

# **2019 UK Parkinson's Audit Speech and language therapy**

**Standards and guidance**

## 2019 UK Parkinson's Audit

### Speech and language therapy

#### **Audit of national standards relating to Parkinson's care, incorporating the Parkinson's NICE guideline and the National Service Framework for Long Term Neurological Conditions quality standards**

#### **Aim**

The aim of the speech and language therapy audit is to establish if speech and language therapy services are providing quality services for people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

#### **Objectives**

1. To evaluate if speech and language therapy services are currently providing assessment and interventions appropriate to the needs of people with Parkinson's, taking into account recommendations made in evidence-based guidelines.
2. To identify areas of good practice and areas for improvement to inform local, regional and UK-wide discussions leading to action plans to improve quality of care.
3. To establish baseline audit data to allow:
  - UK-wide mapping of variations in quality of care
  - local and UK-wide mapping of progress in service provision and patient care through participation in future audit cycles

#### **Background**

The Parkinson's speech and language therapy audit is part of the UK Parkinson's Audit coordinated by Parkinson's UK and led by a steering group of professionals.

This is the fifth round in which speech and language therapists will be able to take part, along with occupational therapists and physiotherapists. Consultants in elderly care and neurology (and their Parkinson's nurses) can participate in the parallel patient management audit. The audit questions for this round of the audit have been refined to reflect feedback from the 2017 audit.

## Standards

Various guidelines published in recent years offer recommendations for speech language therapists in the management of people with Parkinson's. These include in particular the Parkinson's NICE guideline 2017<sup>1</sup>, NICE Quality Standards 2018<sup>2</sup> and sections/quality requirements of the National Service Framework for Long Term Neurological Conditions (NSF LTNC)<sup>3</sup>.

The Royal College of Speech and Language Therapists (RCSLT) has also published guidelines pertinent to Parkinson's in their Clinical Guidelines documents<sup>4</sup> and Communicating Quality (CQ) Live<sup>5</sup>. The Dutch Speech Language Therapy organisation, in conjunction with the wider Parkinson Net organisation, has also published detailed speech and language therapy (SLT) guidelines for Parkinson's<sup>6</sup>.

## Methodology

This audit is open to all speech and language therapy services and individual speech and language therapists that work with people with Parkinson's in the United Kingdom whether hospital or community based, clinic or domiciliary service (excluding acute hospital inpatients).

Standards agreed to be pertinent to speech and language therapy have been transformed into a set of audit standards and statements reviewed by specialist speech and language therapists. The full list of questions is given in Table 1 (Service audit) and Table 2 (Patient audit) at the end of this document.

Please note the importance of logging your participation in this national clinical audit with your Audit Department.

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<sup>1</sup> National Institute of Health and Clinical Excellence. Parkinson's Disease in Adults NG71. (2017) Available at <https://www.nice.org.uk/guidance/ng71>

<sup>2</sup> <https://www.nice.org.uk/guidance/qs164/chapter/Quality-statement-3-Referral-to-physiotherapy-occupational-therapy-or-speech-and-language-therapy>

<sup>3</sup> Department of Health. *National Service Framework for Long Term Neurological Conditions*. (2005) Available at [www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions](http://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions)

<sup>4</sup> Royal College of Speech and Language Therapists/Speechmark. *Royal College of Speech and Language Therapists Clinical Guidelines (Dysarthria)* (2012)

<sup>5</sup> Royal College of Speech and Language Therapists. *Communicating Quality (CQ) Live*. Available at [https://www.rcslt.org/cq\\_live/introduction](https://www.rcslt.org/cq_live/introduction)

<sup>6</sup> H Kalf et al. *Logopedie bij de ziekte van Parkinson (Speech therapy in Parkinson's)*. Lemma (2008). [http://www.parkinsonnet.info/media/14829977/dutch\\_slp\\_guidelines-final.pdf](http://www.parkinsonnet.info/media/14829977/dutch_slp_guidelines-final.pdf)

## Patient sample

The minimum audit sample size is 10 consecutive people with idiopathic Parkinson's referred to a speech and language therapy service and seen during the audit data collection period, which runs from 1 May 2019 to 30 September 2019.

Take account of the need to capture this minimum sample when deciding locally on your start date for collecting a consecutive patient sample. The data collection tool will have the capacity to capture as many consecutive patients as therapists wish to audit.

The inclusion criteria for audited patients are as follows:

- a) Patients who are currently receiving active intervention (including education or counselling) at the start of the audit period.
- b) Those who are seen on a review appointment (irrespective of whether they then go to start another episode of active treatment) during the audit period.
- c) Patients newly referred to your service who undergo full assessment (again irrespective of whether they then proceed to immediate active intervention rather than being placed on review).

## Data collection and entry

Data is entered on an on-line tool; the link is available from [www.parkinsons.org.uk/audit](http://www.parkinsons.org.uk/audit).

- The **service audit** section consists of general questions about your service (and needs to be completed only once by a member of the team familiar with the service set-up and running).
- The **patient audit** section allows you to enter data on individual patients. These include both newly seen people with Parkinson's and follow ups, but each person should only be documented once, even if they attend more than once during this period.

Ideally the person entering data on the tool should not be the person who completed the notes but this may not always be possible. When reviewing someone else's notes, it may be necessary to speak with the clinician or therapist who wrote them.

Appendix A of this document is a version of the patient questions that you can print and use to record data in your clinics if this would be useful.

