

## 2019 UK Parkinson's Audit: complete data tables

The equivalent tables for the previous audit round can be found in the [2017 Reference Report](#).

### 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	
<b>Services</b>	142		124		82		153		79		580	
<b>Patients</b>	3370		2886		958		2099		1022		10335	
<b>Patient characteristics</b>												
<b>Age (years)</b>												
<b>Mean (SD)</b>	77.2 (8.2)		72.0 (9.9)		75.5 (9.0)		73.7 (9.5)		73.7 (9.6)		74.5 (9.4)	
<b>(range)</b>	(20-99)		(33-98)		(31-99)		(29-99)		(34-95)		(20-99)	
<b>Gender</b>												
		%		%		%		%		%		%
<b>Male</b>	2011	59.7	1779	61.6	571	59.6	1318	62.8	686	67.1	6365	61.6
<b>Female</b>	1359	40.3	1105	38.3	386	40.3	781	37.2	336	32.9	3967	38.4
<b>Prefer not to say</b>	0	0	2	0.1	1	0.1	0	0	0	0	3	0
<b>Duration of Parkinson's (years)</b>												
<b>Mean (SD)</b>	5.6 (5.3)		6.0 (5.3)		5.7 (5.7)		5.1 (5.2)		6.6 (6.0)		5.7 (5.4)	
<b>Median</b>	4		5		4		3		5		4	
<b>(range)</b>	(0-34)		(0-55)		(0-46)		(0-33)		(0-36)		(0-55)	
<b>Phase of Parkinson's</b>												
		%		%		%		%		%		%
<b>Diagnosis</b>	351	10.4	236	8.2	133	13.9	280	13.3	75	7.3	1075	10.4
<b>Maintenance</b>	1711	50.8	1437	49.8	466	48.6	1225	58.4	629	61.5	5468	52.9
<b>Complex</b>	1220	36.2	1112	38.5	330	34.4	564	26.9	289	28.3	3515	34.0
<b>Palliative</b>	88	2.6	101	3.5	29	3.0	30	1.4	29	2.8	277	2.7

## Audit findings

### Elderly Care and Neurology

#### Demographics

Table 2: Gender of Elderly Care and Neurology patients

Gender	Elderly Care	Neurology	Elderly Care and Neurology
Male	59.7%	61.6%	60.6%
Female	40.3%	38.3%	39.4%
Other/prefers not to say	0%	0.1%	0%
Number:	3370	2886	6256

Table 3: Patients in each Parkinson's phase

Parkinson's phase	Elderly Care	Neurology	Elderly Care and Neurology
Diagnosis	10.4%	8.2%	9.4%
Maintenance	50.8%	49.8%	50.3%
Complex	36.2%	38.5%	37.3%
Palliative	2.6%	3.5%	3.0%
Number:	3370	2886	6256

Table 4: Ethnicity of Elderly Care and Neurology patients

Ethnicity	Elderly Care	Neurology	Elderly Care and Neurology
White	95.1%	88.4%	92.0%
Asian/Asian British	2.2%	5.9%	3.9%
Black/Black British	0.9%	2.1%	1.5%
Mixed/multiple ethnic background	0%	0.5%	0.2%
Other	1.8%	3.2%	2.4%
Number:	3370	2886	6256

Table 5: Elderly Care and Neurology patients living alone

Patient lives alone	Elderly Care	Neurology	Elderly Care and Neurology
Yes	25.5%	23.7%	24.7%
No	65.9%	71.7%	68.6%
No, at residential home	3.8%	2.3%	3.1%
No, at nursing home	4.8%	2.3%	3.7%
Number:	3370	2886	6256

## Service audit

Table 6: What is the most common model of service provision for medical input in each service?

	<b>Elderly Care</b>	<b>Neurology</b>	<b>Elderly Care and Neurology</b>
Doctor alone	29.6%	33.1%	31.2%
Joint/parallel doctor and nurse specialist clinics	49.3%	53.2%	51.1%
Integrated clinics	21.1%	13.7%	17.7%
Number:	142	124	266

Table 7: Are clinic patients seen within specific Parkinson's/Movement Disorder clinics?

	<b>Elderly Care</b>	<b>Neurology</b>	<b>Elderly Care and Neurology</b>
All patients	65.5%	32.2%	50.0%
Most patients (>75%)	26.1%	30.6%	28.2%
Some patients (25-74%)	7.0%	17.7%	12.0%
Few patients (<25%)	0.7%	3.2%	1.9%
None	0.7%	16.1%	7.9%
Number:	142	124	266

Table 8: Is written information regarding Parkinson's routinely available when patients attend clinic venues?

	<b>Elderly Care</b>	<b>Neurology</b>	<b>Elderly Care and Neurology</b>
All clinics	71.8%	50.8%	62.0%
Most clinics (>75%)	19.0%	30.6%	24.4%
Some clinics	6.3%	12.1%	9.0%
Not routinely available	2.8%	6.5%	4.5%
Number:	142	124	266

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	97.2%	95.2%	96.2%
Physiotherapy	98.6%	97.6%	98.1%
Speech and language therapy	98.6%	96.0%	97.4%
Psychiatry/mental health	88.7%	72.6%	81.2%
Number:	142	124	266

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	31.7%	35.5%	33.5%
No	68.3%	64.4%	66.5%
Number:	142	124	266

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	77.5%	68.5%	73.3%
No	22.5%	31.5%	26.7%
Number:	142	124	266

## Assessments

Table 12: Is formal Activities of Daily Living assessment tool or checklist used when Parkinson's patients are reviewed in this service?

Assessment of ADL conducted	Elderly Care	Neurology	Elderly Care and Neurology
All clinics	33.1%	21.8%	27.8%
Most clinics (>75%)	13.4%	23.4%	18.0%
Some clinics	26.8%	24.2%	25.6%
Not routinely available	26.8%	30.6%	28.6%
Number:	142	124	266

Table 13: Is the Parkinson's non-motor symptoms questionnaire or other form of checklist used to screen for non-motor symptoms when Parkinson's patients are assessed?

<b>Assessment of non-motor symptoms conducted</b>	<b>Elderly Care</b>	<b>Neurology</b>	<b>Elderly Care and Neurology</b>
All clinics	38.7%	33.1%	36.1%
Most clinics (>75%)	23.2%	21.8%	22.6%
Some clinics	25.4%	30.6%	27.8%
Not routinely available	12.7%	14.5%	13.5%
Number:	142	124	166

Table 14: Is a standardised assessment tool routinely available in clinic venues to assess and monitor cognitive function?

<b>Standardised assessment for cognition available</b>	<b>Elderly Care</b>	<b>Neurology</b>	<b>Elderly Care and Neurology</b>
All clinics	67.6%	44.4%	56.8%
Most clinics (>75%)	14.8%	20.2%	17.3%
Some clinics	10.6%	21.0%	15.4%
Not routinely available	7.0%	14.5%	10.5%
Number:	142	124	266

Table 15: Is a standardised assessment tool routinely available in clinic venues to assess mood (anxiety and depression)?

<b>Standardised assessment of mood available</b>	<b>Elderly Care</b>	<b>Neurology</b>	<b>Elderly Care and Neurology</b>
All clinics	45.8%	31.5%	39.1%
Most clinics (>75%)	16.9%	21.8%	19.2%
Some clinics	15.5%	25.8%	20.3%
Not routinely available	21.8%	21.0%	21.4%
Number:	142	124	266

## Consultants

Table 16: 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	91.5%	62.9%	78.2%
No	8.5%	37.1%	21.8%
Number:	142	124	266

## Parkinson's Nurse Specialists

Table 17: Can patients in this service access a Parkinson's Nurse Specialist or equivalent?

