for any new medication?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	53.6%	60.4%	56.9%
No	8.4%	7.5%	8.0%
Not applicable - patient not started on Parkinson's medication for the first time during the previous year	38.0%	32.1%	35.1%
Number:	3305	3184	6489

Specific adverse effect monitoring for patients on Parkinson's medication

Table 21: If excessive daytime sleepiness is documented as present and the patient is a driver, was the impact on driving discussed and advice given?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	73.8%	76.6%	75.3%
No	26.2%	23.4%	24.7%
Number:	730	813	1543

Table 22: Evidence patients taking dopaminergic drugs are monitored re: impulsive/compulsive behaviour

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	59.7%	68.2%	63.9%
No	20.1%	18.2%	19.2%
Not applicable	20.1%	13.7%	17.0%
Number:	3129	3053	6182

Advance care planning

Table 23: Is there evidence the patient/carer has been offered information about, or has set up, a Lasting Power of Attorney (Power of Attorney in Scotland)?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	26.8%	23.7%	25.3%
No	73.2%	76.3%	74.7%
Number:	3305	3184	6489

Table 24: Are there markers of advanced disease e.g. dementia, increasing frailty, impaired swallowing, nursing home level of care required?

Advanced disease markers recorded	Elderly Care	Neurology	Elderly Care and Neurology
Yes	28.5%	22.4%	25.5%
No	71.5%	77.6%	74.5%
Number:	3305	3184	6489

Table 25: Where there are markers of advanced disease, are there any documented discussions regarding end-of-life care issues/care plans within the last 12 months?

End of life care discussion documented	Elderly Care	Neurology	Elderly Care and Neurology
Yes	37.5%	34.7%	36.3%
No	62.5%	65.3%	63.7%
Number:	922	692	1614

Domain scores

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

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

Table 26: Domain 1 – Non-motor assessments during the previous year

Non-motor assessments	Elderly Care	Neurology	Elderly Care and Neurology
Blood pressure documented lying (or sitting) and standing	86.2%	70.9%	78.7%
Evidence of enquiry/assessment re cognitive status	92.9%	88.6%	90.8%
Evidence of enquiry re hallucinations/psychosis	90.4%	88.5%	89.4%
Evidence of enquiry re mood – including anxiety and depression	85.8%	86.5%	86.2%
Evidence of enquiry re communication difficulties	81.4%	81.8%	81.6%
Evidence of enquiry re problems with swallowing function	87.6%	87.2%	87.4%
Evidence of screening for malnutrition	85.4%	62.1%	74.0%
Evidence of enquiry re problems with saliva	72.9%	67.7%	70.4%
Evidence of enquiry re bowel function	90.8%	90.7%	90.8%
Evidence of enquiry re bladder function	86.4%	87.8%	87.1%
Evidence of enquiry re Parkinson's-related pain	61.8%	66.0%	63.9%
Evidence of enquiry re sleep quality	91.3%	92.4%	91.9%
Number of patients:	3305	3184	6489

Table 27: Domain 2 – Assessment of bone health and Activities of Daily Living (ADL) during the previous year

Motor symptoms and Activities of Daily Living	Elderly Care	Neurology	Elderly Care and Neurology
Evidence fracture risk/osteoporosis considered	63.2%	56.6%	60.0%
Evidence of enquiry re problems with transfers	91.9%	90.0%	91.0%
Evidence of enquiry re problems with personal care	85.9%	79.8%	82.9%
Evidence of enquiry re difficulty eating and drinking	80.2%	75.9%	78.1%
Evidence of enquiry re domestic activities	80.4%	75.6%	78.1%
Evidence of enquiry re problems with function at work	98.2%	94.5%	96.4%
Number of patients:	3305	3184	6489

Table 28: Domain 3 – Multidisciplinary involvement during the previous year

Education and multidisciplinary involvement	Elderly Care	Neurology	Elderly Care and Neurology
Evidence of referral/input from Parkinson's nurse	86.3%	94.3%	90.2%
Evidence of physiotherapy referral/assessment/input	87.4%	88.9%	88.1%
Evidence of occupational therapy referral/assessment/input	81.9%	82.9%	82.4%
Evidence of speech and language therapy referral/assessment/input for communication, swallowing and/or saliva issues	80.6%	84.3%	82.5%
Evidence of social work referral/input	87.1%	85.8%	86.5%
Evidence that patient and/or carer has been signposted to Parkinson's UK	76.7%	83.1%	79.8%
Number of patients:	3305	3184	6489

Occupational therapy

Demographics

Table 29: Gender of occupational therapy patients

Gender	Patients
Male	61.9%
Female	38.1%
Other/patient prefers not to say	0
Number:	627

Table 30: Ethnicity of occupational therapy patients

Ethnicity	Patients
White	92.0%
Asian/Asian British	4.5%
Black/African/Caribbean/Black British	1.6%
Mixed/multiple ethnic groups	0.5%
Other ethnic group/prefer not to say	1.4%
Number:	627

Table 31: Phase of Parkinson's on this referral to occupational therapy

Parkinson's phase	Patients
Diagnosis	14.4%
Maintenance	46.3%
Complex	35.7%
Palliative	3.7%
Number:	627

Table 32: Time since diagnosis

	Patients
Less than 1 year	9.3%
1-2 years	22.8%
3-5 years	25.5%
6-10 years	25.5%
11-15 years	10.9%
16-20 years	3.9%
More than 20 years	2.1%
Number:	623

Table 33: Settings in which occupational therapy patients live

Home setting	Patients
Own home	94.4%
Residential care home	2.1%
Nursing home	1.4%
Other	2.1%
Number:	627

Table 34: In what setting was the individual seen?

Health setting	Patients
NHS – outpatient	23.1%
NHS – community	47.4%
At home	28.4%
Other	1.1%
Number:	627

Service audit

Table 35: Describe the setting in which you usually see individuals with Parkinson's?