**Data entry must be completed by 31 October 2019** when the data will be downloaded for analysis.

### **‘No, but...’ answers**

A ‘No, but...’ answer implies there is a pre-determined accepted reason for non-compliance with the standard. The denominator for compliance can then be determined only for those patients where the standard was relevant – ie ‘No, but...’ answers can be removed from calculations of compliance.

## **Confidentiality**

### **Patients**

Please ensure that any information submitted does not include any personally identifiable information about your patients. Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it.<sup>5</sup>

When you complete the patient section of the audit, you will see that there is space for a patient identifier. It is suggested that you use code letters or a number here to help you keep track (for example the patient’s initials or hospital number) – please do not use NHS numbers. It will help if you keep a list of the code words or numbers securely yourself, so that if there is any query about the information you have submitted, you can track back to the original patient.

### **Employers**

The Healthcare Quality Improvement Partnership (HQIP) recommends that services participating in a national clinical audit should be named in the audit reports. The audit reference report will list all participating organisations. It is therefore vital that you inform your clinical audit department about your participation in the audit.

### **Participants**

Individual therapists who participate and submit data will not be named in the audit report.

## **Data security**

The data collection forms, which will be available online for data entry, will be accessed using a username and password chosen by each user. The password will require a minimum length and complexity according to usual online security methods. Please make sure that your username and password are well protected and can’t be accessed by other people. You will be able to indicate that you will work with colleagues on the audit, and you will therefore be able to view entries made by colleagues in your local team. We ask that you comply with your organisation’s Data Protection guidelines at all times.

After the data has been accessed by Parkinson’s UK it will be stored in password-protected files at Parkinson’s UK in accordance with NHS requirements. Within

Parkinson's UK, access to the raw data set is restricted to Kim Davis, Clinical Audit Manager, members of the Clinical Steering Group and Sigita Stankeviciute, the Data and Analytics Adviser.

Raw data will not be accessible in the public domain. Services will be asked to report any discrepancies in the data received by the audit team in a summary sheet before data analysis begins

## **Patient Reported Experience Measure**

All services participating in the audit are encouraged to participate in the Patient Reported Experience Measure (PREM). The PREM takes the form of a short paper questionnaire to be distributed to up to 50 consecutive patients between 1 May and 30 September 2019. These patients do not necessarily have to be those included in the therapy audit.

The questionnaire asks 11 questions about patients' views of their Parkinson's service, and should take only five to 10 minutes to complete. If a carer has accompanied the patient on their clinic visit, they may assist the patient in completion of the form. Patients should feel comfortable and not overlooked while completing their questionnaire.

No identifiable information is collected, and the patient will seal their completed questionnaire in the envelope provided. These envelopes will then need to be collected before the patient leaves the clinic, and all the envelopes will then be returned to the audit team at Parkinson's UK in the large postage-paid envelope provided.

Each service will be provided with the following resources:

- 50 x copies of a paper questionnaire.
- 50 x sealable envelopes.
- 50 x patient information leaflets.
- An A3 laminated poster.
- A large postage-paid envelope for return of sealed envelopes to the audit team.

A minimum of 10 questionnaires will need to be returned for a service's data to be included in the data analysis.

## **How the audit results will be communicated**

The findings of both the clinical audit and the PREM will be presented in the form of a UK-wide summary report and an individual report for each service, benchmarking the results of individual services against the national average for each audit question in their specialty.

The summary report will contain detailed analysis and comments on the data along

with key recommendations for commissioners and clinicians. A reference report will include all the results, and a list of all participating services.

A link to the reports will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The report will also be in the public domain via the Parkinson's UK website.

Data collected during the audit will be used to generate a national picture of service delivery and to compare this with the expectations detailed in national guidance. This data will provide valuable information about priority areas within the existing healthcare provision and will support the development of commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's.

The UK Parkinson's Excellence Network brings together health and social care professionals to transform the care that people with Parkinson's receive across the UK. The Network is there to ensure:

- that everyone affected by Parkinson's has access to high quality Parkinson's services that meet their needs. Their care should be delivered by an expert, integrated, multi-disciplinary team including a consultant, specialist nurse and range of therapists, whose involvement is key to maximising function and maintaining independence
- there are clear pathways to timely, appropriate information, treatments and services from the point of diagnosis, including access to specialist mental health services and the full range of information and support to take control of the condition offered by Parkinson's UK
- services will be involved in continuous quality improvement through audit and engagement of service users in improvement plans

National surveys<sup>7, 8</sup> indicate that SLT provision for people with Parkinson's is highly variable across the country, with potential for improvement in many areas. This audit will allow SLT services to be audited in relation to NICE, NSF LTNC and other key national and international guidelines and enable SLT managers to compare their service with the pattern nationally of all responding SLT services. It will permit colleagues to identify strengths and key areas for development in both overall service organisation (service audit) and in individual case management (patient audit). Repeating the audit in subsequent years will enable services to chart maintenance of strengths and progress in the implementation of action plans.

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<sup>7</sup> Miller N., Noble E., Jones D., Deane K., Gibb C. (2011) 'Survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: patients' and carers' perspectives.' *International Journal of Language and Communication Disorders*. 46 (2):179-188.

<sup>8</sup> Miller N., Deane K., Jones D., Noble E., Gibb C. (2011) 'National survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: therapists' practices.' *International Journal of Language and Communication Disorders*. 46 (2):189-201.

Participating in the PREM will give individual speech and language therapy services direct feedback from their service users about the quality of care, accessibility and general satisfaction.