	Elderly Care	Neurology	Elderly Care and Neurology
Yes – Parkinson's nurse	94.4%	94.4%	94.4%
Yes – other healthcare professional	2.8%	4.0%	3.4%
No	2.8%	1.6%	2.3%
Number:	142	124	266

Table 18: 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	95.7%	93.4%	94.6%
No	2.2%	6.6%	4.2%
No Parkinson's nurse	2.2%	0%	1.2%
Number:	138	122	260

Table 19: 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	47.8%	36.1%	42.3%
Regular face-to-face contact outside clinic	20.3%	19.7%	20.0%
Regular telephone/email contact with occasional face-to-face contact	23.9%	34.4%	28.8%
Telephone/email contact only	5.8%	9.0%	7.3%
No or rare contact	2.2%	0.8%	1.5%
Number:	138	122	260

## Patient audit

Table 20: Is there evidence of a documented Parkinson's and related medication reconciliation at each patient visit?

Medicines reconciliation	Elderly Care	Neurology	Elderly Care and Neurology
Yes	93.3%	94.7%	93.9%
No	3.0%	2.6%	2.8%
Patient on no medication	3.7%	2.7%	3.3%
Number:	3370	2886	6256

## Specialist review

Table 21: Prior to the current appointment, has the patient been reviewed by a specialist within the last year? (can be doctor or nurse specialist)

Review in last year	Elderly Care	Neurology	Elderly Care and Neurology
Yes	96.2%	95.5%	95.9%
No	3.8%	4.5%	4.1%
Number:	3370	2886	6256

Table 22: 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	64.3%	60.8%	62.7%
6-12 months	32.0%	35.1%	33.4%
More than 1 year	1.8%	2.5%	2.1%
More than 2 years	0.2%	0.6%	0.4%
Never	1.8%	1.0%	1.4%
Number:	3370	2886	6256

### New/recent Parkinson's medication

Table 23: 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	51.8%	54.3%	53.0%
No	10.1%	10.0%	10.1%
Not applicable	38.1%	35.6%	37.0%
Number:	3370	2886	6256

### Specific adverse effect monitoring for patients on Parkinson's medication

Table 24: Evidence of enquiry about excessive daytime sleepiness

Enquiry about excessive daytime sleepiness	Elderly Care	Neurology	Elderly Care and Neurology
Yes	72.5%	71.1%	71.8%
No	27.5%	28.9%	28.2%
Number:	3174	2772	5946

Table 25: 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	70.9%	63.4%	67.2%
No	29.1%	36.6%	32.8%
Number:	781	762	1543



Table 26: Evidence patients taking dopaminergic drugs are monitored re: impulsive/compulsive behaviour

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	61.2%	64.0%	62.5%
No	29.2%	27.1%	28.2%
Not applicable	9.5%	8.9%	9.3%
Number:	3174	2772	5946

Table 27: Evidence patients taking dopamine agonists are monitored re: impulsive/compulsive behaviour

	Elderly Care	Neurology	Elderly Care and Neurology
Yes	27.5%	38.1%	32.4%
No	8.8%	7.8%	8.3%
Not applicable	63.7%	54.1%	59.2%
Number:	3174	2772	5946

### Advance care planning

Table 28: 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	23.4%	19.6%	21.6%
No	76.6%	80.4%	78.4%
Number:	3370	2886	6256

Table 29: 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	25.4%	18.5%	22.3%
No	74.6%	81.5%	77.7%
Number:	3370	2886	6256

Table 30: 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	36.2%	38.0%	36.9%
No	63.8%	62.0%	63.1%
Number:	858	537	1395

### 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 31: 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	90.9%	67.0%	79.9%
Evidence of enquiry/assessment re cognitive status	92.5%	89.6%	91.1%
Evidence of enquiry re hallucinations/psychosis	88.9%	85.7%	87.4%
Evidence of enquiry re mood – including anxiety and depression	86.6%	87.6%	87.1%
Evidence of enquiry re communication difficulties	82.7%	78.1%	80.6%
Evidence of enquiry re problems with swallowing function	88.1%	82.8%	85.7%
Evidence of screening for malnutrition	91.4%	62.7%	78.2%
Evidence of enquiry re problems with saliva	70.0%	62.2%	66.4%
Evidence of enquiry re bowel function	92.3%	88.6%	90.6%
Evidence of enquiry re bladder function	88.0%	85.9%	87.1%
Evidence of enquiry re pain	69.9%	66.0%	68.1%
Evidence of enquiry re sleep quality	92.5%	91.3%	91.9%
Number of patients:	3370	2886	6256

Table 32: Domain 2 – Assessment of motor symptoms and Activities of Daily Living (ADL) during the previous year

<b>Motor symptoms and Activities of Daily Living</b>	<b>Elderly Care</b>	<b>Neurology</b>	<b>Elderly Care and Neurology</b>
Evidence of enquiry re 'On/Off' fluctuations	91.3%	89.8%	90.6%
Evidence of enquiry/assessment re problems with gait	93.5%	90.1%	91.9%
Evidence of enquiry re falls and balance	95.7%	93.2%	94.5%
Evidence fracture risk/osteoporosis considered	51.8%	42.6%	47.6%
Evidence of enquiry re problems with bed mobility	78.3%	68.5%	73.8%
Evidence of enquiry re problems with transfers	87.4%	80.3%	84.2%
Evidence of enquiry/assessment of tremor	95.3%	93.2%	94.3%
Evidence of enquiry re problems with dressing	79.8%	71.2%	75.8%
Evidence of enquiry re problems with hygiene	77.7%	69.7%	74.0%
Evidence of enquiry re difficulty eating and drinking	76.5%	70.9%	73.9%
Evidence of enquiry re domestic activities	75.0%	66.1%	70.9%
Evidence of enquiry re problems with function at work	97.3%	95.0%	96.2%
Number of patients:	3370	2886	6256

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

Table 33: Domain 3 – Education and multidisciplinary involvement during the previous year

<b>Education and multidisciplinary involvement</b>	<b>Elderly Care</b>	<b>Neurology</b>	<b>Elderly Care and Neurology</b>
Evidence of referral/input from Parkinson's nurse	88.3%	94.2%	91.0%
Evidence of physiotherapy referral/assessment/input	90.4%	85.8%	88.3%
Evidence of occupational therapy referral/assessment/input	85.3%	76.0%	81.0%
Evidence of speech and language therapy referral/assessment/input for communication	83.4%	77.2%	80.5%
Evidence of speech and language therapy referral/assessment/input for swallowing	85.0%	78.9%	82.2%
Evidence of social work referral/input	90.1%	83.1%	86.9%
Evidence that patient's and carer's entitlement to financial benefits has been considered and advice given	79.5%	76.0%	77.9%
Evidence that patient and/or carer has been signposted to Parkinson's UK	78.0%	79.3%	78.6%
Evidence of communication with carers about their entitlement to carer assessment and support services	83.3%	80.9%	82.2%
Number of patients:	3370	2886	6256

## Occupational therapy

### Demographics

Table 34: Gender of occupational therapy patients

Gender	Patients
Male	59.6%
Female	40.3%
Other/patient prefers not to say	0.1%
Number:	958

Table 35: Ethnicity of occupational therapy patients

Ethnicity	Patients
White	92.8%
Asian/Asian British	3.9%
Black/Black British	1.4%
Mixed/multiple ethnic background	0.3%
Other	1.7%
Number:	958

Table 36: Phase of Parkinson's on referral to occupational therapy

Parkinson's phase	Patients
Diagnosis	13.9%
Maintenance	48.6%
Complex	34.4%
Palliative	3.0%
Number:	958

Table 37: Settings in which occupational therapy patients live

Home setting	Patients
Own home	93.8%
Residential care home	1.4%
Nursing home	1.8%
Other	3.0%
Number:	958

Table 38: In what setting was the individual seen?

