Dysphagia in people with Parkinson's Disease: Clinician questionnaire

A. INTRODUCTION

What is this study about:
The aim of this study is to examine the pathway of care of patients with Parkinson's Disease (PD) who are admitted to hospital when unwell. In particular, to identify and explore multidisciplinary care and review organisational factors in the process of identifying, screening, assessing, treating and monitoring the ability to swallow.

Inclusions
Data will be collected on patients aged 16 and older admitted to hospital with an ICD10 code for Parkinson's Disease over a 8 week period, from Monday 7th January (00:00) – Sunday 3rd March (23:59) 2019.

Exclusions
The following patients are not be included in this study:
• Patients admitted as a day case
• Patients who are admitted to level 3 critical care
• Patients admitted to independent hospitals

Sampling
Eligible cases were identified from the hospital central record system (using ICD10 codes). Up to 4 cases per hospital have been selected for review.

Who should complete this questionnaire?
This questionnaire should be completed by the consultant responsible for the patient at the time of the hospital admission.

Please do not include any patient identifiers in the free text boxes.

Questions or help:
A list of definitions can be found here:
https://www.ncepod.org.uk/pdf/current/Dysphagia/Definitionsforwebsite.pdf

If you have any queries about this study or this questionnaire, please contact: dysphagia@ncepod.org.uk or telephone 020 7251 9060.

CPD accreditation:
Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

About NCEPOD
The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Scotland, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD
Recommendations from NCEPOD reports have had an impact on many areas of healthcare including:

Development of the NICE 'Acutely ill patients in hospital guideline' (CG50) – following publication of the 2005 NCEPOD 'An Acute Problem' report.
Appointment of a National Clinical Director for Trauma Care – following publication of 'Trauma: Who Cares?' 2007.
Development of NICE Clinical Guidelines for Acute Kidney Injury, published 2013 – 'Adding Insult to Injury'

2009.
Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 – ‘On the right trach?’ 2014.
Development of guidelines from the British Society of Gastroenterology: diagnosis and management of acute lower gastrointestinal bleeding, published 2019 – ‘Time to Get Control’ 2015.
Development of the British Thoracic Society’s Quality Standards for NIV, published 2018 – ‘Inspiring Change’ 2017.

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical & Surgical care.

B. PATIENT DETAILS

1. Age

Years ☐ Unknown

2. Sex:

○ Male ○ Female ○ Other ○ Unknown

3. Mode of admission type:

○ Elective ○ Emergency ○ Unknown

C. ADMISSION DETAILS

1a. Please specify the date of admission

☐ Unknown

1b. Please specify the time of admission

☐ Unknown

2a. Where was the patient admitted from?

- ◯ Home
- ◯ Another hospital
- ◯ Residential care home
- ◯ Nursing home
- ◯ Hospice
- ◯ Unknown

If not listed above, please specify here...

2b. Which type of ward was the patient first admitted to?

If admitted via the Emergency Department, please specify the first ward admitted to after the ED

- ◯ Medical assessment unit
- ◯ Surgical assessment unit
- ◯ Medical ward
- ◯ Surgical ward
- ◯ Level 2 care
- ◯ Unknown

If not listed above, please specify here...

3. Under which specialty was the patient admitted?

- ◯ General surgery
- ◯ Urology
- ◯ Trauma & orthopaedics
- ◯ Otorhinolaryngology
- ◯ Ophthalmology
- ◯ Oral surgery
- ◯ Neurosurgery
- ◯ Plastic surgery
- ◯ Cardiothoracic surgery
- ◯ Emergency medicine
- ◯ Anaesthetics
- ◯ Critical care medicine
- ◯ General medicine
- ◯ Gastroenterology
- ◯ Endocrinology
- ◯ Clinical haematology
- ◯ Rehabilitation
- ◯ Palliative medicine
- ◯ Cardiology
- ◯ Acute internal medicine
- ◯ Respiratory medicine
- ◯ Nephrology
- ◯ Neurology
- ◯ Geriatric medicine
- ◯ Obstetrics and gynaecology
- ◯ Clinical oncology
- ◯ Radiology
- ◯ Haematology
- ◯ Unknown

If not listed above, please specify here...