	Services
Integrated medical and therapy Parkinson's clinic	18.9%
Acute outpatient rehabilitation	3.8%
Community rehabilitation service	39.6%
Social services including reablement	1.0%
Outpatient/day hospital	17.0%
Individual's home	20.8%
Number:	53

Table 36: Does your service specialise in the treatment of individuals with neurological conditions?

Service specialises in neurological conditions	Services
Yes	69.8%
No	30.2%
Number:	53

Table 37: Does your service specialise in treatment of people with Parkinson's?

Service specialises in Parkinson's	Services
Yes	75.5%
No	24.5%
Number:	53

Individuals with Parkinson's

Table 38: Approximately what percentage of the individuals referred to your service annual have a diagnosis of Parkinson's?

Service specialises in Parkinson's treatment	Services
0-19%	32.1%
20-39%	24.5%
40-59%	22.6%
60-79%	3.8%
80-100%	17.0%
Number:	53

Occupational therapy professionals

Table 39: Within your service, can you access Parkinson's related continuing professional development (at least yearly)?

Access to yearly CPD	Services
Yes	86.8%
No	13.2%
Number:	53

Table 40: Are there any documented induction and support strategies for new occupational therapists working with people with Parkinson's?

Induction and support strategies available	Services
Yes, specifically in relation to patients with Parkinson's	39.6%
Yes, as part of more general competencies	47.2%
No	13.2%
Number:	53

Table 41: What support (e.g. education, advice) is available to individual therapists in the service?

Support available	Services
Consult any member of the Parkinson's specialist movement disorder team (MDT) of which they are a member	54.7%
Consult members of a general Neurology/Elderly Care specialist service of which they are a member	7.5%
Doesn't work directly in specialist Parkinson's clinics, but has access to Parkinson's specialist multidisciplinary team/Parkinson's nurse	32.1%
Doesn't work directly in a specialist clinic, but has access to advice from a specialist Neurology or Elderly Care multidisciplinary team	5.7%
No access to more specialist advice	0
Number:	53

Clinical practice

Table 42: How does your service approach assessment of an individual with Parkinson's?

Approach to assessment	Services
MDT assessment	83.0%
OT specific assessment	96.2%
Both	79.2%
Number	53

Table 43: How is the assessment undertaken?

This question should enable respondents to choose more than one of the four available options (Interview with patient and carer, assessment during group work, functional assessment and standardised assessment) but in 2022 respondents had only a choice of one option. As such, this data is not robust. This was an error in the data entry system which will be resolved for the next audit round.

Table 44: How do you usually see your patients with Parkinson's?

How patients seen	Services
Individually	86.8%
In a group setting	0
Both individually and in groups	13.2%
Number:	53

Table 45: How are patients seen?

How patients seen	Services
In person	100.0%
Virtually - by video	32.1%
Virtually - by telephone	62.3%
Number:	53

Table 46: Are outcome measures being used?

Outcome measures?	Services
Yes	79.2%
No	20.8%
Number	53

Table 47: If yes, what type?

Outcome measures used	Services
Self report	83.3%
Clinician administered	81.0%
Report by family/carer	57.1%
Service data	33.3%
Number:	42

Table 48: Needs regularly addressed through interventions

	Services
Work roles	66.0%
Family roles	86.8%
Domestic activities of daily living	100.0%
Leisure activities	98.1%
Transfers and mobility	100.0%
Personal self-care activities such as eating, drinking, washing, dressing	100.0%
Environmental issues to improve safety and motor function	98.1%
Mental wellbeing including cognition, emotional, neuro-psychiatric problems	94.3%
Management of fatigue	96.2%
Education of condition and self-management	96.2%
Social interaction/social support	92.5%
Other	20.8%
Number:	53

Table 49: Where do you carry out intervention?

Location of interventions	Services
Individual's home	67.9%
Community setting	3.8%
Outpatient/day hospital/centre	28.3%
Hospital	0
Number:	53

Patient audit

Referral

Table 50: When the person was first referred to any OT service, at what stage of their Parkinson's were they?

Stage of Parkinson's at first referral	Patients
Diagnosis	22.5%
Maintenance	46.7%
Complex	19.1%
Palliative	1.0%
Unknown	10.7%
Number	627

Current episode of care

Table 51: Who made the referral to OT for the current episode of care?

Source of referral	Patients
Neurologist	11.8%
Geriatrician	15.9%
Parkinson's Nurse specialist	30.3%
Allied health professional colleague (physio/SLT)	14.4%
GP	10.0%
Dietician	0
Social Care Worker	3.0%
Self-referral	4.9%
Other	8.6%
Unknown	1.0%
Number:	627

Table 52: Time between the date of referral and the date of the initial appointment for this episode of care

Time between referral and first appointment	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	627

Table 53: Has this referral been triggered as a result of a medical review?

Referral triggered by medical review	Patients
Yes	60.0%
No	37.5%
Unknown	2.6%
Number:	627

Table 54: What was the reason for referral to OT?

	Patients
Work roles	4.0%
Family roles	11.8%
Domestic activities of daily living	36.8%
Leisure activities	21.9%
Transfers and mobility	79.7%
Personal self-care activities such as eating, drinking, washing, dressing	54.9%
Environmental issues to improve safety and motor function	60.0%
Mental wellbeing including cognition, emotional, neuro-psychiatric problems	34.0%
Management of fatigue	17.7%
Other	10.8%

Goals identified

Table 55: Were therapy goals set in collaboration with the patient and/or carer?

Goals set in collaboration	Patients
Yes	87.7%
No	12.3%
Number	627

Table 56: Were standardised assessments used with this patient?

Standardised assessments?	Patients
Yes	38.3%
No	61.7%
Number	627

Table 57: If yes, what areas were you assessing for?

Areas of standardised assessment	Patients
Activity, function, participation	68.4%
Cognition	39.2%
Mood	33.6%
Fatigue	29.0%
Goal setting	50.2%
Health and wellbeing	40.0%
Number	240

Intervention strategies used

Table 58: Which areas of intervention were addressed?