Health setting	Patients
NHS – outpatient	30.8%
NHS – community	26.5%
At home	37.7%
Other	5.0%
Number:	958

## Service audit

Table 39: Describe the setting in which you usually see individuals with Parkinson's?

	Services
Integrated medical and therapy Parkinson's clinic	14.6%
Community rehabilitation service e.g. intermediate care	25.5%
Social services including reablement	1.2%
Outpatient/day hospital	23.2%
Individual's home	26.8%
Other	8.5%
Number:	82

Table 40: Does your service specialise in the treatment of individuals with neurological conditions?

Service specialises in neurological conditions	Services
Yes	58.5%
No	41.5%
Number:	82

Table 41: Does your service specialise in treatment of people with Parkinson's?

Service specialises in Parkinson's treatment	Services
Yes	59.8%
No	40.2%
Number:	82

### ***Occupational therapy professionals***

Table 42: Within your service, can you access Parkinson's related continuing professional development (at least yearly)?

<b>Access to yearly CPD</b>	<b>Services</b>
Yes	90.2%
No	9.8%
Number:	82

Table 43: Are there any documented induction and support strategies for new occupational therapists working with people with Parkinson's?

<b>Induction and support strategies available</b>	<b>Services</b>
Yes, specifically in relation to patients with Parkinson's	40.2%
Yes, as part of more general competencies	32.9%
No	26.8%
Number:	82

Table 44: What support (e.g. education, advice) is available to individual therapists in the service?

<b>Support available</b>	<b>Services</b>
Consult any member of the Parkinson's specialist movement disorder team (MDT) of which they are a member	48.8%
Consult members of a general Neurology/Elderly Care specialist service of which they are a member	13.4%
Doesn't work directly in specialist Parkinson's clinics, but has access to Parkinson's specialist multidisciplinary team/Parkinson's nurse	30.5%
Doesn't work directly in a specialist clinic, but has access to advice from a specialist Neurology or Elderly Care multidisciplinary team	6.1%
No access to more specialist advice	1.2%
Number:	82

### ***Clinical practice***

Table 45: How does your service approach assessment of an individual with Parkinson's?

<b>Approach to assessment</b>	<b>Services</b>
MDT assessment	80.5%
Interview with patients and carers	97.6%
Assessment during group work	22.0%
Functional assessment	93.9%
Standardised assessment	69.5%
Other	13.4%
Number	82

Table 46: How do you usually see your patients with Parkinson's?

<b>How patients seen</b>	<b>Services</b>
Individually	68.3%
Both individually and in groups	31.7%
Number:	82

Table 47: Standardised assessments used

<b>Standardised assessments</b>	<b>Services</b>
Assessment of Motor and Process Skills	11.0%
PRPP Assessment (Perceive, Recall, Plan & Perform Assessment)	2.4%
ACE-111 (Addenbrookes Cognitive Examination 111)	54.9%
MMSE-2 (Mini Mental State Examination – 2)	17.1%
Behavioural Assessment of Dysexecutive Syndrome (BADS)	14.6%
Rivermead Behavioural Memory Test (RBMT)	34.1%
Model of Human Occupation Screening Tool (MOHOST)	4.9%
Other	54.9%
Number	82

Table 48: Outcome measures used

Standardised assessments	Services
Assessment of Motor and Process Skills	8.5%
Canadian Occupational Performance Measure (Law et al 2005)	12.2%
Functional Assessment Measure & Functional Independence Measure (FAM/FIM)	7.3%
Fatigue Impact Scale (FIS) (Whitehead 2009)	23.2%
PRPP Assessment (Perceive, Recall, Plan & Perform Assessment)	2.4%
Parkinson's Disease Questionnaire (PDQ39 or PDQ8)	22.0%
Unified Parkinson's Disease Rating Scale (UPDRS)	4.9%
Non-motor questionnaire	14.6%
ACE-III (Addenbrooke's Cognitive Examination – III)	46.3%
MMSE-2 (Mini Mental State Examination – 2)	13.4%
Mattis Dementia Rating Scale (MDRS)	0%
Behavioural Assessment of Dysexecutive Syndrome (BADS)	13.4%
Rivermead Behavioural Memory Test (RBMT)	29.3%
Scales for Outcomes in Parkinson's Disease – Cognition (SCOPA-COG)	1.2%
Nottingham Extended Activities of Daily Living Assessment (NEADL)	9.8%
Other	46.3%
Number:	82

Table 49: Needs regularly addressed through interventions

	Services
Work roles	62.2%
Family roles	82.9%
Domestic activities of daily living	96.3%
Leisure activities	89.0%
Transfers and mobility	100%
Personal self-care activities such as eating, drinking, washing, dressing	100%
Environmental issues to improve safety and motor function	97.6%
Mental wellbeing including cognition, emotional, neuro-psychiatric problems	93.9%
Management of fatigue	90.2%
Education of condition and self-management	91.5%
Social interaction/social support	89.0%
Other	22.0%
Number:	82



Table 50: Where do you carry out intervention?

Location of interventions	Services
Individual's home	63.4%
Community setting	6.1%
Outpatient/day hospital/centre	26.8%
Hospital	3.7%
Number:	82

## Patient audit

### *Referral*

Table 51: Who made the referral to OT?

Source of referral	Patients
Neurologist	12.0%
Geriatrician	12.5%
Parkinson's Nurse	27.5%
Physiotherapist	12.8%
GP	7.8%
Dietician	0.1%
Social Care Worker	2.4%
Self-referral	5.3%
Other	18.7%
Unknown	0.8%
Number:	958

Table 52: Time from diagnosis and occupational therapy referral to this episode

Duration of Parkinson's	Patients
Less than 1 year	17.6%
1-2 years	15.2%
3-5 years	24.4%
6-10 years	24.8%
11-15 years	10.8%
16-20 years	5.8%
More than 20 years	1.4%
Number	935

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

Referral triggered by medical review	Patients
Yes	57.2%
No	39.2%
Unknown	3.5%
Number:	958

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

	Patients
Work roles	4.2%
Family roles	9.2%
Domestic activities of daily living	33.5%
Leisure activities	18.2%
Transfers and mobility	76.1%
Personal self-care activities such as eating, drinking, washing, dressing	46.9%
Environmental issues to improve safety and motor function	49.0%
Mental wellbeing including cognition, emotional, neuro-psychiatric problems	26.9%
Management of fatigue	19.4%
Other	15.1%

Table 55: Was all the Information essential for occupational therapy assessment and intervention available on referral?

Information available on referral	Patients
Yes, most of it	69.3%
Yes, some of it	24.7%
No	5.9%
Number:	958

Table 56: As an occupational therapist, do you feel that the patient was referred at an appropriate time?