4. What was the presenting complaint? (Please specify)

5a. Please specify the approximate time since diagnosis of Parkinson's Disease:
To the nearest 6 months

Years ☐ Unknown

5b. At the time of admission, what was the Hoehn and Yahr score?
Please see definitions: https://www.ncepod.org.uk/pdf/current/Dysphagia/Definitionsforwebsite.pdf

◯ Stage 1 ◯ Stage 2 ◯ Stage 3 ◯ Stage 4
◯ Stage 5 ◯ Unknown

5c. At the time of admission, what was the Unified Parkinson's Disease Rating Scale (UPDRS-MDS) score?
Please see definitions: https://www.ncepod.org.uk/pdf/current/Dysphagia/Definitionsforwebsite.pdf

Score ☐ Unknown
Value should be no more than 199

5d. At the time of admission, what stage of care was the patient in
Please see definitions: https://www.ncepod.org.uk/pdf/current/Dysphagia/Definitionsforwebsite.pdf

◯ Diagnosis ◯ Maintenance ◯ Complex ◯ End stage
◯ Unknown

6a. Did the patient have any additional comorbidities?

◯ Yes ◯ No ◯ Unknown

6b. If answered "Yes" to [6a] then:
Please specify: (please tick all that apply)

☐ Myocardial infarction
☐ Dementia
☐ Connective tissue disease
☐ Peptic ulcer disease
☐ Hemiplegia
☐ Liver disease
☐ Lymphoma
☐ (Other) Metastatic solid tumour
☐ Any diabetes with end organ damage
☐ Chronic pulmonary disease
☐ Congestive heart failure
☐ Cerebrovascular disease
☐ Gastro-oesophageal reflux disease (GORD)
☐ Renal disease
☐ Head & neck cancer
☐ (Other) Tumour without metastasis
☐ Any diabetes without end organ damage
☐ Unknown

Please specify any additional options here...

7a. Was surgery that required general or regional anaesthesia, or sedation, undertaken during this admission?

◯ Yes ◯ No ◯ Unknown

7b. If answered "Yes" to [7a] then:
Please specify the operation undertaken:

8. Did the patient have a history of aspiration pneumonia prior to this admission?

◯ Yes ◯ No ◯ Unknown

D. INITIAL CLERKING ON ADMISSION

1a. Did the patient arrive in hospital with a referral letter?

◯ Yes ◯ No ◯ Unknown ◯ Not applicable

1b. If answered "Yes" to [1a] then:
Who made the referral?

◯ GP referral
◯ Referred from outpatient clinic
◯ Unknown

If not listed above, please specify here...

1c. If answered "Yes" to [1a] then:
Did the referral letter include details of

☐ The medical case history
☐ Comorbidities
☐ Current medications
☐ Assessment of the PD
☐ Details of tube feeding
☐ Level of risk in the community
☐ Details of any action plan for care in the community
☐ Details of advanced decision planning
☐ Unknown

Please specify any additional options here...

2. Was an assessment made on admission of: (Please tick all that apply)

☐ How the patient was managing at home?
☐ Whether the patient had symptoms of dysphagia on admission?
☐ Whether the patient had difficulty with speech/communication?
☐ Whether the patient had difficulty with controlling saliva?
☐ Medication history and compliance?
☐ Any side effects associated with medications?
☐ Whether the patient was eating and drinking a normal diet prior to admission?
☐ Whether the patient was admitted with dehydration?
☐ Mental capacity
☐ None of the above
☐ Unknown

3. How was hydration status assessed on admission? (Please tick all that apply)

☐ Fluid balance ☐ Urine output ☐ Not documented ☐ Unknown

Please specify any additional options here...

4. Was there any history of choking?

◯ Yes ◯ No ◯ Unknown

5. Was the patient's cognition assessed on admission?

◯ Yes ◯ No ◯ Unknown

6. Was the patient assessed for hallucinations, dementia or depression on admission?

◯ Yes ◯ No ◯ Unknown

7. Was a mental health history taken on admission?

◯ Yes ◯ No ◯ Unknown

8. If admitted via the emergency department or an acute admission unit, did the patient miss any doses of medication?

◯ Yes
◯ No
◯ Unknown
◯ Not applicable - not admitted via ED/admission unit

9. On admission, how was the medication history verified? (Please tick all that apply)

☐ Family member/carer ☐ Blister pack ☐ GP referral letter ☐ Hospital pharmacist
☐ Hospital pharmacist ☐ Unknown

Please specify any additional options here...

10. If any medications were not given, please specify why not: (Please specify)

E. ASSESSMENT OF SWALLOWING

1a. Were there any indicators of dysphagia present on admission?