## **Thank you for your participation in the 2019 National Parkinson's Audit**

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## Speech and language Therapy - Service audit

No.	Question	Data items/ Answer options	Help notes
<b>Your details</b>			
1.1	Name of Lead Therapist	Free text	
1.2	Contact email of Lead Therapist	Free text	
1.3	What is your job description?	<ul style="list-style-type: none"> <li>• Overall SLT (speech-language therapy) service manager</li> <li>• Parkinson's specialist SLT</li> <li>• Specialist SLT who sees patients with Parkinson's</li> <li>• Generalist SLT who sees patients with Parkinson's</li> </ul>	
<b>Service Description</b>			
2.1	Describe the setting in which you usually see individuals with Parkinson's	<ul style="list-style-type: none"> <li>• In a specialist clinic for people with Parkinson's</li> <li>• In more general neurology clinic</li> <li>• In an elderly care/older person's clinic</li> <li>• In SLT adult/acquired disorders service mainly based in a hospital</li> <li>• In SLT adult/acquired disorders service mainly based in a community clinic</li> <li>• In SLT adult/acquired disorders service mainly domiciliary based</li> <li>• In generalist SLT service mainly based in a hospital</li> <li>• In generalist SLT service mainly based in a</li> </ul>	Choose one – the most common setting for the service

		<p>community clinic</p> <ul style="list-style-type: none"> <li>• In generalist SLT service mainly domiciliary based</li> </ul>	
2.2	Does your service specialise in the treatment of individuals with neurological conditions?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	
2.3	Does your service specialise in the treatment of individuals with Parkinson's?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	
2.4	Does your service offer the Lee Silverman Voice Treatment (LSVT) for individuals with Parkinson's who meet inclusion criteria (louder voice stimulable; motivated; physically able to cope with intensity)?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• Not all eligible candidates able to receive full service</li> <li>• Variant(s) of LSVT offered</li> <li>• LSVT not offered because there's no LSVT trained SLT</li> <li>• LSVT not offered because there's no service delivery decision</li> </ul>	
2.5	Are individuals assessed by ENT before LSVT starts?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No – no access to ENT</li> <li>• No – service level decision not to refer to ENT before treatment</li> </ul>	
2.6	Is SLT available for all individuals with Parkinson's for issues with communication irrespective of when in the course of their Parkinson's the referral was made?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• Restricted service</li> <li>• No</li> </ul>	
2.7	Is SLT available for all individuals with Parkinson's for issues with eating/swallowing irrespective of when in the course of their Parkinson's the (re)referral was made?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• Restricted service</li> <li>• No</li> </ul>	

2.8	Is SLT available for all individuals with Parkinson's for issues with drooling irrespective of when in the course of their Parkinson's the (re)referral was made?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• Restricted service</li> <li>• No</li> </ul>	
2.9	Are individuals who require assistive technology (AAC) able to receive timely, appropriate equipment and support to help them to live independently?	<ul style="list-style-type: none"> <li>• Yes, it is part of the service</li> <li>• Yes, full access via other AAC service</li> <li>• Restricted AAC service due to financial restrictions</li> <li>• Restricted AAC service due to equipment range</li> <li>• AAC service available via specialist technology service if referral criteria met</li> <li>• No service</li> </ul>	
<b>Individuals with Parkinson's</b>			
3.1	Approximately what percentage of the individuals referred to your service annually have a diagnosis of Parkinson's?	<ul style="list-style-type: none"> <li>• 0-19%</li> <li>• 20-39%</li> <li>• 40-59%</li> <li>• 60-79%</li> <li>• 80-100%</li> </ul>	
<b>Speech and Language therapy professionals</b>			
4.1	Within your service, can you access Parkinson's related continuing professional development (at least yearly)?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	Training includes in-service within the Trust/similar body/Board/Local Health Board or external courses, RCSLT CENs
4.2	Are there documented induction and support strategies for new SLT therapists working with individuals with Parkinson's?	<ul style="list-style-type: none"> <li>• Yes, specifically in relation to patients with Parkinson's</li> <li>• Yes, as part of more general competencies</li> <li>• No</li> </ul>	

4.3	What support (e.g. education, advice) is available to individual therapists working in the service?	<ul style="list-style-type: none"> <li>• They can consult any member of the Parkinson's specialist MDT as they are a member</li> <li>• They can consult members of a general neurology/elderly care specialist service of which they are a member</li> <li>• They do not work directly in Parkinson's clinics but can readily access a Parkinson's MDT/Parkinson's Nurse Specialist</li> <li>• They do not work directly in a specialist clinic but can readily access advice from a specialist neurology or elderly care MDT</li> <li>• There is access to motor speech disorder specialist colleagues in the SLT team</li> <li>• No support available</li> </ul>	Choose one
4.4	Are SLT assistants involved in the delivery of care to individuals with Parkinson's?	<ul style="list-style-type: none"> <li>• Always</li> <li>• Sometimes</li> <li>• Never</li> </ul>	
<b>Clinical Practice</b>			
5.1	Are there specifically stipulated measures that must be carried out at initial assessment and at each review?		
5.1a	Communication	<ul style="list-style-type: none"> <li>• Standardised assessments of all speech/voice and language variables</li> <li>• Selective range of speech-voice and/or language formal assessments</li> <li>• Disease-specific informal assessment proforma used</li> <li>• No</li> </ul>	

5.1b	Swallowing	<ul style="list-style-type: none"> <li>• Standardised assessments of swallowing</li> <li>• Selective range of formal assessments</li> <li>• Disease specific informal assessment proforma used</li> <li>• No</li> </ul>	
5.1c	Is saliva management included in the SLT assessment and treatment plan if required?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	