Areas of intervention addressed	Patients
Staying well	53.3%
Self management	65.6%
Specific strategies for initiating and maintaining movement - intrinsic or extrinsic cues	61.8%
Cognitive and emotional wellbeing	44.4%
Engagement/motivation	39.4%
Equipment provision/environmental adaptation	74.6%
Moving and handling guidance	35.9%
Carer support	38.4%
Onward referrals and support	48.5%

Occupational therapist Band

Table 59: What band (grade) is the occupational therapist who carried out the initial assessment of this person?

	Patients
Band 4	4.8%
Band 5	7.0%
Band 6	55.2%
Band 7	33.8%
Band 8a	1.8%
Social service grade – junior OT	0
Social service grade – senior OT	2.2%
Other	0
Number:	627

Table 60: Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?

Caseload	Services
0–19%	30.9%
20–39%	24.7%
40–59%	17.5%
60–79%	3.3%
80–99%	12.0%
100%	8.0%
Unknown	3.5%
Number:	627

Evidence base

Table 61: Which of the following did the audited therapist use to inform clinical practice or guide intervention?

Type of evidence used by the audited therapist for this patient	Patients
Clinical experience	99.4%
Advice from colleague or supervisor	55.2%
Occupational therapy for people with Parkinson's: best practice guides 2 nd edition (2018)	68.3%
Information from Parkinson's UK website	54.1%
National Service Framework for Long term Conditions (2005)	41.8%
NICE – Parkinson's disease: diagnosis and management in primary and secondary care (2017)	55.5%
Progressive Neurological Conditions toolkit 2019	6.7%
Allied Health Professionals' competency framework for progressive neurological conditions	23.6%
Published evidence in a peer-reviewed journal	20.3%
Training courses	52.8%
Webinars, social media	28.7%
None	1.1%
Other	2.4%

Physiotherapy

Demographics

Table 62: Gender of Physiotherapy patients

Gender	Patients
Male	61.6%
Female	38.4%
Number:	1837

Table 63: Ethnicity of Physiotherapy patients

Ethnicity	Patients
White	90.2%
Asian/Asian British	5.2%
Black/African/Caribbean/Black British	1.3%
Mixed/multiple ethnic groups	0.5%
Other ethnic group/prefer not to say	2.7%
Number:	1837

Table 64: What setting does this client live in?

Home setting	Patients
Own home	95.0%
Residential care home	1.6%
Nursing home	1.7%
Other	1.7%
Number:	1837

Table 65: In what health setting was the patient seen?

Healthcare setting	Patients
NHS – outpatient	55.0%
NHS – community	26.2%
Private clinic	0.5%
At home	17.9%
Other	0.3%
Number:	1837

Table 66: Phase of Parkinson's on this referral to physiotherapy

Parkinson's phase	Patients
Diagnosis	12.6%
Maintenance	55.1%
Complex	31.4%
Palliative	1.0%
Number:	1837

Table 67: Time since diagnosis

	Patients
Less than 1 year	11.6%
1-2 years	23.8%
3-5 years	24.1%
6-10 years	24.7%
11-15 years	9.6%
16-20 years	4.1%
More than 20 years	2.2%
Number:	1821

Service Audit

Service description

Table 68: Describe the setting in which you usually see individuals with Parkinson's?

Settings patients seen	Services
Integrated medical and therapy Parkinson's clinic	5.6%
Acute outpatient rehabilitation	6.5%
Community rehabilitation service	41.9%
Social services including reablement	0
Outpatient/day hospital	33.1%
Individual's home	9.7%
Other	3.2%
Number:	124

Table 69: How does your service offer assessments?

How assessments are offered	Services
In person	100.0%
Virtually - by telephone	55.6%
Virtually - by video	27.4%
Number:	124

Table 70: Does your service specialise in the treatment of individuals with neurological conditions/individuals with Parkinson's?

Service specialisation	Yes	No
Specialise in treatment of neurological conditions	75.8%	24.2%
Specialise in treatment of Parkinson's	66.1%	33.9%
Number:	124	124

Table 71: Approximately what percentage of the individuals referred to your service annually have a diagnosis of Parkinson's?

Percentage referred	Services
0–19%	26.6%
20–39%	37.1%
40–59%	21.0%
60–79%	4.0%
80–100%	11.3%
Number:	124

Physiotherapy professionals

Table 72: Within your service, can you access Parkinson's-related continuous professional development (at least yearly)?

Access to CPD yearly	Services
Yes	91.1%
No	8.9%
Number:	124

Table 73: Are there any documented induction and support strategies for new physiotherapists working with people with Parkinson's?

Induction and support strategies	Services
Yes, specifically in relation to patients with Parkinson's	32.8%
Yes, as part of more general competencies	46.0%
No	21.8%
Number:	124

Table 74: What support (e.g. education, advice) is available to individual physiotherapists working in the service?

Type of support	Services
Can consult any member of the Parkinson's specialist MDT of which they are a member	40.3%
Can consult members of a general neurology/elderly care specialist service of which they are a member	7.3%
Don't work directly in specialist Parkinson's clinics but access to Parkinson's specialist MDT/Parkinson's nurse	44.4%
Don't work directly in a specialist clinic but access to advice from a specialist neurology or elderly care MDT	7.3%
No support available	0.8%
Number:	124

Clinical practice

Table 75: How does your service offer assessment of a patient with Parkinson's?

Assessment	Services
MDT assessment	58.1%
Physiotherapy assessment	96.8%
Other	21.8%
Number:	124

Table 76: How do you usually see your clients with Parkinson's?

How patients seen	Services
Individually	53.2%
In a group setting	0
Both individually and in groups	34.7%
In either a group or individual setting, but can refer to the other	12.1%
Number:	124

Table 77: If your intervention includes group work, what needs are addressed in these groups?

Needs addressed	Services
Education	81.0%
Exercise	96.9%

Table 78: Do you provide information about non-NHS/external services (e.g. Parkinson's UK, leisure centre classes)?