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
Which of the following indicators of dysphagia present on admission? (Please tick all that apply)

- ☐ Difficult, slow chewing or swallowing
- ☐ Regurgitation of undigested food
- ☐ Difficulty controlling food or liquid in the mouth
- ☐ Drooling
- ☐ Coughing or choking before, during or after swallowing
- ☐ Hoarse voice
- ☐ Globus sensation
- ☐ Nasal regurgitation
- ☐ Feeling of obstruction
- ☐ Unintentional weight loss
- ☐ Wet voice quality
- ☐ Change in respiration pattern
- ☐ Unexplained temperature spikes
- ☐ Xerostomia
- ☐ Avoiding social occasions
- ☐ Heartburn
- ☐ Food sticking in throat
- ☐ Food remaining in mouth
- ☐ Prolonged chewing
- ☐ Prolonged time to complete a meal
- ☐ Change to consistency to food e.g. soft/puree diet
- ☐ Avoiding particular foods e.g. dry/hard
- ☐ Difficulty in swallowing pills
- ☐ Atypical chest pain
- ☐ Frequent throat clearing
- ☐ Recurrent chest infections
- ☐ Unknown

Please specify any additional options here...

2a. Was dysphagia assessed using a formal tool?

◯ Yes ◯ No ◯ Unknown
◯ NA - dysphagia not present

2b. If answered "Yes" to [2a] then:
Please specify which tool:

3a. Was a formal assessment of swallowing undertaken during this admission?

◯ Yes ◯ No ◯ Unknown

3b. If answered "Yes" to [3a] then:
How was this undertaken? (Please tick all that apply)

- ☐ Clinical assessment of swallowing
- ☐ Video Fluoroscopy
- ☐ Fibreoptic endoscopic evaluation of swallowing (FEES)
- ☐ Unknown

Please specify any additional options here...

3c. If answered "Yes" to [3a] then:
Please specify the date that this was first undertaken:

☐ Unknown

3d. If answered "Yes" to [3a] then:
How often was this undertaken?

- ◯ Only on admission
- ◯ 3-4 times per week during the admission
- ◯ Daily
- ◯ Unknown
- ◯ Single assessment during the admission
- ◯ Weekly
- ◯ When there were any changes in condition

If not listed above, please specify here...

3e. If answered "Yes" to [3a] then:
During the admission, how many times was a formal assessment made?

Number ☐ Unknown

4. Was a timed water swallow test (TWST) undertaken?

◯ Yes ◯ No ◯ Unknown

5a. Was a nebulised citric acid test for cough reflex undertaken?

◯ Yes ◯ No ◯ Unknown

5b. Did the patient choke during a swallow test within this admission?

◯ Yes ◯ No ◯ Unknown
◯ NA – not undertaken

6a. Is there a record of a nutritional screening undertaken on admission?

◯ Yes ◯ No ◯ Unknown

6b. If answered "Yes" to [6a] then:
What method of assessment was used? (Please tick all that apply)

- ☐ Malnutrition Universal Screening Tool (MUST)
- ☐ Estimated weight
- ☐ Family/carers
- ☐ Unknown

Please specify any additional options here...

6c. If answered "Yes" to [6a] then:
Were there any delays to this assessment being undertaken?

◯ Yes ◯ No ◯ Unknown

6d. If answered "Yes" to [6a] then:
What steps were taken as a result of the nutrition screening? (Please tick all that apply)

- ☐ Local protocol/nutrition care plan (based on MUST score) followed
- ☐ Patient referred to dietitian
- ☐ Food/fluid intake encouraged
- ☐ Oral nutritional supplements (sip feeds) given
- ☐ Unknown
- ☐ Nothing

Please specify any additional options here...

7a. Was the patient referred to the Speech and Language Therapy (SLT) team ON admission?

- ◯ Yes – for dysphagia
- ◯ Yes – for communication
- ◯ Yes – for both dysphagia and communication
- ◯ No
- ◯ Unknown
- ◯ Not applicable

7b. If answered "Yes – for dysphagia", "Yes – for communication" or "Yes – for both dysphagia and communication" to [7a] then:
Please specify the date of referral:

☐ Unknown

F. ONGOING CARE DURING THE ADMISSION

1a. Was this patient under the care of a Parkinson's Disease service prior to their admission?

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
What date was the Parkinson's Disease service normally responsible for the patient's care informed of the admission?

☐ Unknown

2a. Was any medication missed during the patient's admission?

◯ Yes - once ◯ Yes - more than once ◯ No
◯ Unknown

2b. If answered "Yes - once" or "Yes - more than once" to [2a] then:
What were the reasons for this? (Please tick all that apply)

☐ Not available in pharmacy
☐ Patient nil by mouth
☐ Patient away from the ward
☐ Awaiting medication review
☐ Awaiting confirmation of NG tube placement
☐ Not available on the ward
☐ Not suitable medication for a feeding tube
☐ Patient refused
☐ Patient unable to take
☐ Unknown

Please specify any additional options here...