## Speech & language therapy - patient audit

No.	Question	Answer options	Help notes
<b>1. Demographics</b>			
1.1	Patient identifier	This can be used by you to identify audited patients	This data will be removed by the data entry tool when you submit your data
1.2	Gender	<ul style="list-style-type: none"> <li>• Male</li> <li>• Female</li> <li>• Other/patient prefers not to say</li> </ul>	
1.3	Ethnicity	<ul style="list-style-type: none"> <li>• White               <ul style="list-style-type: none"> <li>○ British,</li> <li>○ Irish</li> <li>○ Traveller</li> <li>○ Any other White background)</li> </ul> </li> <li>• Asian/Asian British               <ul style="list-style-type: none"> <li>○ Bangladeshi</li> <li>○ Chinese</li> <li>○ Indian</li> <li>○ Pakistani</li> <li>○ Any other Asian background</li> </ul> </li> <li>• Black/Black British               <ul style="list-style-type: none"> <li>○ African</li> <li>○ Caribbean</li> <li>○ any other Black background</li> </ul> </li> <li>• Mixed/multiple ethnic backgrounds               <ul style="list-style-type: none"> <li>○ mixed - White and Black</li> <li>○ mixed White and Asian</li> <li>○ mixed any other background)</li> </ul> </li> </ul>	

		<ul style="list-style-type: none"> <li>• Other <ul style="list-style-type: none"> <li>○ Arab</li> <li>○ Other</li> </ul> </li> <li>• prefer not to say</li> </ul>	
1.4	Year of birth		
1.5	What setting does this patient live in?	<ul style="list-style-type: none"> <li>• Own home</li> <li>• Residential care home</li> <li>• Nursing home</li> <li>• Other (please specify)</li> </ul>	
1.6	In what health setting was the patient seen?	<ul style="list-style-type: none"> <li>• NHS – outpatient</li> <li>• NHS – community</li> <li>• Private clinic</li> <li>• At home</li> <li>• Other (please specify)</li> </ul>	
1.7	Parkinson's phase	<ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Maintenance</li> <li>• Complex</li> <li>• Palliative</li> </ul>	<p><b>Definitions of phases</b></p> <p><b>Diagnosis</b></p> <ul style="list-style-type: none"> <li>• From first recognition of symptoms/sign/problem</li> <li>• Diagnosis not established or accepted.</li> </ul> <p><b>Maintenance</b></p> <ul style="list-style-type: none"> <li>• Established diagnosis of Parkinson's</li> <li>• Reconciled to diagnosis</li> <li>• No drugs or medication 4 or less doses/day</li> <li>• Stable medication for &gt;3/12</li> <li>• Absence of postural instability.</li> </ul> <p><b>Complex</b></p> <ul style="list-style-type: none"> <li>• Drugs – 5 or more doses/day</li> <li>• Any infusion therapy (apomorphine or duodopa)</li> <li>• Dyskinesia</li> </ul>

			<ul style="list-style-type: none"> <li>• Neuro-surgery considered / DBS in situ</li> <li>• Psychiatric manifestations &gt;mild symptoms of depression/anxiety/hallucinations/psychosis</li> <li>• Autonomic problems – hypotension either drug or non-drug induced</li> <li>• Unstable co-morbidities</li> <li>• Frequent changes to medication (&lt;3/12)</li> <li>• Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues).</li> </ul> <p><b>Palliative</b></p> <ul style="list-style-type: none"> <li>• Inability to tolerate adequate dopaminergic therapy</li> <li>• Unsuitable for surgery</li> <li>• Advanced co-morbidity (life threatening or disabling).</li> </ul>
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## 2. Referral

**Standard A: Consider referring people who are in the early stages of Parkinson's disease to a speech and language therapist with experience of Parkinson's disease for assessment, education and advice (NICE 1.7.7)**

2.1	Year of Parkinson's diagnosis		
2.2	Year of individual's first access to SLT input		
2.3	When the person was first referred to any SLT service, at what stage of their Parkinson's were they?	<ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Maintenance</li> <li>• Complex</li> <li>• Palliative</li> <li>• Not known</li> </ul>	
2.4	Referred by for current episode of care:	<ul style="list-style-type: none"> <li>• Elderly care clinic</li> <li>• General neurology clinic</li> </ul>	



		<ul style="list-style-type: none"> <li>• Parkinson's nurse specialist</li> <li>• General/non PDNS nurse</li> <li>• Allied health professions colleague (PT, OT)</li> <li>• SLT colleague</li> <li>• Self/relative</li> <li>• Other (please specify)</li> </ul>	
2.5	Reason for referral to service involved in the current audit	<ul style="list-style-type: none"> <li>• Speech</li> <li>• Language</li> <li>• Cognition</li> <li>• Swallow</li> <li>• Drooling</li> <li>• Not specified</li> </ul>	Tick all that apply
2.6	Is this the first episode of SLT care for this patient in any SLT service?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Not known</li> </ul>	
2.7	Was the target time from referral to first SLT appointment met for this episode of care?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No, and no reason documented</li> <li>• No, but reason documented (e.g. clinician leave)</li> </ul>	
2.8	What has been offered in the current episode of care?	<ul style="list-style-type: none"> <li>• Initial assessment</li> <li>• Review</li> <li>• Individual treatment</li> <li>• Group treatment</li> <li>• Group and individual treatment</li> </ul>	
<b>3. Assessments</b>			
<b>Standard B: It is recommended to make audio or video recordings of spontaneous speech (Dutch Guidelines: R9a, RCSLT Guidelines)</b>			