Information provided	Services
Yes	100.0%
No	0
Number:	124

Patient audit

Table 79: How was this person assessed?

How the individual was assessed	Patients
In person	97.2%
Virtually - by video	1.7%
Virtually - by telephone	16.5%

Referral

Table 80: When the person was first referred to any physiotherapy service, at what stage of their Parkinson's were they?

Stage at first referral	Patients
Diagnosis	25.3%
Maintenance	51.7%
Complex	14.9%
Palliative	0.2%
Unknown	7.9%
Number:	1837

Referral to this episode

Table 81: Who made the referral to physiotherapy for the current episode of care?

Source of referral	Patients
Elderly care consultant	10.3%
Neurologist	23.7%
Parkinson's Nurse specialist	34.7%
General/non-PDNS nurse	1.7%
GP	11.6%
Allied health professional colleague (OT/SLT)	7.5%
Dietician	0.1%
Social Care Worker	0.9%
Self-referral/relative	4.0%
Other	5.0%
Unknown	0.4%
Number:	1837

Table 82: Was the referral urgent or routine?

Referral type	Patients
Urgent	16.2%
Routine	82.9%
Unknown	0.9%
Number:	1837

Table 83: Time between date of referral letter and date of initial appointment for this episode of care

Time between diagnosis and referral	Patients
1 to 4 weeks	38.8%
5 to 8 weeks	23.2%
9 to 12 weeks	13.0%
13 to 18 weeks	11.8%
More than 18 weeks	13.1%
Number:	1835

Table 84: If the patient is in the complex or palliative phase, is there evidence of anticipatory care planning in the last 12 months?

Anticipatory care planning	Patients
Yes	7.0%
No	20.3%
Not in complex or palliative phase	51.1%
Not indicated	21.6%
Number:	1837

Implementation of national recommendations

Table 85: Were Parkinson's-specific outcome measures used in this case?

Outcome measures used	Patients
Yes	79.7%
No	20.3%
Number:	1837

Table 86: Outcome measures used

	Patients
3-step falls predictor	0.5%
10 meter walk	29.2%
Activities Balance Confidence (ABC) Scale	2.9%
Berg Balance Scale	35.9%
Borg Scale	0.2%
Dynamic Gait Index (DGI)	2.3%
Exercise diary	4.8%
Falls Efficacy Scale International (FES-I)	2.7%
Falls diary	4.0%
Five Times Sit to Stand	22.3%
Functional Gait Assessment	14.8%
Goal Attaining Scaling (GAS)	10.0%
History of Falls questionnaire	20.8%
Lindop Parkinson's Assessment Scale (LPAS)	20.9%
Mini-BES Test	6.5%
Modified Parkinson's Activity Scale (M-PAS)	1.7%
New Freezing of Gait questionnaire (NFOG-Q)	3.2%
Patient Specific Index for Parkinson's Disease (PSI-PD)	0.3%
Push & Release Test	2.9%
Rapid Turns Test	0.8%
Six Minute Walk distance	6.6%
Timed Get up & Go	43.8%
Tragus to Wall (posture measure)	17.1%
Unified Parkinson's Disease Rating Scale (UPDRS)	4.6%
Other	23.0%
Number:	1837

Table 87: Was exercise advice/intervention offered to this individual?

Exercise/intervention offered	Patients
Yes	93.3%
No	2.7%
Not appropriate	4.0%
Number:	1837

Table 88: Exercise/intervention type offered

Exercise/intervention type 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%
Number:	1837

About the physiotherapist

Table 89: What band (grade) is the physiotherapist who carried out the initial assessment of this person?

	Patients
Band 4	3.8%
Band 5	9.4%
Band 6	45.9%
Band 7	36.1%
Band 8a	4.2%
Band 8b	0
Other	0.5%
Number:	1837

Table 90: Approximately what percentage of people seen by the audited physiotherapist in a year have Parkinson's?

	Patients
0-19%	22.2%
20-39%	33.7%
40-59%	24.8%
60-79%	2.6%
80-99%	11.4%
100%	1.8%
Unknown	3.6%
Number:	1837

Evidence base

Table 91: Which of the following did the audited therapist use to inform clinical practice or guide intervention?

Type of evidence	Patients
Clinical experience	94.9%
Advice from colleague or supervisor	39.4%
European Physiotherapy Guideline for Parkinson's Disease (2013)	45.1%
Allied Health Professionals' competency framework for progressive neurological conditions	31.6%
Information from Parkinson's UK website	47.1%
NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017)	58.7%
Published evidence in a peer reviewed journal (read within last 12 months)	21.2%
Postgraduate training within last 24 months	42.5%
Other	2.1%
None	0
Number:	1837

Speech and language therapy

Demographics

Table 92: Gender of speech and language therapy patients

Gender	Patients
Male	70.4%
Female	29.6%
Number:	807

Table 93: Ethnicity of speech and language therapy patients

Ethnicity	Patients
White	87.7%
Asian/Asian British	4.6%
Black/African/Caribbean/Black British	1.6%
Mixed/multiple ethnic groups	0.2%
Other ethnic group/prefer not to say	5.6%
Number:	805

Table 94: Phase of Parkinson's on this referral to speech and language therapy

Parkinson's phase	Patients
Diagnosis	8.3%
Maintenance	60.5%
Complex	28.3%
Palliative	3.0%
Number:	807

Table 95: Time since diagnosis

	Patients
Less than 1 year	9.2%
1-2 years	20.4%
3-5 years	24.8%
6-10 years	24.4%
11-15 years	12.8%
16-20 years	5.8%
More than 20 years	2.6%
Number:	795

Table 96: What setting does this patient live in?

Home setting	Patients
Own home	89.3%
Residential care home	4.3%
Nursing home	5.2%
Other	1.1%
Number:	807

Service audit

Table 97: Job description of the audited therapist

Job description of audited therapist	Services
Overall SLT manager	28.1%
Parkinson's specialist SLT	10.9%
Specialist SLT who sees patients with Parkinson's	48.4%
Generalist SLT who sees patients with Parkinson's	12.5%
Number:	64

Service description

Table 98: Describe the setting in which you usually see individuals with Parkinson's?