3. Were the patient's usual Parkinson's Disease medications available in hospital?

◯ Yes ◯ No ◯ Unknown ◯ Not applicable

4a. Was the patient nil by mouth following admission?

◯ Yes ◯ No ◯ Unknown

4b. If answered "Yes" to [4a] then:
For how many days?

Days

4c. If answered "Yes" to [4a] then:
Why was the patient made nil by mouth?

☐ Surgery needed ☐ Unknown

Please specify any additional options here...

5. During the admission which of the following professionals were involved in the patient's care? (Please tick all that apply)

☐ Physiotherapy
☐ Speech & language therapy (SLT)
☐ Pharmacy
☐ Specialist Parkinson's Disease nurse
☐ Nurse
☐ None
☐ Occupational Therapy (OT)
☐ Dietitian
☐ Nutrition team
☐ Parkinson's Disease consultant
☐ Unknown

Please specify any additional options here...

6a. If answered "Speech & language therapy (SLT)" to [5] then:
At what point was the patient referred to SLT following admission?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hours ◯ Unknown

If not listed above, please specify here...

6b. If answered "Speech & language therapy (SLT)" to [5] then:
How long following referral did it take to be assessed by an SLT?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hours ◯ Unknown

If not listed above, please specify here...

6c. If answered "Speech & language therapy (SLT)" to [5] then:
Thereafter how often did the patient see a SLT?

◯ Daily ◯ 2-3 times a week ◯ Weekly ◯ Less often
◯ Unknown

6d. If answered "Speech & language therapy (SLT)" to [5] then:
Was this appropriate to the needs of the patient?

◯ Yes ◯ No – too little ◯ No – too much ◯ Unknown

7a. If answered "Nutrition team" to [5] then:
At what point was the patient referred to the nutrition team following admission?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hrs ◯ Unknown

If not listed above, please specify here...

7b. If answered "Nutrition team" to [5] then:
How long following referral did it take to be assessed by a nutritionist?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hrs ◯ Unknown

If not listed above, please specify here...

7c. If answered "Nutrition team" to [5] then:
Thereafter how often did the nutrition team see the patient?

◯ Daily ◯ 2-3 times a week ◯ Weekly ◯ Less often
◯ Unknown

7d. If answered "Nutrition team" to [5] then:
Was this appropriate to the needs of the patient?

◯ Yes ◯ No – too little ◯ No – too much ◯ Unknown

8a. If answered "Dietitian" to [5] then:
At what point was the patient referred to dietetics following admission?

◯ <24 hrs ◯ >48 hrs ◯ Between 24-48 hrs ◯ Unknown

If not listed above, please specify here...

8b. If answered "Dietitian" to [5] then:
How long following referral did it take to be assessed by a dietitian?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hrs ◯ Unknown

If not listed above, please specify here...

8c. If answered "Dietitian" to [5] then:
Thereafter how often did the patient see a dietitian?

◯ Daily ◯ 2-3 times a week ◯ Weekly ◯ Less often
◯ Unknown

8d. If answered "Dietitian" to [5] then:
Was this appropriate to the needs of the patient?

◯ Yes ◯ No ◯ Unknown

9a. If answered "Occupational Therapy (OT)" to [5] then:
At what point was the patient referred to OT following admission?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hrs ◯ Unknown

If not listed above, please specify here...

9b. If answered "Occupational Therapy (OT)" to [5] then:
How long following referral did it take to be assessed by an OT?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hrs ◯ Unknown

If not listed above, please specify here...

9c. If answered "Occupational Therapy (OT)" to [5] then:
Thereafter how often did the patient see an OT?

◯ Daily ◯ 2-3 times a week ◯ Weekly ◯ Less often
◯ Unknown

9d. If answered "Occupational Therapy (OT)" to [5] then:
Was this appropriate to the needs of the patient?

◯ Yes ◯ No ◯ Unknown

10a. If answered "Physiotherapy" to [5] then:
At what point was the patient referred to physiotherapy following admission?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hrs ◯ Unknown

If not listed above, please specify here...

10b. If answered "Physiotherapy" to [5] then:
How long following referral did it take to be assessed by a physiotherapist?

◯ <24 hrs ◯ Between 24-48 hrs ◯ >48 hrs ◯ Unknown

If not listed above, please specify here...

10c. If answered "Physiotherapy" to [5] then:
Thereafter how often did the patient see a physiotherapist?

◯ Daily ◯ 2-3 times a week ◯ Weekly ◯ Less often
◯ Unknown

10d. If answered "Physiotherapy" to [5] then:
Was this appropriate to the needs of the patient?

◯ Yes ◯ No ◯ Unknown

11a. Were there any communication difficulties during this admission between the patient and clinicians?

