

Round 1 Questionnaire: Developing consensus on speech and language therapy best practice for patients in prolonged disorders of consciousness

Introduction:

This study uses the Delphi technique - a research method which aims to ascertain the degree of consensus on a topic. Here it involves answering two questionnaires about one month apart (also known as Round 1 and Round 2). The Round 1 questionnaire asks participants for their opinions on a topic, ideally with some justification for their views. The information from the Round 1 questionnaire is then analysed and additional items added, based on participants' comments, to make the Round 2 questionnaire. The results are passed on to participants to review before completing the Round 2 questionnaire giving them the opportunity to reflect on different people's opinions and appraise their previous answers before deciding whether their opinions remain the same or not.

This questionnaire has four sections – participant demographics, assessment, management and service delivery. It should take you between 15-30 minutes to complete. You can stop and save what you have done at any time and complete the questionnaire later if needed. Consent will be inferred through return of the questionnaire.

We are not asking about current practice. We are simply seeking your opinion about what you feel best practice is for patients in prolonged disorders of consciousness in an 'ideal world' (i.e. with adequate staffing, resources and equipment). This is not a test, there are no wrong or right answers.

Once completed please email the questionnaire to hannah.roberts10@nhs.net by 5pm on **Friday 9th June 2017**. Once the questionnaires have been received and analysed, you will be emailed the results, along with a copy of the Round 2 questionnaire to complete.

Definition of prolonged disorders of consciousness (PDOC):

- Disorder of consciousness is the overarching term used in the UK to describe three states – coma, vegetative state and minimally conscious state
- Prolonged, in this context, means persisting for more than four weeks after sudden onset brain injury

Section 1: Demographics

Please **bold or type** the appropriate answer as applicable

Participant demographics	
<p>1. I confirm that I am, either:</p> <ul style="list-style-type: none"> • An SLT currently employed in a static post on a neurosciences, neurosurgery or neurorehabilitation ward/unit that accepts adult PDOC patients OR • A practising SLT with three or more years' past/current experience of working with adult PDOC patients as a regular part of my caseload 	<p>a. Yes</p> <p>b. No (if no, unfortunately you do not meet the inclusion criteria for this study and you need not continue completing the questionnaire)</p>

2. What area/s of the care pathway do you currently work in? (select more than one if appropriate)	a. Specialist acute hospital b. General acute hospital c. Hyperacute neurorehabilitation unit d. Neurorehabilitation unit e. Community f. Other – please specify:
3. In what geographical area/s do you currently work? (select more than one if appropriate)	a. England b. Wales c. Scotland d. Northern Ireland e. Other – please specify:
4. What sector/s are you currently employed by? (select more than one if appropriate)	a. NHS b. Charity c. Private d. Other – please specify:
5. What is your current banding (or equivalent if non-NHS)?	a. Band 5 b. Band 6 c. Band 7 d. Band 8a e. Band 8b f. Other – please specify:
6. How long (in years) have you been working as an SLT? years
7. How long (in years) have you been working, or worked, with patients in PDOC? years
8. In what setting/s have you worked with patients in PDOC? (select more than one if appropriate)	a. Specialist acute hospital b. General acute hospital c. Hyperacute neurorehabilitation unit d. Neurorehabilitation unit e. Community f. Other – please specify:
9. In what country did you train to be an SLT?
10. Did your SLT qualification include any teaching on PDOC?	a. Yes b. No c. I do not remember
11. Have you attended any formal training on working with patients in PDOC since qualifying as an SLT e.g. study day by national experts?	a. Yes b. No c. I do not remember
12. How else have you developed your skills/knowledge of working with patients in PDOC? (select more than one if appropriate)	a. Informal on the job training e.g. shadowing, observation b. Formal on the job/in-house training e.g. competency framework, in-house talks/lectures c. Other – please specify:
13. Do you independently manage patients with tracheostomies?	a. Yes b. No (if no, please write N/A next to later questions about tracheostomy)