	Services
Integrated medical and therapy Parkinson's clinic	3.1%
Acute outpatient rehabilitation/Rapid Response Service/Early Supported Discharge service	0
Community rehabilitation service	26.6%
Social services including reablement	0
Outpatient/day hospital	26.6%
Individual's home	37.5%
Other	6.3%
Number:	64

Table 99: How does your service offer assessments?

How assessments are offered	Services
In person	100%
Virtually - by video	78.1%
Virtually - by telephone	68.7%
Number:	64

Table 100: Does your service specialise in the treatment of individuals with neurological conditions?

Specialising in neurological conditions	Services
Yes	84.4%
No	15.6%
Number:	64

Table 101: Does your service specialise in the treatment of individuals with Parkinson's?

Specialising in Parkinson's	Services
Yes	54.7%
No	45.3%
Number:	64

Table 102: Does your service offer the Lee Silverman Voice Treatment (LSVT) for individuals with Parkinson's who meet inclusion criteria (louder voice stimuable; motivated; physically able to cope with intensity)?

LSVT treatment availability	Services
Yes - all eligible candidates	34.4%
Yes - limited service available to selected candidates only	26.6%
Alternative attention to effort volume therapy offered	23.4%
LSVT not offered due to lack of LSVT trained speech and language therapist	6.3%
LSVT not offered due to no service delivery decision	9.4%
Number:	64

Table 103: Approximately what percentage of eligible candidates seen by the service are offered LSVT?

LSVT percentage of eligible candidates seen	Services
0-25%	53.8%
25-50%	7.7%
50-75%	7.7%
75-100%	30.8%
Number:	39

Table 104: Is speech and language therapy available for all people with Parkinson's for issues with communication, irrespective of when in the course of their Parkinson's the referral was made?

Service offered for communication issues	Services
Yes	95.3%
Not consistently due to restricted capacity/service demands	4.7%
No	0
Number:	64

Table 105: Is speech and language therapy available for individuals with Parkinson's for eating/swallowing issues irrespective of when in the course of their Parkinson's the (re)referral was made?

Service offered for eating/swallowing issues	Services
Yes	100%
Not consistently due to restricted capacity/service demands	0
No	0
Number:	100%

Table 106: Is Speech and Language Therapy available for all individuals with Parkinson's for drooling issues irrespective of when in the course of their Parkinson's the (re)referral was made?

Service offered for drooling issues	Services
Yes	85.9%
Not consistently due to restricted capacity/service demands	12.5%
No	1.6%
Number:	64

Table 107: Are individuals who require assistive technology (AAC) able to receive timely, appropriate equipment and support to help them to live independently?

AAC available	Services
Yes, it is part of the service	35.9%
Yes, full access via other AAC service	12.5%
Restricted AAC service due to financial restrictions	10.9%
Restricted AAC service due to equipment range	9.4%
AAC service available via specialist technology service if referral criteria met	31.3%
No service	0
Number:	64

Individuals with Parkinson's

Table 108: Approximately what percentage of the individuals referred to your service have a diagnosis of Parkinson's?

Percentage referred	Services
0–19%	48.4%
20–39%	32.8%
40–59%	9.4%
60–79%	1.6%
80–100%	7.8%
Number:	64

Speech and language therapy professionals

Table 109: Within your service, can you access Parkinson's related continuing professional development (at least yearly)?

Access to CPD yearly	Services
Yes	87.5%
No	12.5%
Number:	64

Table 110: Are there documented induction and support strategies for new SLT therapists working with individuals with Parkinson's?

Induction and support strategies	Services
Yes, specifically in relation to patients with Parkinson's	40.6%
Yes, as part of more general competencies	48.4%
No	10.9%
Number:	64

Patient audit

Table 111: In what health setting was the patient seen?

Healthcare setting	Patients
NHS – outpatient	27.6%
NHS – community	42.3%
Private clinic	0.1%
At home	26.8%
Other	3.2%
Number:	807

Table 112: How was this person assessed?

Healthcare setting	Patients
In person	90.0%
Virtually - by video	13.7%*
Virtually - by telephone	26.7%*

*excludes patients seen at home

Referral

Table 113: When the person was first referred to any SLT service, at what stage of their Parkinson's were they?

Healthcare setting	Patients
Diagnosis	16.5%
Maintenance	56.6%
Complex	15.5%
Palliative	0.9%
Not known	10.5%
Number:	807

Table 114: Time between the date of the referral letter and the date of the 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:	806

Table 115: Who made the referral to SLT for the current episode of care?

Referral source	Patients
Elderly Care consultant	11.4%
Neurologist	13.1%
Parkinson's nurse specialist	32.3%
General/non-Parkinson's nurse	4.2%
GP	14.3%
Allied health professions colleague (OT/Physio)	12.3%
Dietician	0.4%
Social care worker	1.5%
Self-referral/relative	2.1%
Other	7.8%
Unknown	0.6%
Number:	807

Table 116: What has been offered in the current episode of care?

Current episode of care - what offered	Patients
Initial assessment and advice only	18.8%
Assessment and review	33.1%
Individual treatment	37.9%
Group treatment	3.7%
Group and individual treatment	6.4%
Number:	807

Assessments

Table 117: Was there documentation of on-off phase of assessment?

On/off phase documented	Patients
Yes	36.7%
No	63.3%
Number:	807

Table 118: Is an assessment of communication recorded at initial assessment?

Communication assessed	Patients
Yes	70.0%
No	5.5%
No, but reasons why assessment was inappropriate documented	5.9%
No, referred for swallow/drooling assessment only	18.6%
Number:	807

Table 119: Did the communication assessment also include a screening question about swallowing?