◯ Yes ◯ No ◯ Unknown

11b. If answered "Yes" to [11a] then:
What were these? (Please tick all that apply)

- ☐ Language difficulties
- ☐ Learning disability
- ☐ English not first language
- ☐ Unknown
- ☐ Hearing difficulties
- ☐ Communication or speech difficulties
- ☐ Dementia

Please specify any additional options here...

11c. If answered "Yes" to [11a] then:
Please give further details:

12. Were any audio or video recordings made of the patient's spontaneous speech during the admission?

- ○ Yes
- ○ No
- ○ Unknown

13. What treatment advice was given with regard to choking and aspiration? (Please tick all that apply)

- ☐ Explanation of dual tasking
- ☐ Swallowing exercises
- ☐ Unknown
- ☐ Not applicable
- ☐ Made aware of safe swallowing
- ☐ Swallowing rehabilitation programme initiated
- ☐ No advice given

Please specify any additional options here...

14a. Was an ENT specialist involved during the patient's admission?

- ○ Yes
- ○ No
- ○ Unknown

14b. If answered "Yes" to [14a] then:
If yes, in what capacity? (Please tick all that apply)

- ☐ Swallowing evaluation team
- ☐ To exclude vocal cord paralysis
- ☐ Surgical review
- ☐ Fibreoptic endoscopic evaluation of swallowing (FEES)
- ☐ Main admitting consultant
- ☐ Unknown

Please specify any additional options here...

15a. During the admission is there evidence oral hygiene was assessed by nursing staff?

- ○ Yes
- ○ No
- ○ Unknown

15b. If answered "Yes" to [15a] then:
Was oral hygiene managed?

◯ Yes ◯ No ◯ Unknown

16a. Did the patient require assistance with eating and drinking?

◯ Yes ◯ No ◯ Unknown

16b. If answered "Yes" to [16a] then:
Was there someone to help with feeding?

◯ Yes - all the time ◯ Yes - sometimes ◯ No ◯ Not recorded
◯ Unknown

16c. If answered "Yes" to [16a] and "Yes - all the time" or "Yes - sometimes" to [16b] then:
In general who was this? (Please tick all that apply)

☐ Healthcare professional ☐ Nutrition assistant ☐ Healthcare assistant
☐ Registered nurse ☐ Volunteer ☐ Family member
☐ Unknown

Please specify any additional options here...

17a. Was the risk of dehydration and its impact documented?

◯ Yes ◯ No ◯ Unknown

17b. If answered "Yes" to [17a] then:
What actions were taken following this?

18a. Was the risk of malnutrition and its impact documented?

◯ Yes ◯ No ◯ Unknown

18b. If answered "Yes" to [18a] then:
What actions were taken following this?

19a. Was an NG tube inserted during this admission for feeding/nutrition/hydration?

◯ Yes ◯ No ◯ Unknown

19b. If answered "Yes" to [19a] then:
Did the patient see a dietitian prior to insertion?

◯ Yes ◯ No ◯ Unknown

19c. If answered "Yes" to [19a] then:
Was there any delay in the NG tube being inserted?

◯ Yes ◯ No ◯ Unknown

19d. If answered "Yes" to [19a] then:
What was the time between the decision to insert the tube being made and the insertion?
Please round up to the nearest hour

Hours ☐ Unknown

19e. If answered "Yes" to [19a] then:
What was the time between the tube insertion and feeding being commenced?
Please round up to the nearest hour

Hours ☐ Unknown

19f. If answered "Yes" to [19a] then:
Was this communicated to pharmacy for medication management?

◯ Yes ◯ No ◯ Unknown

19g. If answered "Yes" to [19a] then:
Was medication managed appropriately?

◯ Yes ◯ No ◯ Unknown

19h. If answered "Yes" to [19a] then:
Was there a clear plan to review the NG tube before discharge?

◯ Yes ◯ No ◯ Unknown

20a. Was a NJ tube inserted during this admission for feeding/nutrition/hydration?

◯ Yes ◯ No ◯ Unknown

20b. If answered "Yes" to [20a] then:
Ddid the patient see a dietitian prior to insertion?

◯ Yes ◯ No ◯ Unknown

20c. If answered "Yes" to [20a] then:
Was there any delay in the NJ being inserted?

◯ Yes ◯ No ◯ Unknown

20d. If answered "Yes" to [20a] then:
What was the time between the decision to insert the tube being made and the insertion?
Please round up to the nearest hour

Hours ☐ Unknown

20e. If answered "Yes" to [20a] then:
What was the time between the tube insertion and feeding being commenced?
Please round up to the nearest hour

Hours ☐ Unknown

20f. If answered "Yes" to [20a] then:
Was this communicated to pharmacy for medication management?