Referral at appropriate time	Patients
Yes	91.1%
No	5.9%
Don't know	2.9%
Number:	958

Table 57: Were reports made back to the referrer/other key people at the conclusion of the intervention period (or interim reports where treatment lasts a longer time)?

Reports made	Patients
Yes	54.5%
No	14.3%
No, but will be at the conclusion of this intervention	31.2%
Number:	958

### **Goals identified**

Table 58: What occupational therapy goals were identified?

Occupational therapy goals	Patients
Self-care	69.4%
Productivity	34.9%
Leisure	30.0%
Other	32.4%

Table 59: Who identified goals?

Who identified goals	Patients
Patient	22.1%
Therapist	7.9%
Family	2.4%
Collaboration	64.2%
Other	3.3%
Number	958

Table 60: End of life care: who identified goals?

End of life care - who identified goals	Patients
Patient	0.4%
Therapist	0.4%
Family	0.7%
Collaboration	3.2%
Not appropriate at this stage	95.2%
Number	958

### ***Intervention strategies used***

Table 61: Interventions used for initiating and maintaining movement

<b>Intervention strategies used</b>	<b>Patients</b>
Promoting occupational performance abilities through trial of intrinsic cueing techniques	30.6%
Promoting functional abilities through trial of extrinsic cueing techniques	34.8%
Promoting functional ability throughout a typical day, taking account of medication	50.4%
Promoting functional ability throughout a typical day taking into account fatigue	54.1%
None of the above treatment strategies applicable	23.5%
Number:	958

Table 62: Interventions used for engagement, motivation, learning and carry-over

<b>Intervention strategies used</b>	<b>Patients</b>
Promoting mental wellbeing	55.8%
Promoting new learning	47.1%
None of the treatment strategies applicable	26.5%
Number:	958

Table 63: Interventions that included assessment of environmental adaptations/assistive technology

<b>Assessment</b>	<b>Patients</b>
Small aids and adaptations	67.7%
Wheelchair and seating	19.4%
Major adaptations	8.5%
Assistive technology	9.2%
Other	8.7%
None of the treatment strategies applicable	17.7%
Number:	958

Table 64: Services to which referrals were made to support community rehabilitation and social support

Referrals made	Patients
Social services OT	13.2%
Social worker/carers	11.7%
Other allied health professionals	35.6%
Respite care	2.2%
Voluntary services	9.7%
Access to work	0.7%
Social prescribing	6.4%
Other	11.6%
None of the treatment strategies applicable	32.3%
Number:	958

Table 65: Advice and guidance provided to support patient's self-management

Information provided	Patients
Work advice and resources	4.9%
Specific ADL techniques	65.8%
Cognitive strategies	31.5%
Fatigue management	39.0%
Relaxation/stress management	23.4%
None of the treatment strategies applicable	16.6%
Number:	958

Table 66: Information and support provided for family and carers

Information provided	Patients
Optimising function	56.3%
Safe moving and handling	49.3%
Support services	30.4%
Managing changes in mood, cognition or behaviour	25.4%
Parkinson's general education	43.3%
Medicines education	18.2%
Other	3.8%
None of the treatment strategies applicable	20.3%
Number:	958

Table 67: Support provided to enable choice and control

Support provided	Patients
Positive attitude/emotional set	49.8%
Developing self awareness/adjustment to limitations	61.0%
Increasing confidence	63.5%
Explore new occupations	12.6%
Other	2.0%
None of the treatment strategies applicable	18.6%
Number:	958

### ***Occupational therapist Band***

Table 68: What band (grade) is the occupational therapist who carried out the initial assessment of this person?

	Patients
Band 4	3.5%
Band 5	10.4%
Band 6	57.5%
Band 7	23.7%
Band 8a	1.1%
Social service grade – junior OT	0.6%
Social service grade – senior OT	0.7%
Other	2.3%
Number:	958

Table 69: Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?

Referred	Services
0–19%	35.4%
20–39%	24.6%
40–59%	16.4%
60–79%	4.5%
80–99%	8.8%
100%	3.1%
Unknown	7.2%
Number:	958

## **Evidence base**

Table 70: Which of the following did the audited therapist use to inform clinical practise or guide intervention?

<b>Type of evidence</b>	<b>Patients</b>
Clinical experience	97.5%
Advice from colleague or supervisor	55.4%
Occupational therapy for people with Parkinson's: best practice guides 2 <sup>nd</sup> edition (2018)	57.6%
Information from Parkinson's UK website	49.8%
National Service Framework for Long term Conditions (2005)	37.1%
NICE – Parkinson's disease: diagnosis and management in primary and secondary care (2017)	49.7%
Published evidence in a peer-reviewed journal	14.7%
Training courses	52.0%
Webinars, social media	10.3%
None	1.1%
Other	5.6%

## Physiotherapy

### Demographics

Table 71: Gender of Physiotherapy patients

Gender	Patients
Male	62.8%
Female	37.2%
Number:	2099

Table 72: Ethnicity of Physiotherapy patients

Ethnicity	Patients
White	91.9%
Asian/Asian British	3.8%
Black/Black British	1.0%
Mixed/multiple ethnic background	0.3%
Other	3.0%
Number:	2099

Table 73: What setting does this client live in?

Home setting	Patients
Own home	95.2%
Residential care home	1.8%
Nursing home	1.1%
Other	2.0%
Number:	2099

Table 74: In what health setting was the patient seen?

Healthcare setting	Patients
NHS – outpatient	56.3%
NHS – community	25.7%
Private clinic	3.8%
At home	12.1%
Other	2.2%
Number:	2099



Table 75: Phase of Parkinson's on referral to physiotherapy

Parkinson's phase	Patients
Diagnosis	13.3%
Maintenance	58.4%
Complex	26.9%
Palliative	1.4%
Number:	2099

## Service Audit

### *Service description*

Table 76: Describe the setting in which you usually see individuals with Parkinson's?

Settings patients seen	Services
Integrated medical and therapy Parkinson's clinic	13.7%
Acute outpatient rehabilitation	17.0%
Community rehabilitation service	47.7%
Other	21.6%
Number:	153

Table 77: 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	70.6%	29.4%
Specialise in treatment of Parkinson's	60.8%	39.2%
Number:	153	153

Table 78: Approximately what percentage of the individuals referred to your service annually have a diagnosis of Parkinson's?

Percentage referred	Services
0–19%	32.7%
20–39%	39.2%
40–59%	19.6%
60–79%	0%
80–100%	8.5%
Number:	153

### *Physiotherapy professionals*

Table 79: Within your service, can you access Parkinson's-related continuous professional development (at least yearly)?

Access to CPD yearly	Services
Yes	91.5%
No	8.5%
Number:	153

Table 80: Are there any documented induction and support strategies for new physiotherapists working with people with Parkinson's?

Induction and support strategies	Services
Yes	57.5%
No	42.5%
Number:	153

Table 81: 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	30.1%
Can consult members of a general neurology/elderly care specialist service of which they are a member	13.1%
Don't work directly in specialist Parkinson's clinics but access to Parkinson's specialist MDT/Parkinson's nurse	48.4%
Don't work directly in a specialist clinic but access to advice from a specialist neurology or elderly care MDT	6.5%
No support available	2.0%
Number:	153

### ***Clinical practice***

Table 82: How does your service offer assessment of a patient with Parkinson's?