**Standard C: It is recommended that the speech and language therapist expressly takes note of the individual's "on/off" periods during treatment (Dutch Guidelines:R6, R19b)**

**Standard D: A full profile of each individual's communication skills should be carried out to include at a minimum:**

- **Strengths and needs**
- **Usage in current and likely environments**
- **Partner's own skills and usage**
- **Impact of environment on communication**
- **Identification of helpful or disadvantageous factors in environment**

(RCSLT Guidelines)

**Standard E: Particular consideration should be given to review and management to support the safety and efficiency of swallowing and to minimise the risk of aspiration:**

- **There should be early referral to SLT for assessment, swallowing advice and where indicated further instrumental assessment**
- **Problems associated with eating and swallowing should be managed on a case by case basis**
- **Problems should be anticipated and supportive measures employed to prevent complications where possible**

(RCSLT Guidelines)

3.1	Was there documentation of on-off phase at assessment?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	
3.2	Is an assessment of communication recorded at initial assessment?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• No, but reasons for not appropriate to assess documented</li> <li>• No, referred for swallow/drooling assessment only</li> </ul>	If NO go to question 3.7
3.3	Did the communication assessment also include a screening question	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	

	about swallowing?		
3.4	Was communication reassessed at reviews?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No reference to assessments documented</li> <li>• No, but reasons for not appropriate to assess documented</li> <li>• Initial assessment only</li> <li>• No, referred for swallow assessment only</li> </ul>	
3.5	Is an initial audio or video recording included in the record?	<ul style="list-style-type: none"> <li>• Yes and available</li> <li>• Yes but not available</li> <li>• No, Trust/Board governance rules do not permit acquisition or storage of digital data</li> <li>• No, equipment not available</li> <li>• No, client did not consent</li> <li>• No</li> </ul>	
3.6	Are strengths and needs for communication in current and likely environments documented?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	
3.7	Was an assessment of swallowing recorded at initial assessment?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No, but reasons for not appropriate to assess documented</li> </ul>	If NO go to question 3.10

		<ul style="list-style-type: none"> <li>No reference to assessments documented</li> <li>No, referred for communication assessment only</li> </ul>	
3.8	Was swallowing reassessed at reviews?	<ul style="list-style-type: none"> <li>Yes</li> <li>No</li> <li>No, but reasons for not appropriate to assess documented</li> <li>Initial assessment only</li> <li>No, referred for communication assessment only</li> </ul>	
3.9	Was drooling assessed?	<ul style="list-style-type: none"> <li>Yes - formal published assessment used</li> <li>Yes - informal observation checklist used</li> <li>Yes - clinical observations documented</li> <li>Yes - patient report recorded</li> <li>No, as not reported/ observed</li> <li>No</li> </ul>	
3.10	Is there a clear plan of management based on assessment outcomes?	<ul style="list-style-type: none"> <li>All plans detailed in notes</li> <li>Some restricted plans documented</li> <li>No plans documented</li> </ul>	
<b>Assessment of speech, language and communication subsystems</b>			
<b>Standard F: A perceptual assessment should be made, including respiration, phonation, resonance, articulation, prosody and</b>			

	<p><b>intelligibility, to acquire an accurate profile for analysis (RCSLT Clinical Guidelines)</b></p> <p><b>Standard G: People with Parkinson's should be asked explicitly about difficulties with word finding and conversations (Dutch Guidelines: R11)</b></p> <p><b>Standard H: Consider referring people for alternative and augmentative communication equipment that meets their communication needs as Parkinson's disease progresses and their needs change (NICE R 1.7.9)</b></p>		
3.11	Which speech subsystems were assessed and documented?	<ul style="list-style-type: none"> <li>• Phonation including voice quality</li> <li>• Loudness/amplitude level and variation</li> <li>• Prosody including pitch, pitch range and variation</li> <li>• Oromotor skills</li> <li>• Articulation and speech rate</li> <li>• No assessments documented but justification documented</li> <li>• No assessments and no justification documented</li> </ul>	<p>Tick all that apply</p> <p>Questions 3.11 to 3.16 only to be completed if Q3.2 answered YES</p> <p>If Q3.2 answered NO go to Q3.17</p>
3.12	What tasks/contextes does assessment cover?	<ul style="list-style-type: none"> <li>• Speaking</li> <li>• Reading</li> <li>• One to one context</li> <li>• Group context</li> </ul>	Tick all that apply
3.13	Was intelligibility assessed?	<ul style="list-style-type: none"> <li>• Standardised diagnostic intelligibility test completed</li> <li>• Informal assessment, non-standardised tool/subsection of other test completed</li> <li>• Informal assessment (e.g. rating scale) completed</li> <li>• No assessment/results documented</li> </ul>	