◯ Yes ◯ No ◯ Unknown

20g. If answered "Yes" to [20a] then:
Was medication managed appropriately?

◯ Yes ◯ No ◯ Unknown

20h. If answered "Yes" to [20a] then:
Was there a clear plan to review the NJ before discharge?

◯ Yes ◯ No ◯ Unknown

21a. Was a gastrostomy tube inserted during this admission for feeding/nutrition/hydration?

◯ Yes ◯ No ◯ Unknown

21b. If answered "Yes" to [21a] then:
Did the patient see a dietitian prior to insertion?

◯ Yes ◯ No ◯ Unknown

21c. If answered "Yes" to [21a] then:
Was there any delay in the gastrostomy being inserted?

◯ Yes ◯ No ◯ Unknown

21d. If answered "Yes" to [21a] then:
What was the time between the decision to insert the tube being made and the insertion?

Hours ☐ Unknown

21e. If answered "Yes" to [21a] then:
What was the time between the tube insertion and feeding being commenced?

Hours

21f. If answered "Yes" to [21a] then:
Was this communicated to pharmacy for medication management?

◯ Yes ◯ No ◯ Unknown

21g. If answered "Yes" to [21a] then:
Was medication managed appropriately?

◯ Yes ◯ No ◯ Unknown

21h. If answered "Yes" to [21a] then:
Was there a clear plan to review the gastrostomy before discharge?

◯ Yes ◯ No ◯ Unknown

22a. Was this patient's care reviewed at an MDT meeting during this admission?

◯ Yes ◯ No
◯ Unknown ◯ NA – elective surgical admission

22b. If answered "Yes" to [22a] then:
Which teams participated in the MDT? (Please tick all that apply)

☐ SLT
☐ Physiotherapy
☐ Dietetics
☐ Specialist PD nurses
☐ Nursing
☐ Clinical team caring for the patient
☐ Neurologist
☐ Pharmacist
☐ Relatives
☐ Carers
☐ The primary clinician responsible for the patient in the community
☐ Patient
☐ Unknown

Please specify any additional options here...

22c. If answered "Yes" to [22a] then:
Is there a record of the MDT discussion in the case notes?

◯ Yes ◯ No ◯ Unknown

23a. Did the patient receive physiotherapy assistance with movement?

◯ Yes ◯ No ◯ Unknown

23b. If answered "Yes" to [23a] then:
Please specify: (please tick all that apply)

☐ Chest physiotherapy ☐ Mobility ☐ Posture ☐ Balance/Falls
☐ Transfers ☐ Unknown

Please specify any additional options here...

24a. Did the patient experience drooling at any point during the admission?

◯ Yes ◯ No ◯ Unknown

24b. If answered "Yes" to [24a] then:
Was any assessment of drooling made?

◯ Yes ◯ No ◯ Unknown

24c. If answered "Yes" to [24a] then:
What steps were taken to reduce the effects of drooling? (Please tick all that apply)

☐ Referral to physiotherapy ☐ Referral to OT ☐ Botox
☐ Review by SLT ☐ Prescribed medication ☐ Swallow reminder
☐ Handkerchief/chewing gum ☐ Unknown

Please specify any additional options here...

25a. Were any adverse events documented during the admission?

◯ Yes ◯ No ◯ Unknown

25b. If answered "Yes" to [25a] then:
Please give further details:

26. At any point during the admission, were the patients family or carers involved in the direct care of the patient?

◯ Yes ◯ No ◯ Unknown

G. DIETARY MODIFICATIONS

1a. Was a modified diet indicated at any point during the admission?

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
Was a modified diet provided?

◯ Yes ◯ No ◯ Unknown

2a. Were modified fluids indicated at any point during the admission?

◯ Yes ◯ No ◯ Unknown

2b. If answered "Yes" to [2a] then:
Was thickener advised?

◯ Yes ◯ No ◯ Unknown

2c. If answered "Yes" to [2a] then:
Was a thickener used?

◯ Yes ◯ No ◯ Unknown

2d. If answered "Yes" to [2a] and "Yes" to [2c] then:
Was this communicated to pharmacy for medication management?

◯ Yes ◯ No ◯ Unknown

2e. If answered "Yes" to [2a] and "Yes" to [2c] then:
Was medication managed appropriately?