Assessment	Services
MDT assessment	62.1%
Physiotherapy assessment	96.7%
Other	24.8%
Number:	153

Table 83: How do you usually see your clients with Parkinson's?

How patients seen	Services
Individually	30.1%
In a group setting	0.7%
Both individually and in groups	54.2%
In either a group or individual setting, but can refer to the other	15.0%
Number:	153

Table 84: If your intervention includes group work, what needs are addressed in these groups?

Needs addressed	Services
Education	68.6%
Exercise	75.8%
No group work	20.9%
Other	16.3%
Number:	153

Table 85: Do you provide information about non-NHS/external services (e.g. Parkinson's UK, leisure centre classes)?

Information provided	Services
Yes	98.7%
No	1.3%
Number:	153

Table 86: What physical self-management advice typically provide for your patients?

Physical self-management advice	Services
High intensity	69.3%
LSVT-BIG	24.8%
Parkinson's wellness and recovery (PWR)	13.1%
Boxing	28.8%
Alexander Technique	7.8%
Tai Chi	43.8%
Other	88.2%
Number:	153

## Patient audit

Table 87: Time between diagnosis and first physiotherapy referral letter

Time between diagnosis and referral	Patients
Less than 1 year	34.8%
1–2 years	27.6%
3–5 years	17.7%
6–10 years	13.5%
11–15 years	5.2%
16–20 years	0.9%
More than 20 years	0.3%
Number:	790

Table 88: Was the referral urgent or routine?

Referral type	Patients
Urgent	9.3%
Routine	90.1%
Unknown	0.6%
Number:	2099

Table 89: Did the referral meet your local standard for time from referral to initial assessment for urgent or routine?

Local standard met	Patients
Yes	60.0%
No	20.3%
No local standard	19.7%
Number:	2099

Table 90: Were reports made back to the referrer/other key people at the conclusion of the intervention period (or in interim reports where treatment lasts a longer time)?

Reports made	Patients
Yes	48.3%
No	13.5%
No but will be done at end of this intervention	38.2%
Number:	2099

Table 91: Do the physiotherapy notes include an action/goal plan?

Action/goal plan included	Patients
Yes	96.6%
No	3.4%
Number:	2099

Table 92: Were Parkinson's-specific outcome measures used in this case?

Outcome measures used	Patients
Yes	78.5%
No	21.5%
Number:	2099

Table 93: Outcome measures used

	Patients
UPDRS	3.9%
MDS-UPDRS	1.2%
Lindop Parkinson's Assessment (LPAS)	30.0%
Berg	31.9%
Six minute walk distance	8.8%
10 metre walk	46.2%
Time Up and Go (TUG)	55.7%
Modified Parkinson's Activity Scale (M-PAS) Gait	1.9%
Modified Parkinson's Activity Scale (M-PAS) Chair	2.8%
Modified Parkinson's Activity Scale (M-PAS) Bed	1.9%
Activities Balance Confidence scale (ABC)	1.7%
Retropulsion Test	4.9%
Push & Release Test	3.7%
Tragus to wall	26.7%
Five times sit to stand test (FTSTS)	15.5%
Dynamic Gait index	4.0%
Functional Gait Assessment	13.3%
New Freezing of Gait questionnaire	4.5%
Rapid turns test	1.2%
History of Falls Questionnaire	9.9%
3-Step Falls Prediction model	3.5%
Goal attainment scaling	8.4%
The Falls Efficacy Scale – International (Short FES-I)	4.4%
Mini BEST	10.6%
EQ-5D tool	6.5%
Patient Specific Index for Parkinson's Disease (PSI-PD)	0.7%
Other	40.5%
Number:	1654

Table 94: Was exercise advice/intervention offered to this individual?

Exercise/intervention offered	Patients
Yes	95.2%
No	4.8%
Number:	2099

Table 95: Exercise/intervention type offered

Exercise/intervention type offered	Patients
High intensity	35.3%
LSVT-BIG	8.0%
Parkinson's wellness and recovery (PWR)	5.1%
Boxing	6.4%
Alexander Technique	1.6%
Tai Chi	8.1%
Other	76.6%
Number:	2099

### ***About the physiotherapist***

Table 96: What NHS band (grade) is the physiotherapist who carried out the initial assessment of this person?

	Patients
Band 4	2.7%
Band 5	6.7%
Band 6	55.1%
Band 7	30.1%
Band 8a	2.9%
Band 8b	0%
Other	2.6%
Number:	2099

Table 97: Approximately what percentage of people seen by the audited physiotherapist in a year have Parkinson's?

	Patients
0-19%	30.3%
20-39%	41.9%
40-59%	16.4%
60-79%	3.7%
80-99%	4.3%
100%	0.9%
Unknown	2.5%
Number:	2099

Table 98: Which of the following did the audited therapist use to inform clinical practice or guide intervention?

Type of evidence	Patients
Clinical experience	98.8%
Advice from colleague or supervisor	48.8%
European Physiotherapy Guideline for Parkinson's Disease (2013)	51.5%
Quick Reference Cards (UK, 2009)	24.5%
Information from Parkinson's UK website	50.2%
NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017)	65.7%
Published evidence in a peer reviewed journal (read within last 12 months)	40.1%
Postgraduate training within last 24 months	52.7%
Other	8.6%
None	1.9%
Number:	2099

## Speech and language therapy

### Demographics

Table 99: Gender of speech and language therapy patients

Gender	Patients
Male	67.1%
Female	32.9%
Number:	1022

Table 100: Ethnicity of speech and language therapy patients

Ethnicity	Patients
White	86.1%
Asian/Asian British	5.1%
Black/Black British	0.9%
Mixed/multiple ethnic background	0.1%
Other	7.8%
Number:	1022

Table 101: Phase of Parkinson's on referral to speech and language therapy

Parkinson's phase	Patients
Diagnosis	7.3%
Maintenance	61.5%
Complex	28.3%
Palliative	2.8%
Number:	1022

Table 102: What setting does this patient live in?

Home setting	Patients
Own home	89.5%
Residential care home	4.4%
Nursing home	4.6%
Other	1.5%
Number:	1022



## Service audit

### Service description

Table 103: Describe the setting in which you usually see individuals with Parkinson's?

	Services
In a specialist clinic for patients with Parkinson's	11.4%
In more general specialist neurology clinics	1.3%
In an elderly/older person's clinic	1.3%
In SLT adult/acquired disorders service mainly based in a hospital	20.3%
In SLT adult/acquired disorders service mainly based in a community clinic	25.3%
In SLT adult/acquired disorders service mainly domiciliary based	29.1%
In generalist SLT service mainly based in a hospital	1.3%
In generalist SLT service mainly based in a community clinic	5.1%
In generalist SLT service mainly domiciliary based	5.1%
Number:	79

Table 104: Does your service specialise in the treatment of individuals with neurological conditions?

Specialising in neurological conditions	Services
Yes	77.2%
No	27.8%
Number:	79

Table 105: Does your service specialise in the treatment of individuals with Parkinson's?

Specialising in Parkinson's	Services
Yes	54.4%
No	45.6%
Number:	79

Table 106: 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	55.7%
Not all eligible candidates able to receive full service	7.6%
Variant(s) of LSVT offered	17.7%
LSVT not offered due to lack of LSVT trained speech and language therapist	6.3%
LSVT not offered due to no service delivery decision	12.7%
Number:	79

Table 107: Are individuals assessed by ENT before LSVT starts?