		but justification given <ul style="list-style-type: none"> <li>No assessment documented and no justification given</li> </ul>	
3.14	Is word finding assessed?	<ul style="list-style-type: none"> <li>Formal standardized word finding assessment</li> <li>Informal word finding assessment</li> <li>Observations recorded</li> <li>Self report documented but not assessed</li> <li>No</li> </ul>	Tick one
3.15	Was the need for AAC identified and addressed?	<ul style="list-style-type: none"> <li>Yes</li> <li>No</li> <li>Not applicable</li> </ul>	
3.16	Communication - does assessment cover:	<ul style="list-style-type: none"> <li>communication participation</li> <li>the impact of Parkinson's on communication</li> <li>the impact of communication changes on partner and/or carer</li> </ul>	Tick all that apply
<b>Results of assessment</b>			
3.17	Were assessment results and rationale for management plan discussed with patient and carer?	<ul style="list-style-type: none"> <li>Yes</li> <li>No, but justification documented</li> <li>No and no justification</li> </ul>	
3.18	Was information about communication and/or swallowing provided to patient and carer?	<ul style="list-style-type: none"> <li>Yes, verbal and written information provided</li> <li>No, but justification documented</li> <li>No and no justification</li> </ul>	
3.19	Where notes recommend onward referrals (e.g. ENT,	<ul style="list-style-type: none"> <li>Yes</li> <li>None and reasons documented</li> <li>None and reasons not documented</li> </ul>	

	video fluoroscopy), have these been made?	<ul style="list-style-type: none"> <li>No onward referrals recommended</li> </ul>	
3.20	If a patient is in complex or palliative phase, is there evidence of anticipatory care planning in the last 12 months?	<ul style="list-style-type: none"> <li>Yes</li> <li>No</li> <li>Not in complex or palliative phase</li> <li>Not indicated</li> </ul>	
<b>4. Interventions</b>			
<p><b>Standard I: Speech and language therapy should be offered to people experiencing communication problems and should include strategies to improve speech and communication, such as attention to effort therapies (NICE: R1.7.8)</b></p> <p><b>Standard J: Offer speech and language therapy for people with Parkinson's disease who are experiencing problems with swallowing or saliva. This should include: strategies to improve the safety and efficiency of swallowing to minimise the risk of aspiration, such as expiratory muscle strength training (EMST) (NICE R1.7.8)</b></p> <p><b>Standard K: Speech and language therapists should report back to the referrer at the conclusion of an intervention period. Reports should detail intervention, duration, frequency, effects and expected prognosis (Dutch Guidelines: R2b)</b></p>			
4.1	Communication – which of the following interventions were offered?	<ul style="list-style-type: none"> <li>Pitch (range)</li> <li>Prosody</li> <li>Improvement of vocal loudness</li> <li>Strategies to optimise intelligibility</li> <li>Word finding/language change</li> <li>Patient education/advice</li> <li>Managing patient participation</li> <li>Managing patient impact</li> <li>Managing generalisation outside clinic</li> <li>Carer education/advice</li> <li>Managing career impact</li> <li>Other</li> <li>Not applicable – seen for swallowing/drooling only</li> </ul>	Tick all that apply

4.2	Swallow – which of the following interventions were offered:	<ul style="list-style-type: none"> <li>• Strategies for safer swallowing</li> <li>• Fluid and diet modification</li> <li>• Positioning</li> <li>• Feeding advice for carers</li> <li>• Expiratory Muscle Strength Training</li> <li>• Information on risks and warning signs</li> <li>• Other (please describe)</li> <li>• Not applicable – seen for communication/drooling only</li> </ul>	Tick all that apply
4.3	Drooling – which of the following interventions were offered:	<ul style="list-style-type: none"> <li>• Strategies to manage saliva</li> <li>• Swallow reminder tools</li> <li>• Referral on for medication</li> <li>• Other (please describe)</li> <li>• Not applicable – seen for communication/swallowing only</li> </ul>	Tick all that apply
4.4	Were reports made back to the referrer/other key people at the conclusion of an intervention period (or when treatment lasts a longer time there are interim reports)?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Not applicable as assessment/intervention still in progress</li> </ul>	
4.4a	Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	
<b>5. About the Speech and Language Therapist</b>			
5.1	What band (grade) is the speech and language	<ul style="list-style-type: none"> <li>• 4</li> <li>• 5</li> </ul>	



	therapist who carried out the initial assessment of this person?	<ul style="list-style-type: none"> <li>• 6</li> <li>• 7</li> <li>• 8a</li> <li>• 8b</li> <li>• 8c</li> </ul>	
5.2	Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?	<ul style="list-style-type: none"> <li>• 0-19%</li> <li>• 20-39%</li> <li>• 40-59%</li> <li>• 60-79%</li> <li>• 80-99%</li> <li>• 100%</li> <li>• Unknown</li> </ul>	The individual who is seeing the person for this episode of care
<b>6. Evidence base</b>			
6.1	Which of the following did the audited therapist use to inform clinical practice or guide intervention?	<ul style="list-style-type: none"> <li>• Own clinical experience</li> <li>• Advice from colleagues</li> <li>• RCSLT Clinical Guidelines (CQ Live)</li> <li>• RCSLT Communicating Quality Live</li> <li>• 2017 NICE Guideline: Parkinson's disease: Diagnosis and management in primary and secondary care and other relevant NICE guidelines</li> <li>• National Service Framework for Long Term Neurological Conditions (NSF – LTNC) guidelines</li> <li>• Published evidence in a peer reviewed journal</li> <li>• None</li> <li>• Other (please specify)</li> </ul>	Tick all that apply