Screening question about swallowing in communication assessment	Patients
Yes	91.5%
No	8.5%
Number:	565

Table 120: Is an initial audio or video recording included in the record?

Recording made	Patients
Yes and available	8.0%
Yes, but not available	4.8%
No, Trust or Board governance rules do not permit acquisition or storage of digital data	14.9%
No, equipment not available	10.4%
No, client did not consent	0.2%
No	61.8%
Number:	565

Table 121: Was an assessment of swallowing recorded at initial assessment?

Swallowing assessed	Patients
Yes	65.7%
No, but reasons why assessment was not appropriate documented	13.6%
No reference to assessments documented	1.0%
No, referred for communication assessment only	19.7%
Number:	807

Table 122: Was drooling assessed?

Assessment of drooling	Patients
Yes – formal published assessment used	1.7%
Yes – informal observation checklist used	4.3%
Yes – clinical observations documented	20.0%
Yes – patient report recorded	24.8%
No, as not reported/observed	40.3%
No	8.6%
Number:	804

Assessment of speech, language and communication subsystems

Table 123: Which speech subsystems were assessed and documented?

Speech subsystems assessed and documented	Patients
Phonation including voice quality	85.1%
Loudness/amplitude level and variation	89.7%
Stimulability of volume	60.5%
Prosody including pitch, pitch range and variation	65.5%
Oromotor skills	61.9%
Articulation and speech rate	78.8%
No assessments documented but justification documented	11.5%
No assessments and no justification documented	3.4%
Number:	565

Table 124: Was intelligibility assessed?

Assessment of intelligibility	Patients
Standardised diagnostic intelligibility test completed	5.0%
Informal assessment, non-standardised tool/subsection of other test completed	25.1%
Informal assessment (e.g. rating scale) completed	48.8%
No assessment/results documented but justification given	10.8%
No assessment documented and no justification given	10.3%
Number:	565

Table 125: Is word finding assessed?

Assessment of word finding	Patients
Formal standardised word finding assessment	3.9%
Informal word finding assessment	9.2%
Observations recorded	22.5%
Self report documented but not assessed	17.2%
No	47.3%
Number:	565

Table 126: Was the need for AAC identified and addressed?

Need for AAC identified and addressed	Patients
Yes	12.2%
No	9.6%
Not applicable	78.2%
Number:	565

Table 127: Scope of communication assessment

Communication assessment scope	Patients
Communication participation	87.1%
The impact of Parkinson's on communication	88.3%
The impact of communication changes on partner and/or carer	68.1%
Number:	565

Results of assessments

Table 128: Were assessment results and rationale for management plan discussed with patient and carer?

Results discussed	Patients
Yes	96.8%
No, but justification documented	1.6%
No and no justification documented	1.6%
Number:	807

Table 129: Was information about communication and/or swallowing provided to patient and carer?

Information provided	Patients
Yes, verbal and written information provided	93.1%
No, but justification documented	4.1%
No and no justification documented	2.9%
Number:	807

Table 130: If a patient is in the complex or palliative phase, is there evidence of anticipatory care planning in the last 12 months?

Anticipatory care planning	Patients
Yes	9.9%
No	9.7%
Not in complex or palliative phase	52.3%
Not indicated	28.1%
Number:	807

Interventions

Table 131: Interventions offered - communication

Interventions offered - communication	Patients
Pitch (range)	33.6%
Prosody	27.3%
Improvement of vocal loudness	61.5%
Strategies to optimise intelligibility	58.0%
Word finding/language change	15.7%
Patient education/advice	62.7%
Managing patient participation	51.4%
Managing patient impact	48.3%
Managing generalisation outside clinic	46.5%
Carer education/advice	40.8%
Managing career impact	11.6%
Other	7.6%
Not applicable - seen for swallow/drooling only	36.1%
Number:	807

Table 132: Interventions offered - swallow

Interventions offered - swallow	Patients
Strategies for safer swallowing	62.1%
Fluid and diet modification	49.8%
Positioning	44.9%
Feeding advice for carers	29.1%
Environmental/external cueing	25.9%
Expiratory Muscle Strength Training	1.9%
Information on risks and warning signs	59.4%
Other	10.7%
Not applicable – seen for communication/drooling only	46.0%
Number:	807

Table 133: Interventions offered - drooling

Interventions offered - drooling	Patients
Strategies to manage saliva	31.2%
Swallow reminder tools	9.7%
Referral on for botulinum toxin/medical management	3.3%
Other	5.1%
Not applicable – seen for communication/drooling only	56.1%
Number:	807

Table 134: Were reports made back to referrer or other key people at the conclusion of intervention (or interim reports where treatment lasts longer)?

Reports made	Patients
Yes	67.4%
No, but will be done at the end of this assessment/intervention	24.8%
No	7.8%
Number:	807

About the speech and language therapist

Table 135: What band (grade) is the Speech and Language Therapist who carried out the initial assessment of this person?

	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%
Band 8c	0
Number:	807

Table 136: Approximately what percentage of people seen by the audit therapist in a year have Parkinson's?

	Patients
0-19%	34.4%
20-39%	25.2%
40-59%	13.1%
60-79%	8.6%
80-99%	1.7%
100%	2.1%
Unknown	14.9%
Number:	807

Table 137: Which of the following did the audited therapist use to inform clinical practice or guide intervention?