Assessed by ENT	Services
Yes	49.4%
No – no access to ENT	3.8%
No – service level decision not to refer to ENT before treatment	46.8%
Number:	79

Table 108: 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	98.7%
No	1.3%
Number:	79

Table 109: 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	97.5%
Restricted service	1.3%
No	1.3%
Number:	79

Table 110: 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	93.7%
Restricted service	1.3%
No	5.1%
Number:	79

Table 111: 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	43.0%
Yes, full access via other AAC service	11.4%
Restricted AAC service due to financial restrictions	8.9%
Restricted AAC service due to equipment range	6.3%
AAC service available via specialist technology service if referral criteria met	30.4%
Number:	79

### ***Individuals with Parkinson's***

Table 112: Approximately what percentage of the individuals referred to your service have a diagnosis of Parkinson's?

Percentage referred	Services
0–19%	57.0%
20–39%	24.1%
40–59%	10.1%
60–79%	1.3%
80–100%	7.6%
Number:	79

### ***Speech and language therapy professionals***

Table 113: Within your service, can you access Parkinson's related continuing professional development (at least yearly)?

Access to CPD yearly	Services
Yes	87.3%
No	12.7%
Number:	79

Table 114: 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	19.0%
Yes, as part of more general competencies	50.6%
No	30.4%
Number:	79

Table 115: 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	24.1%
Consult members of a general Neurology/Elderly Care specialist service of which they are a member	6.3%
Doesn't work directly in specialist Parkinson's clinics, but has access to Parkinson's specialist multidisciplinary team/Parkinson's nurse specialist	63.3%
Doesn't work directly in a specialist clinic, but has access to advice from a specialist Neurology or Elderly Care multidisciplinary team	5.1%
Access to motor speech disorder specialist in the speech and language therapy team	1.3%
No support available	0%
Number:	79

Table 116: Are Speech and Language Therapy assistants involved in the delivery of care to individuals with Parkinson's?

Involvement of assistants	Services
Always	6.3%
Sometimes	62.0%
Never	31.6%
Number:	79

### ***Clinical practice***

Table 117: Are there communication measures specifically stipulated to be carried out at initial assessment and each review point?

Measures carried out	Services
Standardised assessments of all speech/voice and language variables	12.7%
Selective range of speech/voice and/or language formal assessments	36.7%
Informal disease-specific assessment proforma	27.8%
No	22.8%
Number:	79

Table 118: Are there swallowing measures specifically stipulated to be carried out at initial assessment and each review point?

Initial swallowing assessment	Services
Standardised assessments of swallowing	11.4%
Selective range of formal assessments	21.5%
Informal disease-specific assessment proforma	32.9%
No	34.2%
Number:	79

Table 119: Is there saliva management included in the speech and language therapy assessment and treatment plan if required

Saliva management	Services
Yes	97.5%
No	2.5%
Number:	79

## Patient audit

Table 120: In what health setting was the patient seen?

Healthcare setting	Patients
NHS – outpatient	46.2%
NHS – community	27.1%
At home	22.4%
Other	4.3%
Number:	1022

## Referral

Table 121: Time between diagnosis and first referral letter to speech and language therapy

	Patients
Less than 1 year	18.4%
1-2 years	27.4%
3-5 years	20.5%
6-10 years	20.2%
11-15 years	8.3%
16-20 years	3.2%
More than 20 years	2.0%
Number:	1020

Table 122: Source of referral

Referral source	Patients
Elderly Care clinic	4.3%
General Neurology clinic	14.2%
Parkinson's nurse specialist	37.2%
General/non-Parkinson's nurse	2.3%
Allied health professions colleague	11.2%
Speech and language therapy colleague	5.4%
Self/relative	3.0%
Other	22.5%
Number:	1022

Table 123: Reason for referral to the audited service

Referral reason	Patients
Speech	70.8%
Language	8.0%
Cognition	2.8%
Swallow	53.5%
Drooling	11.1%
Not specified	2.8%
Number:	1022

Table 124: Is this the first episode of Speech and Language Therapy care for this patient in any Speech and Language Therapy service?

First episode of speech and language therapy care	Patients
Yes	54.3%
No	41.8%
Not known	3.9%
Number:	1022

Table 125: Was the target time from referral to first SLT appointment met for this episode of care?

Target met	Patients
Yes	84.1%
No, and no reason documented	11.9%
No, but reason documented (eg clinician leave)	4.0%
Number:	1022

Table 126: What has been offered in the current episode of care?

Current episode of care	Patients
Initial assessment	29.8%
Review	13.8%
Individual treatment	40.3%
Group treatment	7.0%
Group and individual treatment	9.0%
Number:	1022

## Assessments

Table 127: Was there documentation of on-off phase of assessment?

On/off phase documented	Patients
Yes	31.2%
No	68.8%
Number:	1022

Table 128: Is an assessment of communication recorded at initial assessment?

Communication assessed	Patients
Yes	75.4%
No	4.8%
No, but reasons why assessment was inappropriate documented	5.6%
No, referred for swallow/drooling assessment only	14.2%
Number:	1022

Table 129: Did the communication assessment also include a screening question about swallowing?

Screening question about swallowing in communication assessment	Patients
Yes	88.6%
No	11.4%
Number:	771

Table 130: Was communication reassessed at reviews?

Communication assessment at review	Patients
Yes	68.6%
No reference to assessments documented	1.3%
No, but reasons why assessment was inappropriate documented	4.0%
Initial assessment only	24.1%
No, referred for swallow assessment only	1.9%
Number:	771

Table 131: Is an initial audio or video recording included in the record?

Recording made	Patients
Yes and available	13.1%
Yes, but not available	8.2%
No, Trust or Board governance rules do not permit acquisition or storage of digital data	12.3%
No, equipment not available	13.7%
No, client did not consent	1.0%
No	51.6%
Number:	771

Table 132: Are strengths and needs for communication in current and likely environments documented?

Strengths and needs for communication documented	Patients
Yes	79.6%
No	20.4%
Number:	771

Table 133: Was an assessment of swallowing recorded at initial assessment?

Swallowing assessed	Patients
Yes	59.4%
No, but reasons why assessment was not appropriate documented	14.8%
No reference to assessments documented	0.7%
No, referred for communication assessment only	25.1%
Number:	1022

Table 134: Was swallowing re-assessed at reviews?

Swallowing assessment at review	Patients
Yes	53.4%
No	3.1%
No, but reasons why assessment was inappropriate documented	9.4%
Initial assessment only at this stage	32.6%
No, referred for communication assessment only	1.5%
Number:	607



Table 135: Was drooling assessed?

Assessment of drooling	Patients
Yes – formal published assessment used	2.3%
Yes – informal observation checklist used	3.6%
Yes – clinical observations documented	19.1%
Yes – patient report recorded	18.9%
No, as not reported/observed	48.4%
No	7.6%
Number:	607

Table 136: Is there a clear plan of management based on assessment outcomes?

Plan of management based on assessment outcomes	Patients
All plans detailed in notes	94.9%
Some restricted plans documented	4.8%
No plans documented	0.3%
Number:	1022

### ***Assessment of speech, language and communication subsystems***

Table 137: Which speech subsystems were assessed and documented?