◯ Yes ◯ No ◯ Unknown

H. MEDICATION OPTIMISATION

1a. What medications was the patient taking for PD prior to admission? (Please tick all that apply)

- ☐ Levodopa
- ☐ Dopamine agonists
- ☐ COMT inhibitors
- ☐ MAO-B inhibitors
- ☐ Anticholinergics
- ☐ Amantidine
- ☐ Other
- ☐ Unknown

1b. If answered "Other" to [1a] then:
If other, please specify

1c. If answered "Levodopa", "Dopamine agonists", "COMT inhibitors", "MAO-B inhibitors", "Anticholinergics", "Amantidine" or "Other" to [1a] then:
Was the patient experiencing any side-effects as a result of these medications?

- ◯ Yes
- ◯ No
- ◯ Unknown

1d. If answered "Levodopa", "Dopamine agonists", "COMT inhibitors", "MAO-B inhibitors", "Anticholinergics", "Amantidine" or "Other" to [1a] and "Yes" to [1c] then:
What were these? (Please tick all that apply)

- ☐ Confusion
- ☐ Hallucinations
- ☐ Delusions
- ☐ Sleeping disorders
- ☐ Response fluctuations
- ☐ Nausea
- ☐ Dry mouth
- ☐ Orthostasis
- ☐ Unknown

Please specify any additional options here...

2. On admission, was it checked that the patient had taken their last scheduled dose of medication for their Parkinson's Disease?

- ◯ Yes
- ◯ No
- ◯ Unknown

3a. Was the patient's Parkinson's medication altered during this admission?

- ◯ Yes
- ◯ No
- ◯ Unknown

3b. If answered "Yes" to [3a] then:
Please specify why? (Please tick all that apply)

- ☐ Swallowing difficulties
- ☐ Patient experiencing nausea/vomiting
- ☐ Patient experiencing confusion/agitation/hallucinations/altered level of consciousness
- ☐ Non-availability of medicines
- ☐ Worsening of condition
- ☐ Progression of disease
- ☐ Unknown

Please specify any additional options here...

4a. Was the patient prescribed a Rotigotine patch whilst in hospital?

- ◯ Yes
- ◯ No
- ◯ Unknown

4b. If answered "Yes" to [4a] then:
Were alternative forms of medication considered prior to administration?

- ◯ Yes
- ◯ No
- ◯ Unknown

4c. If answered "Yes" to [4a] then:
Was the Parkinson's Disease UK medication optimisation statement consulted to aid decision making?

- ◯ Yes
- ◯ No
- ◯ Unknown

4d. If answered "Yes" to [4a] then:
Was there a clear plan to review the Rotigotine patch before discharge?

◯ Yes ◯ No ◯ Unknown

4e. If answered "Yes" to [4a] then:
Should they have been?

◯ Yes ◯ No ◯ Unknown

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5. Did the patient/carer receive any information on the administration of medicines prior to discharge?

◯ Yes ◯ No ◯ Unknown

I. RISK FEEDING

1a. Was the patient risk feeding prior to admission?
Please see definitions

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
Was there a re-evaluation of risk feeding on admission?

◯ Yes ◯ No ◯ Unknown

1c. If answered "No" to [1a] then:
Was risk feeding considered on or following admission?

◯ Yes ◯ No ◯ Unknown

1d. If answered "No" to [1a] and "Yes" to [1c] then:
Was an assessment undertaken prior to risk feeding?

◯ Yes ◯ No ◯ Unknown

1e. If answered "No" to [1a] and "Yes" to [1c] and "Yes" to [1d] then:
Did this include an assessment of mental capacity around risk feeding?

◯ Yes ◯ No ◯ Unknown

1f. If answered "No" to [1a] and "Yes" to [1c] and "Yes" to [1d] and "Yes" to [1e] then:
Was mental capacity established?

◯ Yes ◯ No ◯ Unknown

1g. If answered "No" to [1a] and "Yes" to [1c] and "Yes" to [1d] and "Yes" to [1e] and "No" to [1f] then:
Was a best interest meeting held around the decision to risk feed?

◯ Yes ◯ No ◯ Unknown

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2. If the patient was risk feeding during this admission, was a formal protocol followed?

◯ Yes ◯ No
◯ Unknown ◯ NA - not risk feeding during this admission

J. END OF LIFE CARE

1a. Was end of life care discussed during this admission?

◯ Yes ◯ No ◯ Unknown

1b. If answered "Yes" to [1a] then:
Who was included in this discussion? (Please tick all that apply)

☐ Patient
☐ Carers
☐ Other family members
☐ Usual Parkinson's Disease specialist
☐ GP
☐ Community team
☐ Unknown

Please specify any additional options here...

2. Did the patient have an advanced care directive of any sort in place?

◯ Yes ◯ No ◯ Unknown

3a. Were markers of advanced disease present in this patient?