## Appendix A: Printable Patient Audit sheet

1. Demographics		
1.1	Patient identifier	
1.2	Gender	<ul style="list-style-type: none"> <li>• Male</li> <li>• Female</li> <li>• Other/patient prefers not to say</li> </ul>
1.3	Ethnicity	<ul style="list-style-type: none"> <li>• White               <ul style="list-style-type: none"> <li>○ British,</li> <li>○ Irish</li> <li>○ Traveller</li> <li>○ Any other White background)</li> </ul> </li> <li>• Asian/Asian British               <ul style="list-style-type: none"> <li>○ Bangladeshi</li> <li>○ Chinese</li> <li>○ Indian</li> <li>○ Pakistani</li> <li>○ Any other Asian background</li> </ul> </li> <li>• Black/Black British               <ul style="list-style-type: none"> <li>○ African</li> <li>○ Caribbean</li> <li>○ any other Black background</li> </ul> </li> <li>• Mixed/multiple ethnic backgrounds               <ul style="list-style-type: none"> <li>○ mixed - White and Black</li> <li>○ mixed White and Asian</li> <li>○ mixed any other background)</li> </ul> </li> <li>• Other               <ul style="list-style-type: none"> <li>○ Arab</li> <li>○ Other</li> </ul> </li> <li>• prefer not to say</li> </ul>
1.4	Year of birth	
1.5	What setting does this patient live in?	<ul style="list-style-type: none"> <li>• Own home</li> <li>• Residential care home</li> <li>• Nursing home</li> <li>• Other (please specify)</li> </ul>
1.6	In what health setting was the patient seen?	<ul style="list-style-type: none"> <li>• NHS – outpatient</li> <li>• NHS – community</li> <li>• Private clinic</li> <li>• At home</li> <li>• Other (please specify)</li> </ul>
1.7	Parkinson's phase	<ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Maintenance</li> </ul>

		<ul style="list-style-type: none"> <li>• Complex</li> <li>• Palliative</li> </ul>
<b>2. Referral</b>		
2.1	Year of Parkinson's diagnosis	
2.2	Year of individual's first access to SLT input	
2.3	When the person was first referred to any SLT service, at what stage of their Parkinson's were they?	<ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Maintenance</li> <li>• Complex</li> <li>• Palliative</li> <li>• Not known</li> </ul>
2.4	Referred by for current episode of care:	<ul style="list-style-type: none"> <li>• Elderly care clinic</li> <li>• General neurology clinic</li> <li>• Parkinson's nurse specialist</li> <li>• General/non PDNS nurse</li> <li>• Allied health professions colleague (PT, OT)</li> <li>• SLT colleague</li> <li>• Self/relative</li> <li>• Other (please specify)</li> </ul>
2.5	Reason for referral to service involved in the current audit  Tick all that apply	<ul style="list-style-type: none"> <li>• Speech</li> <li>• Language</li> <li>• Cognition</li> <li>• Swallow</li> <li>• Drooling</li> <li>• Not specified</li> </ul>
2.6	Is this the first episode of SLT care for this patient in any SLT service?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Not known</li> </ul>
2.7	Was the target time from referral to first SLT appointment met for this episode of care?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No, and no reason documented</li> <li>• No, but reason documented (e.g. clinician leave)</li> </ul>
2.8	What has been offered in the current episode of care?	<ul style="list-style-type: none"> <li>• Initial assessment</li> <li>• Review</li> <li>• Individual treatment</li> <li>• Group treatment</li> <li>• Group and individual treatment</li> </ul>
<b>3. Assessments</b>		
3.1	Was there documentation of on-off phase at assessment?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>

3.2	Is an assessment of communication recorded at initial assessment?  <b>If no, go to Q3.7</b>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• No, but reasons for not appropriate to assess documented</li> <li>• No, referred for swallow/drooling assessment only</li> </ul>
3.3	Did the communication assessment also include a screening question about swallowing?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
3.4	Was communication reassessed at reviews?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No reference to assessments documented</li> <li>• No, but reasons for not appropriate to assess documented</li> <li>• Initial assessment only</li> <li>• No, referred for swallow assessment only</li> </ul>
3.5	Is an initial audio or video recording included in the record?	<ul style="list-style-type: none"> <li>• Yes and available</li> <li>• Yes but not available</li> <li>• No, Trust/Board governance rules do not permit acquisition or storage of digital data</li> <li>• No, equipment not available</li> <li>• No, client did not consent</li> <li>• No</li> </ul>
3.6	Are strengths and needs for communication in current and likely environments documented?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
3.7	Was an assessment of swallowing recorded at initial assessment?  <b>If yes, answer questions 3.8 to 3.10</b>  <b>If no, go to question 3.10</b>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No, but reasons for not appropriate to assess documented</li> <li>• No reference to assessments documented</li> <li>• No, referred for communication assessment only</li> </ul>
3.8	Was swallowing reassessed at reviews?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• No, but reasons for not appropriate to assess documented</li> <li>• Initial assessment only</li> <li>• No, referred for communication assessment only</li> </ul>