	Patients
Own clinical experience	95.8%
Advice from colleagues	70.5%
RCSLT Clinical Guidelines (CQ Live)	66.4%
RCSLT Communicating Quality Live	32.1%
2017 NICE Guideline: Parkinson's disease: Diagnosis and management in primary and secondary care and other relevant NICE guidelines	78.4%
National Service Framework for Long Term Neurological Conditions (NSF-LTNC) guidelines	41.0%
Allied Health Professionals' competency framework for progressive neurological conditions	36.4%
Published evidence in peer reviewed journal	52.9%
None	1.0%
Other	5.6%

Patient Reported Experience Measure (PREM) questionnaire

About the patient

Table 138: Age of people with Parkinson's represented in the PREM

Age	
Under 20	0.0%
20–29	0.0%
30–39	0.2%
40–49	1.4%
50–59	6.1%
60–69	21.1%
70–79	44.5%
80–89	24.8%
Over 90	1.9%
Number:	6737

Table 139: Gender of people with Parkinson's represented in the PREM

Gender	
Male	61.7%
Female	38.1%
Other	0.0%
Prefer not to say	0.1%
Number:	6732

Table 140: Ethnicity of people with Parkinson's represented in the PREM

Ethnicity	
White	93.0%
Asian/Asian British/Indian/Pakistani/Bangladeshi/Chinese/other Asian background	4.2%
Black/Black British/African/Caribbean/any other Black background	1.4%
Mixed/multiple ethnic groups	0.4%
Other ethnic group/prefer not to say	1.0%
Number:	6678

Table 141: What are your living arrangements?

Living arrangements	
Live with husband/wife/partner	71.0%
Live with family/friends	6.2%
Live on their own	19.6%
Live in care home	2.5%
Other	0.7%
Number:	6660

Table 142: How long ago were you diagnosed?

Parkinson's duration	
Less than 2 years	21.2%
2-10 years	59.2%
11–20 years	16.7%
Over 20 years	2.8%
Number:	6669

Table 143: Approximately how long have you been attending your current Parkinson's service?

Duration of service attendance	
Less than 1 year	18.2%
1–2 years	20.0%
3–5 years	27.1%
Over 5 years	34.7%
Number:	6541

About the patient's Parkinson's service

Table 144: Are you satisfied that the amount of contact you have with your Parkinson's specialist doctor or Parkinson's nurse (if you have one) meets your needs?

Contact meets needs – Parkinson's specialist doctor	
Yes	78.7%
No - less than I need	17.1%
No – more than I need	1.7%
I don't have one	2.5%
Number:	6142

Contact meets needs – Parkinson's nurse	
Yes	80.3%
No - less than I need	12.2%
No – more than I need	1.4%
I don't have one	6.0%
Number:	5924

Table 145: Are you able to access the following services - Parkinson's Nurse?

Parkinson's Nurse access	
Yes	85.5%
No – but I have tried	4.1%
No – I haven't needed it	5.8%
Not sure	4.5%
Number:	6452

Table 146: Are you able to access the following services - Occupational Therapist?

Occupational therapy access	
Yes	45.3%
No – but I have tried	5.2%
No – I haven't needed it	37.9%
Not sure	11.6%
Number:	5340

Table 147: Are you able to access the following services - Physiotherapist?

Physiotherapy access	
Yes	61.5%
No – but I have tried	6.1%
No – I haven't needed it	23.3%
Not sure	9.1%
Number:	5615

Table 148: Are you able to access the following services - Speech and Language therapist?

Speech and language therapy access	
Yes	39.6%
No – but I have tried	5.1%
No – I haven't needed it	47.0%
Not sure	8.3%
Number:	5374

Table 149: Are you able to access the following services - Mental health services (psychology/psychiatry)?

Mental health services access	
Yes	17.6%
No – but I have tried	5.0%
No – I haven't needed it	65.4%
Not sure	12.0%
Number:	5100

Table 150: If using any of these services, are you able to contact them between scheduled reviews - Parkinson's nurse?

Parkinson's Nurse access between reviews	
Yes	78.9%
No – but I have tried	5.0%
No – I haven't needed it	10.3%
Not sure	5.8%
Number:	6266

Table 151: If using any of these services, are you able to contact them between scheduled reviews - occupational therapist?

Occupational therapy access between reviews	
Yes	33.0%
No – but I have tried	5.8%
No – I haven't needed it	46.4%
Not sure	14.8%
Number:	4845

Table 152: If using any of these services, are you able to contact them between scheduled reviews - physiotherapist?

Physiotherapy access between reviews	
Yes	44.0%
No – but I have tried	6.7%
No – I haven't needed it	34.7%
Not sure	14.6%
Number:	5090

Table 153: If using any of these services, are you able to contact them between scheduled reviews - speech and language therapist?

Speech and language therapy access between reviews	
Yes	27.9%
No – but have tried	5.7%
No – don't need it	53.1%
Not sure	13.2%
Number:	4848

Table 154: If using any of these services, are you able to contact them between scheduled reviews - mental health services?

Mental health services access between reviews	
Yes	12.5%
No – but I have tried	5.4%
No – I haven't needed it	67.1%
Not sure	15.0%
Number:	4589

Table 155: How would you rate the quality of service provided by the various parts of your Parkinson's service - Parkinson's specialist doctor?

Quality of service – specialist doctor	
Excellent	55.5%
Good	29.0%
Fair	7.7%
Poor	2.7%
Very poor	1.0%
Don't use this service	2.3%
Not sure	1.9%
Number:	6335

Table 156: How would you rate the quality of service provided by the various parts of your Parkinson's service - Parkinson's nurse?

Quality of service – Parkinson's nurse	
Excellent	59.7%
Good	24.2%
Fair	4.8%
Poor	1.7%
Very poor	0.9%
Don't use this service	6.1%
Not sure	2.5%
Number:	6228

Table 157: How would you rate the quality of service provided by the various parts of your Parkinson's service - occupational therapist?

Quality of service – occupational therapist	
Excellent	21.4%
Good	17.0%
Fair	4.5%
Poor	1.0%
Very poor	0.5%
Don't use this service	48.9%
Not sure	6.8%
Number:	4899

Table 158: How would you rate the quality of service provided by the various parts of your Parkinson's service - physiotherapist?

Quality of service – physiotherapist	
Excellent	32.4%
Good	20.9%
Fair	5.0%
Poor	1.4%
Very poor	0.9%
Don't use this service	32.7%
Not sure	6.6%
Number:	5197

Table 159: How would you rate the quality of service provided by the various parts of your Parkinson's service - speech and language therapist?