◯ Yes ◯ No ◯ Unknown

3b. If answered "Yes" to [3a] then:
What were they? (Please tick all that apply)

☐ Care home placement
☐ Dementia Aspiration pneumonia
☐ Recurrent falls
☐ Unplanned weight loss
☐ Unknown

Please specify any additional options here...

3c. If answered "Yes" to [3a] then:
Was an advanced care plan in place prior to admission?

◯ Yes ◯ No ◯ Unknown ◯ Not applicable

3d. If answered "Yes" to [3a] then:
During the admission was an escalation plan in place?

◯ Yes ◯ No ◯ Unknown

3e. If answered "Yes" to [3a] then:
Was an advanced care plan discussed prior to discharge?

◯ Yes ◯ No ◯ Unknown

4a. Was the patient receiving palliative care on admission?

◯ Yes ◯ No ◯ Unknown

4b. If answered "Yes" to [4a] then:
Prior to admission, where was the patient's palliative care managed?

☐ Hospital ☐ Home ☐ Hospice ☐ Unknown
☐ Not applicable

Please specify any additional options here...

4c. If answered "No" to [4a] then:
Did the patient receive any palliative care during the admission?

◯ Yes ◯ No ◯ Unknown

K. DISCHARGE

1. What was the outcome of this admission?

◯ Patient discharged alive ◯ Patient died ◯ Unknown

2a. Please specify the date of discharge/death:

☐ Unknown

2b. Please specify the time of discharge/death:

☐ Unknown

3. If answered "Patient discharged alive" to [1] then:
What was the discharge destination of the patient?

◯ Home ◯ Another hospital ◯ Residential care home
◯ Nursing home ◯ Hospice ◯ Unknown

If not listed above, please specify here...

4. If answered "Patient discharged alive" to [1] then:
Were any formal referrals made to care in the community at discharge?

◯ Yes ◯ No
◯ Unknown
◯ NA – already under the care of a community team

5. If answered "Patient discharged alive" to [1] then:
Were the patient's home carers involved in discharge planning?

◯ Yes ◯ No ◯ Unknown ◯ Not applicable

6a. If answered "Patient discharged alive" to [1] then:
Was the patient's level of swallowing/aspiration risk in the community assessed prior to discharge?

◯ Yes ◯ No ◯ Unknown

6b. If answered "Patient discharged alive" to [1] and "Yes" to [6a] then:
Was an action plan put in place?

◯ Yes ◯ No ◯ Unknown

7. If answered "Patient discharged alive" to [1] then:
Was there planned follow-up with regard to diet and nutrition following discharge?

◯ Yes ◯ No ◯ Unknown

8. If answered "Patient discharged alive" to [1] then:
Was the patient prescribed thickeners on discharge?

◯ Yes ◯ No ◯ Unknown ◯ Not applicable

9a. If answered "Patient discharged alive" to [1] then:
Was a discharge summary provided on discharge from this hospital?

◯ Yes ◯ No ◯ Unknown

9b. If answered "Patient discharged alive" to [1] and "Yes" to [9a] then:
What information was included in the discharge summary? (Please tick all that apply)

- ☐ Implemented interventions
- ☐ The effects and expected prognosis
- ☐ The administration of medication
- ☐ Dietary recommendations
- ☐ Unknown
- ☐ Treatment period and frequencies
- ☐ Measuring tools results
- ☐ An advanced care plan
- ☐ Changes in drug sensitivity/intolerance

Please specify any additional options here...

9c. If answered "Patient discharged alive" to [1] and "Yes" to [9a] then:
Who received a copy of the discharge summary?

- ☐ General practitioner
- ☐ Community based team
- ☐ SLT
- ☐ Clinician caring for the patient at the time of the admission
- ☐ Physiotherapist
- ☐ OT
- ☐ Specialist PD nurse
- ☐ Dietitian
- ☐ Patient and carers
- ☐ Community pharmacist
- ☐ Residential home
- ☐ Nursing home
- ☐ Parkinson's Disease Consultant
- ☐ Unknown

Please specify any additional options here...

10. If answered "Patient died" to [1] then:
Was the death:

◯ Expected ◯ Unexpected ◯ Unknown

11. If answered "Patient died" to [1] then:
What was considered to be the primary cause of death? (Free text)

12. If answered "Patient died" to [1] then:
Was the patient's case discussed at a morbidity and mortality meeting?

◯ Yes ◯ No ◯ Unknown

L. DYSPHAGIA DURING THE ADMISSION

1. **On reflection of this case, at any point during this admission did the patient have dysphagia?**

   ◯ Yes ◯ No ◯ Unknown

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

By doing so you have contributed to the dataset that will form the report and recommendations due for release in November 2020