14. Are you SMART (Sensory Modality Rehabilitation and Assessment Technique) trained?	a. Yes b. No
15. Are you FOTT (Facial-Oral Tract Therapy) trained?	a. Yes b. No

Section 2: Assessment

Please put an **X** in the box that best represents your views of best practice in an *'ideal world'* when working with patients in PDOC. It would be helpful if you could provide a justification of your view where possible/relevant, along with any other comments you have about the statements, as this helps with the Delphi process.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Justification/ Comments
Assessment of patients in PDOC						
1. In conjunction with a multidisciplinary team (MDT), SLTs should complete formal assessments of the awareness level of patients in PDOC						
2. SLTs should complete informal assessments of the awareness level of patients in PDOC						
3. SLT assessment should include observation of the communicative behaviours of patients in PDOC in a range of settings, including with family and friends						
4. SLT assessment should include observation of the communicative behaviours of patients in PDOC with both familiar and unfamiliar stimuli						
5. SLT assessment should include assessment of the ability of patients in PDOC to answer yes/no questions						

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Justification/ Comments
6. SLT assessment should include assessment of the ability of patients in PDOC to follow commands						
7. SLT assessment should include assessment of the ability of patients in PDOC to make meaningful choices						
8. SLT assessment should include assessment of the ability of patients in PDOC to use alternative and augmentative communication (AAC)						
9. SLT assessment should include assessment of oral hypersensitivity / oral reflexes of patients in PDOC						
10. SLT assessment should include assessment of the ability of patients in PDOC to manage their oral secretions						
11. SLT assessment should include bedside assessment of swallowing of patients in PDOC						
12. SLT assessment should include instrumental assessment of swallowing of patients in PDOC						
13. All patients in PDOC should have an instrumental swallowing assessment before commencing oral trials/therapeutic feeding						
14. Patients in PDOC are frequently able to tolerate videofluoroscopy						

15. Patients in PDOC are frequently able to tolerate fiberoptic endoscopic evaluation of swallowing						
16. SLT assessment should include assessment of the ability of patients in PDOC to tolerate cuff deflation and speaking valve (for tracheostomy patients)						
Should SLT assessment include any other area not listed above? If you think it should, please specify:						

Section 3: Management

Please put an **X** in the box that best represents your views of best practice in ***an 'ideal world'*** when working with patients in PDOC. It would be helpful if you could provide a justification of your view where possible/relevant, along with any other comments you have about the statements, as this helps with the Delphi process.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Justification/ Comments
Management of patients in PDOC						
1. SLTs should regularly monitor for changes in communicative behaviours of patients in PDOC						
2. SLTs should provide communication advice regarding patients in PDOC to other professionals						
3. SLTs should provide communication advice to family/friends of patients in PDOC						
4. SLTs should provide training to staff and families regarding opportunities for interaction for patients in PDOC						

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Justification/ Comments
5. SLTs should provide programmes for PDOC patients to practice use of AAC						
6. SLTs should be involved in delivering sensory stimulation interventions to patients in PDOC						
7. SLTs should provide programmes to manage oral hypersensitivity in patients in PDOC						
8. SLTs should provide FOTT to patients in PDOC						
9. SLTs should be involved in decision making regarding the management of oral secretions of patients in PDOC						
10. SLTs should consider use of oral trials as part of their management plan for patients in PDOC						
11. SLTs should provide swallowing advice to other professionals regarding patients in PDOC						
12. SLTs should provide swallowing advice to family/friends of patients in PDOC						
13. SLTs should be involved in planning tracheostomy weaning of patients in PDOC						
14. SLTs should be involved in MDT decision making for patients in PDOC						

Should SLT management include any other area not listed above? If you think it should, please specify:

Section 4: Service Delivery

For questions 1-13 please **bold** the answer that best represents your views of best practice in ***an ideal world*** when working with patients in PDOC. For questions 14-15 please mark your answer with an **X**. It would be helpful if you could provide a justification of your view where possible/relevant, along with any other comments you have about the statements, as this helps with the Delphi process.