Quality of service – speech and language therapist	
Excellent	18.4%
Good	13.1%
Fair	3.6%
Poor	1.1%
Very poor	0.8%
Don't use this service	55.8%
Not sure	7.2%
Number:	4982

Table 160: How would you rate the quality of service provided by the various parts of your Parkinson's service - mental health services?

Quality of service – mental health services	
Excellent	6.7%
Good	5.5%
Fair	2.5%
Poor	1.0%
Very poor	0.6%
Don't use this service	74.5%
Not sure	9.1%
Number:	4705

Table 161: Thinking back to when you were diagnosed, do you think you were given enough information about Parkinson's?

Enough information received at diagnosis	
Yes	59.5%
No	24.9%
Not sure	15.6%
Number:	6614

Table 162: When being prescribed new medication, do you feel you are given enough information, including potential side-effects

Enough information provided about new medication*	
Yes	70.5%
No	16.7%
Not sure	12.2%
Number:	6326

*excludes patients who haven't started any medication

Table 163: Does your Parkinson's service give you information about: Parkinson's UK (the charity)

Information provided about Parkinson's UK	
Yes	65.1%
No	23.5%
Not sure	11.3%
Number:	6285

Table 164: Does your Parkinson's service give you information about: The role of social workers and other professionals who support people with Parkinson's?

Information provided about social work	
Yes	40.5%
No	37.7%
Not sure	21.8%
Number:	5804

Table 165: Does your Parkinson's service give you information about: Support for carers?

Information provided about carer support	
Yes	30.6%
No	44.1%
Not sure	25.3%
Number:	5520

Table 166: Does your Parkinson's service give you information about: Keeping active/physical exercise?

Information provided about keeping active	
Yes	74.0%
No	16.0%
Not sure	9.9%
Number:	5920

Table 167: Does your Parkinson's service give you information about: Research (trials, surveys, interviews) if suitable?

Information provided about taking part in research	
Yes	32.9%
No	40.6%
Not sure	26.5%
Number:	5498

Table 168: Have you raised concerns and/or been asked if you have any concerns regarding:

Concerns raised	
Balance and falls	60.2%
Osteoporosis/brittle bones/fracture risk	18.5%
Mood and memory (including dementia)	33.3%
Mood, depression, anxiety	40.3%
Speech, swallowing or salivary (drooling) problems	45.9%
Bladder problems	39.8%
Constipation	44.5%
Sleep	44.4%
Uncontrollable movements (e.g. tremor, dyskinesia)	47.2%

If yes, what was the response?

Table 169: Balance and falls response

Balance and falls response	
Referral to a specialist	41.2%
Advice or medication	64.5%
I feel I wasn't listened to	3.2%
Number:	3589

Table 170: Osteoporosis/brittle bones/fracture risk response

Osteoporosis/fracture risk response	
Referral to a specialist	35.5%
Advice or medication	69.1%
I feel I wasn't listened to	4.0%
Number:	990

Table 171: Memory/cognition issues (including dementia) s response

Memory/cognition issues response	
Referral to a specialist	35.1%
Advice or medication	66.3%
I feel I wasn't listened to	4.3%
Number:	1743

Table 172: Mood, depression, anxiety response

Mood/depression/anxiety response	
Referral to a specialist	24.2%
Advice or medication	76.0%
I feel I wasn't listened to	4.8%
Number:	2158

Table 173: Speech, swallowing or salivary problems response

Speech, swallowing, salivary response	
Referral to a specialist	51.9%
Advice or medication	51.4%
I feel I wasn't listened to	2.7%
Number:	2579

Table 174: Bladder problems response

Bladder problems response	
Referral to a specialist	37.8%
Advice or medication	66.2%
I feel I wasn't listened to	3.2%
Number:	2203

Table 175: Constipation response

Constipation response	
Referral to a specialist	16.0%
Advice or medication	87.0%
I feel I wasn't listened to	1.7%
Number:	2455

Table 176: Sleep response

Sleep response	
Referral to a specialist	13.0%
Advice or medication	86.1%
I feel I wasn't listened to	4.1%
Number:	2327

Table 177: Uncontrollable movements (tremor, dyskinesia) response

Uncontrollable movements response	
Referral to a specialist	26.0%
Advice or medication	79.4%
I feel I wasn't listened to	2.6%
Number:	2736

Table 178: If you currently drive, have you been given verbal and/or written advice by your Parkinson's service about contacting the DVLA and your car insurance company?

Advice given	
Yes	43.7%
No	9.3%
Not sure	2.0%
Not a current driver	45.0%
Number:	6349

Table 179: Have you been admitted to hospital in the last 12 months?

Hospital this year	
Yes	21.2%
No	78.8%
Number:	6647

Table 180: If yes, how often did you receive your Parkinson's medication on time (ie within 30 minutes of the usual time)?

Medication on time	
Always	42.1%
Mostly	28.1%
Sometimes	9.8%
Rarely	6.0%
Never	4.2%
Not sure	9.9%
Number:	1293

Table 181: If you didn't get your Parkinson's medication on time in hospital, to what extent do you think this affected your condition?

Effect experienced	
Significant negative effect	17.3%
Negative effect	22.3%
No effect	14.6%
Positive effect	6.4%
Not sure	39.4%
Number:	658

Table 182: While in hospital, did you want to manage and take your own Parkinson's medication which you brought from home?

Wanted to self-medicate	
Yes	48.0%
No	32.5%
Number:	1268

Table 183: Do you feel your Parkinson's service treats you as an individual, taking into account your own unique concerns and cultural needs (this may include other conditions you have, if relevant)?

Treated as a whole person	
Always	64.7%
Mostly	23.5%
Sometimes	4.4%
Rarely	1.3%
Never	0.8%
Not sure	5.4%
Number:	6375

Table 184: Do you feel your Parkinson's service is improving or getting worse?

Service improving or getting worse	
Improving	24.0%
Staying the same – already good	59.1%
Staying the same – needs to improve	14.5%
Getting worse	2.4%
Number:	6309