Speech subsystems assessed and documented	Patients
Phonation including voice quality	83.5%
Loudness/amplitude level and variation	94.4%
Prosody including pitch, pitch range and variation	60.7%
Oromotor skills	58.5%
Articulation and speech rate	76.8%
No assessments documented but justification documented	6.6%
No assessments and no justification documented	1.9%
Number:	771

Table 138: What tasks/contents does assessment cover?

Task covered	Patients
Speaking	98.4%
Reading	44.7%
One-to-one context	93.0%
Group context	24.0%
Number:	771

Table 139: Was intelligibility assessed?

<b>Assessment of intelligibility</b>	<b>Patients</b>
Standardised diagnostic intelligibility test completed	14.4%
Informal assessment, non-standardised tool/subsection of other test completed	23.6%
Informal assessment (e.g. rating scale) completed	44.1%
No assessment/results documented but justification given	8.7%
No assessment documented and no justification given	9.2%
Number:	771

Table 140: Is word finding assessed?

<b>Assessment of word finding</b>	<b>Patients</b>
Formal standardised word finding assessment	2.5%
Informal word finding assessment	5.2%
Observations recorded	16.3%
Self report documented but not assessed	16.0%
No	60.1%
Number:	771

Table 141: Was the need for AAC identified and addressed?

<b>Need for AAC identified and addressed</b>	<b>Patients</b>
Yes	10.8%
No	6.7%
Not applicable	82.5%
Number:	771

Table 142: Scope of communication assessment

<b>Communication assessment scope</b>	<b>Patients</b>
Communication participation	83.9%
The impact of Parkinson's on communication	87.4%
The impact of communication changes on partner and/or carer	61.6%
Number:	771

### **Results of assessments**

Table 143: Were assessment results and rationale for management plan discussed with patient and carer?

<b>Results discussed</b>	<b>Patients</b>
Yes	98.2%
No, but justification documented	0.7%
No and no justification documented	1.1%
Number:	1022

Table 144: Was information about communication and/or swallowing provided to patient and carer?

<b>Information provided</b>	<b>Patients</b>
Yes, verbal and written information provided	92.5%
No, but justification documented	2.4%
No and no justification documented	5.1%
Number:	1022

Table 145: Where notes recommend onward referrals (e.g. ENT, video fluoroscopy), have these been made?

<b>Onward referrals</b>	<b>Patients</b>
Yes	29.6%
None and reasons documented	1.3%
None and reasons not documented	0.4%
No onward referrals recommended	68.7%
Number:	1022

Table 146: If a patient is in complex or palliative phase, is there evidence of anticipatory care planning in the last 12 months?

<b>Anticipatory care planning</b>	<b>Patients</b>
Yes	7.6%
No	9.2%
Not in complex or palliative phase	57.9%
Not indicated	25.2%
Number:	1022

## Interventions

Table 147: Interventions offered - communication

Interventions offered - communication	Patients
Pitch (range)	36.3%
Prosody	31.4%
Improvement of vocal loudness	67.5%
Strategies to optimise intelligibility	60.4%
Word finding/language change	11.4%
Patient education/advice	70.5%
Managing patient participation	52.7%
Managing patient impact	52.2%
Managing generalisation outside clinic	52.4%
Carer education/advice	38.1%
Managing career impact	14.4%
Other	6.1%
Not applicable - seen for swallow/drooling only	25.6%
Number:	1022

Table 148: Interventions offered - swallow

Interventions offered - swallow	Patients
Strategies for safer swallowing	52.0%
Fluid and diet modification	38.5%
Positioning	29.2%
Feeding advice for carers	21.5%
Expiratory Muscle Strength Training	1.1%
Information on risks and warning signs	48.2%
Other	8.1%
Not applicable – seen for communication/drooling only	41.8%
Number:	1022

Table 149: Interventions offered - drooling

Interventions offered - drooling	Patients
Strategies to manage saliva	23.3%
Swallow reminder tools	7.2%
Referral on for medication	7.2%
Other	2.7%
Not applicable – seen for communication/drooling only	67.5%
Number:	1022

Table 150: 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	67.7%
No	8.0%
Not applicable as assessment/intervention still in progress	24.3%
Number:	1022

Table 151: Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?

Report contents	Patients
Yes	83.1%
No	16.9%
Number:	693

### ***About the speech and language therapist***

Table 152: What band (grade) is the Speech and Language Therapist who carried out the initial assessment of this person?

	Patients
Band 5	17.1%
Band 6	45.5%
Band 7	30.2%
Band 8a	6.0%
Band 8b	1.2%
Number:	1022

Table 153: Approximately what percentage of people seen by the audit therapist in a year have Parkinson's?

	Patients
0-19%	41.5%
20-39%	33.8%
40-59%	7.3%
60-79%	3.7%
80-99%	2.2%
Unknown	11.5%
Number:	1022

Table 154: Which of the following did the audited therapist use to inform clinical practise or guide intervention?

	<b>Patients</b>
Own clinical experience	99.6%
Advice from colleagues	66.3%
RCSLT Clinical Guidelines (CQ Live)	68.3%
RCSLT Communicating Quality Live	44.9%
2017 NICE Guideline	79.5%
National Service Framework LTNC	43.9%
Published evidence in peer reviewed journal	41.2%
None	1.1%
Other	5.7%
Number:	1022

## Patient Reported Experience Measure (PREM) questionnaire

### *About the patient*

Table 155: Age of people with Parkinson's represented in the PREM

Age	
Under 20	0.1%
20–29	0.1%
30–39	0.2%
40–49	1.1%
50–59	5.8%
60–69	19.3%
70–79	44.8%
80–89	26.6%
Over 90	2.0%
Number:	8190

Table 156: Gender of people with Parkinson's represented in the PREM

Gender	
Male	61.7%
Female	38.0%
Other	0.1%
Prefer not to say	0.1%
Number:	8208

Table 157: Ethnicity of people with Parkinson's represented in the PREM

Ethnicity	
White	94.6%
Asian/Asian British	3.4%
Black/Black British	1.1%
Mixed/multiple ethnic background	0.3%
Other ethnic group/prefer not to say	0.5%
Number:	8068

Table 158: What are your living arrangements?

Living arrangements	
Live with husband/wife/partner	70.1%
Live with family/friends	5.6%
Live on their own	20.8%
Live in care home	2.9%
Other	0.7%
Number:	8173

Table 159: How long ago were you diagnosed?

Parkinson's duration	
Less than 2 years	22.6%
2-10 years	59.5%
11-20 years	14.9%
Over 20 years	3.0%
Number:	8148

Table 160: 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	21.8%
3-5 years	28.0%
Over 5 years	32.0%
Number:	7879

### ***About the patient's Parkinson's service***

Table 161: Do you feel the amount of times you see your Parkinson's specialist doctor or Parkinson's nurse (if you have one) for a review at a face-to-face appointment or by telephone meets your needs?

Meets needs – Parkinson's specialist doctor	
Yes	79.4%
No - less than needed	15.9%
No – more than needed	2.2%
No access	2.5%
Number:	7484



Table 162: Do you feel the amount of times you see your Parkinson’s specialist doctor or Parkinson’s nurse (if you have one) for a review at a face-to-face appointment or by telephone meets your needs?

<b>Meets needs - Parkinson’s nurse</b>	
Yes	80.3%
No - less than needed	12.7%
No – more than needed	2.0%
No access	5.0%
Number:	6936

Table 163: Are you able to access the following services - Parkinson’s Nurse?