Service delivery for patients in PDOC	Justification/ Comments
1. AAC assessment and intervention for patients in PDOC should commence: <ul style="list-style-type: none"> a. On the intensive care unit b. On the acute hospital ward c. At the neurorehabilitation unit d. Other – please specify: 	
2. A trial of the ability of a patient in PDOC to use an AAC device should last: <ul style="list-style-type: none"> a. Less than 1 week b. 1 week c. 2 weeks d. 3 weeks e. 1 month f. Longer than 1 month g. Other – please specify: 	
3. The frequency of sessions during an AAC trial for a patient in PDOC should be: <ul style="list-style-type: none"> a. More than once per day b. Daily (including weekends) c. Daily (weekdays only) d. 3-4 times per week e. 1-2 times per week f. Less than weekly g. Other – please specify: 	

<p>4. Sessions during an AAC trial for a patient in PDOC should be delivered by: <i>(please select one or more options)</i></p> <ul style="list-style-type: none"> a. An SLT b. An allied health professional (AHP) assistant with SLT guidance c. Nursing staff with SLT guidance d. Family members with SLT guidance e. Other – please specify: 	
<p>5. Oral hypersensitivity assessment and intervention for patients in PDOC should commence:</p> <ul style="list-style-type: none"> a. On the intensive care unit b. On the acute hospital ward c. At the neurorehabilitation unit d. Other – please specify: 	
<p>6. A trial of an oral hypersensitivity programme for a patient in PDOC should last:</p> <ul style="list-style-type: none"> a. Less than 1 week b. 1 week c. 2 weeks d. 3 weeks e. 1 month f. Longer than 1 month g. Other – please specify: 	
<p>7. Oral hypersensitivity programmes for patients in PDOC should be delivered:</p> <ul style="list-style-type: none"> a. More than once per day b. Daily (including weekends) c. Daily (weekdays only) d. 3-4 times per week e. 1-2 times per week f. Less than weekly g. Other – please specify: 	
<p>8. Oral hypersensitivity programmes for patients in PDOC should be delivered by: <i>(please select one or more options)</i></p> <ul style="list-style-type: none"> a. An SLT b. An AHP assistant with SLT guidance c. Nursing staff with SLT guidance d. Family members with SLT guidance e. Other – please specify: 	

<p>9. Assessment and intervention for oral feeding of patients in PDOC should be commenced:</p> <ul style="list-style-type: none"> a. On the intensive care unit b. On the acute hospital ward c. At the neurorehabilitation unit d. Other – please specify: 						
<p>10. For PDOC patients commencing oral trials, these should be delivered by: <i>(please select one or more options)</i></p> <ul style="list-style-type: none"> a. An SLT b. An AHP assistant with SLT guidance c. Nursing staff with SLT guidance d. Family members with SLT guidance e. Other – please specify: 						
<p>11. Tracheostomy weaning of patients in PDOC should be commenced:</p> <ul style="list-style-type: none"> a. On the intensive care unit b. On the acute hospital ward c. At the neurorehabilitation unit d. Other – please specify: 						
<p>12. The frequency of delivery/involvement in tracheostomy weaning of patients in PDOC by an SLT should be:</p> <ul style="list-style-type: none"> a. More than daily b. Daily (including weekends) c. Daily (weekdays only) d. 3-4 times per week e. 1-2 times per week f. Less than weekly g. Other – please specify: 						
<p>13. Tracheostomy weaning of patients in PDOC should be conducted by: <i>(please select one or more options)</i></p> <ul style="list-style-type: none"> a. An SLT b. A physiotherapist c. Nursing staff d. Other – please specify: 						
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Justification/ Comments
<p>14. There is sufficient training for SLTs on working with patients in PDOC</p>						
<p>15. SLTs working with PDOC patients should offer a 7 day service</p>						

Other service delivery, please specify:

Please add any other comments or thoughts you have that you feel might be relevant to this topic:

Thank you very much for completing this questionnaire, your opinions are greatly appreciated. Please now return it via email to hannah.roberts10@nhs.net