3.9	Was drooling assessed?	<ul style="list-style-type: none"> <li>• Yes - formal published assessment used</li> <li>• Yes - informal observation checklist used</li> <li>• Yes - clinical observations documented</li> <li>• Yes - patient report recorded</li> <li>• No, as not reported/ observed</li> <li>• No</li> </ul>
3.10	Is there a clear plan of management based on assessment outcomes?	<ul style="list-style-type: none"> <li>• All plans detailed in notes</li> <li>• Some restricted plans documented</li> <li>• No plans documented</li> </ul>
3.11	Which speech subsystems were assessed and documented?  Tick all that apply	<ul style="list-style-type: none"> <li>• Phonation including voice quality</li> <li>• Loudness/amplitude level and variation</li> <li>• Prosody including pitch, pitch range and variation</li> <li>• Oromotor skills</li> <li>• Articulation and speech rate</li> <li>• No assessments documented but justification documented</li> <li>• No assessments and no justification documented</li> </ul>
<p><b>Questions 3.12 to 3.16 only to be completed if Q3.2 answered 'yes'</b>  <b>If questions 3.2 answered 'no' go to question 3.17</b></p>		
3.12	What tasks/contexts does assessment cover?  Tick all that apply	<ul style="list-style-type: none"> <li>• Speaking</li> <li>• Reading</li> <li>• One to one context</li> <li>• Group context</li> </ul>
3.13	Was intelligibility assessed?	<ul style="list-style-type: none"> <li>• Standardised diagnostic intelligibility test completed</li> <li>• Informal assessment, non-standardised tool/subsection of other test completed</li> <li>• Informal assessment (e.g. rating scale) completed</li> <li>• No assessment/results documented but justification given</li> <li>• No assessment documented and no justification given</li> </ul>
3.14	Is word finding assessed?  Tick one	<ul style="list-style-type: none"> <li>• Formal standardized word finding assessment</li> <li>• Informal word finding assessment</li> <li>• Observations recorded</li> <li>• Self report documented but not assessed</li> <li>• No</li> </ul>
3.15	Was the need for AAC identified and addressed?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Not applicable</li> </ul>
3.16	Communication - does assessment cover:  Tick all that apply	<ul style="list-style-type: none"> <li>• communication participation</li> <li>• the impact of Parkinson's on communication</li> <li>• the impact of communication changes on partner and/or carer</li> </ul>

<b>Results of assessment</b>		
3.17	Were assessment results and rationale for management plan discussed with patient and carer?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No, but justification documented</li> <li>• No and no justification</li> </ul>
3.18	Was information about communication and/or swallowing provided to patient and carer?	<ul style="list-style-type: none"> <li>• Yes, verbal and written information provided</li> <li>• No, but justification documented</li> <li>• No and no justification</li> </ul>
3.19	Where notes recommend onward referrals (e.g. ENT, video fluoroscopy), have these been made?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• None and reasons documented</li> <li>• None and reasons not documented</li> <li>• No onward referrals recommended</li> </ul>
3.20	If a patient is in complex or palliative phase, is there evidence of anticipatory care planning in the last 12 months?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Not in complex or palliative phase</li> <li>• Not indicated</li> </ul>
<b>4. Interventions</b>		
4.1	<p>Communication – which of the following interventions were offered?</p> <p>Tick all that apply</p>	<ul style="list-style-type: none"> <li>• Pitch (range)</li> <li>• Prosody</li> <li>• Improvement of vocal loudness</li> <li>• Strategies to optimise intelligibility</li> <li>• Word finding/language change</li> <li>• Patient education/advice</li> <li>• Managing patient participation</li> <li>• Managing patient impact</li> <li>• Managing generalisation outside clinic</li> <li>• Carer education/advice</li> <li>• Managing carer impact</li> <li>• Other</li> <li>• Not applicable – seen for swallowing/drooling only</li> </ul>
4.2	<p>Swallow – which of the following interventions were offered:</p> <p>Tick all that apply</p>	<ul style="list-style-type: none"> <li>• Strategies for safer swallowing</li> <li>• Fluid and diet modification</li> <li>• Positioning</li> <li>• Feeding advice for carers</li> <li>• Expiratory Muscle Strength Training</li> <li>• Information on risks and warning signs</li> <li>• Other (please describe)</li> <li>• Not applicable – seen for communication/drooling only</li> </ul>

4.3	<p>Droling – which of the following interventions were offered:</p> <p>Tick all that apply</p>	<ul style="list-style-type: none"> <li>• Strategies to manage saliva</li> <li>• Swallow reminder tools</li> <li>• Referral on for medication</li> <li>• Other (please describe)</li> <li>• Not applicable – seen for communication/swallowing only</li> </ul>
4.4	<p>Were reports made back to the referrer/other key people at the conclusion of an intervention period (or when treatment lasts a longer time there are interim reports)?</p>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Not applicable as assessment/intervention still in progress</li> </ul>
4.4a	<p>Did reports detail the intervention, duration, frequency, effects and expected prognosis and provide results from (re)assessments?</p>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>
<b>5. About the Speech and Language Therapist</b>		
5.1	<p>What band (grade) is the speech and language therapist who carried out the initial assessment of this person?</p>	<ul style="list-style-type: none"> <li>• 4</li> <li>• 5</li> <li>• 6</li> <li>• 7</li> <li>• 8a</li> <li>• 8b</li> <li>• 8c</li> </ul>
5.2	<p>Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?</p> <p>i.e. the individual who is seeing the person for this episode of care</p>	<ul style="list-style-type: none"> <li>• 0-19%</li> <li>• 20-39%</li> <li>• 40-59%</li> <li>• 60-79%</li> <li>• 80-99%</li> <li>• 100%</li> <li>• Unknown</li> </ul>
<b>6. Evidence base</b>		
6.1	<p>Which of the following did the audited therapist use to inform clinical practice or guide intervention?</p> <p>Tick all that apply</p>	<ul style="list-style-type: none"> <li>• Own clinical experience</li> <li>• Advice from colleagues</li> <li>• RCSLT Clinical Guidelines (CQ Live)</li> <li>• RCSLT Communicating Quality Live</li> <li>• 2017 NICE Guideline: Parkinson's disease: Diagnosis and management in primary and secondary care and other relevant NICE guidelines</li> <li>• National Service Framework for Long Term Neurological Conditions (NSF – LTNC) guidelines</li> </ul>

		<ul style="list-style-type: none"><li>• Published evidence in a peer reviewed journal</li><li>• None</li><li>• Other (please specify)</li></ul>
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