<b>Parkinson’s Nurse access</b>	
Yes	88.7%
No – but have tried	3.5%
No – don’t need it	3.0%
Not sure	4.9%
Number:	7905

Table 164: Are you able to access the following services - Occupational Therapist?

<b>Occupational therapy access</b>	
Yes	53.8%
No – but have tried	4.0%
No – don’t need it	26.9%
Not sure	15.3%
Number:	6252

Table 165: Are you able to access the following services - Physiotherapist?

<b>Physiotherapy access</b>	
Yes	66.3%
No – but have tried	4.5%
No – don’t need it	17.1%
Not sure	12.1%
Number:	6585

Table 166: Are you able to access the following services - Speech and Language therapist?

<b>Speech and language therapy access</b>	
Yes	47.8%
No – but have tried	4.1%
No – don't need it	35.3%
Not sure	12.8%
Number:	6225

Table 167: If using any of these services, are you able to contact them between scheduled reviews?

<b>Parkinson's Nurse access between reviews</b>	
Yes	83.7%
No – but have tried	4.0%
No – don't need it	4.4%
Not sure	7.9%
Number:	7677

Table 168: If using any of these services, are you able to contact them between scheduled reviews?

<b>Occupational therapy access between reviews</b>	
Yes	43.9%
No – but have tried	4.2%
No – don't need it	28.9%
Not sure	23.1%
Number:	5433

Table 169: If using any of these services, are you able to contact them between scheduled reviews?

<b>Physiotherapy access between reviews</b>	
Yes	53.7%
No – but have tried	4.4%
No – don't need it	20.1%
Not sure	21.8%
Number:	5764

Table 170: If using any of these services, are you able to contact them between scheduled reviews?

<b>Speech and language therapy access between reviews</b>	
Yes	38.7%
No – but have tried	3.9%
No – don't need it	36.1%
Not sure	21.2%
Number:	5373

Table 171: How would you rate the quality of service provided by the various parts of your Parkinson's service?

<b>Quality of service – specialist doctor</b>	
Excellent	58.2%
Good	30.4%
Fair	5.7%
Poor	1.7%
Very poor	0.5%
Don't use this service	2.0%
Not sure	1.6%
Number:	7710

Table 172: How would you rate the quality of service provided by the various parts of your Parkinson's service?

<b>Quality of service – Parkinson's nurse</b>	
Excellent	62.6%
Good	24.6%
Fair	4.3%
Poor	1.2%
Very poor	0.6%
Don't use this service	4.3%
Not sure	2.4%
Number:	7484

Table 173: How would you rate the quality of service provided by the various parts of your Parkinson's service?

<b>Quality of service – occupational therapist</b>	
Excellent	29.2%
Good	19.9%
Fair	3.9%
Poor	0.9%
Very poor	0.4%
Don't use this service	37.9%
Not sure	7.8%
Number:	5590

Table 174: How would you rate the quality of service provided by the various parts of your Parkinson's service?

<b>Quality of service – physiotherapist</b>	
Excellent	39.2%
Good	22.1%
Fair	3.9%
Poor	1.3%
Very poor	0.6%
Don't use this service	26.1%
Not sure	6.7%
Number:	6004

Table 175: How would you rate the quality of service provided by the various parts of your Parkinson's service?

<b>Quality of service – speech and language therapist</b>	
Excellent	25.2%
Good	16.1%
Fair	3.1%
Poor	0.9%
Very poor	0.5%
Don't use this service	46.4%
Not sure	7.9%
Number:	5550

Table 176: Thinking back to when you were diagnosed, do you think you were given enough information about Parkinson's?

<b>Enough information received at diagnosis</b>	
Yes	60.7%
No	24.3%
Not sure	15.0%
Number:	8080

Table 177: When being prescribed new medication, do you feel you are given enough information, including potential side-effects?

<b>Enough information provided about new medication</b>	
Yes	68.7%
No	18.2%
Not sure	13.1%
Number:	7824

Table 178: Does your Parkinson's service give you information about: How to access Parkinson's UK support services?

<b>Information provided about Parkinson's UK</b>	
Yes	74.4%
No	14.6%
Not sure	11.0%
Number:	7778

Table 179: Does your Parkinson's service give you information about: The role of social workers and other professionals who support people with Parkinson's?

<b>Information provided about social work</b>	
Yes	49.8%
No	28.1%
Not sure	22.1%
Number:	6933

Table 180: Does your Parkinson's service give you information about: Support for carers?

<b>Information provided about carer support</b>	
Yes	38.0%
No	35.5%
Not sure	26.6%
Number:	6563

Table 181: Does your Parkinson's service give you information about: How to take part in clinical trials?

Information provided about taking part in clinical trials	
Yes	27.6%
No	47.2%
Not sure	25.1%
Number:	6703

Table 182: Have you raised concerns and/or been asked if you have any concerns regarding:

Concerns raised	
Balance and falls	76.3%
Mood and memory (including dementia)	55.4%
Mood, depression, anxiety	59.4%
Speech, swallowing or salivary (drooling) problems	63.6%
Bladder problems	57.3%
Your bowels (constipation)	43.4%
Sleep	62.8%
Uncontrollable movements (e.g. tremor, dyskinesia)	63.6%
Number:	8247

Table 183: 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	82.0%
No	15.3%
Not sure	2.7%
Number:	4207

Table 184: Do you feel your Parkinson's service involves you in decisions about your care?

Involved in decisions	
Always	49.1%
Mostly	27.7%
Sometimes	9.3%
Rarely	2.5%
Never	2.4%
Not sure	8.9%
Number:	8005

Table 185: Do you feel listened to by your Parkinson's service?

<b>Feel listened to</b>	
Always	61.2%
Mostly	26.8%
Sometimes	6.3%
Rarely	1.0%
Never	0.8%
Not sure	4.0%
Number:	8051

Table 186: Have you been admitted to hospital in the last 12 months?

<b>Hospital this year</b>	
Yes	23.2%
No	76.8%
Number:	8140

Table 187: If yes, how often did you receive your Parkinson's medication on time?

<b>Medication on time</b>	
Always	47.0%
Mostly	29.6%
Sometimes	11.3%
Rarely	4.6%
Never	2.8%
Not sure	4.9%
Number:	1773

Table 188: If you didn't get your Parkinson's medication on time in hospital, to what extent do you think this affected your condition?

<b>Effect experienced</b>	
Significant negative effect	18.3%
Negative effect	22.7%
No effect	21.5%
Positive effect	3.7%
Not sure	33.8%
Number:	1114

Table 189: While in hospital, did you want to manage and take your own Parkinson's medication which you brought from home?

<b>Wanted to self-medicate</b>	
Yes	57.3%
No	42.7%
Number:	1723

Table 190: Was it possible for you to manage and take your own Parkinson's medication in hospital?

<b>Able to self-medicate</b>	
Yes	36.7%
No	50.1%
Not sure	13.3%
Number:	1734

Table 191: 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)?

<b>Treated as a whole person</b>	
Always	64.1%
Mostly	25.9%
Sometimes	4.7%
Rarely	0.9%
Never	0.6%
Not sure	3.8%
Number:	7798

Table 192: Do you feel your Parkinson's service is improving or getting worse?

<b>Service improving or getting worse</b>	
Improving	27.0%
Staying the same – already good	60.1%
Staying the same – needs to improve	11.2%
Getting worse	1.6%
Number:	7800