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## **International Journal of Language & Communication Disorders**

### **Speech and language therapy best practice for patients in prolonged disorders of consciousness – a modified Delphi study**

#### **Abstract**

#### **Background**

Research regarding speech and language therapy (SLT) for patients in prolonged disorders of consciousness (PDOC) is very limited. The Royal College of Physicians' (RCP) PDOC guideline provides recommendations regarding best practice but does not give details on many aspects of assessment and management. As a result, speech and language therapists (SLTs) have little information regarding best practice for this complex patient group.

#### **Aims**

This study aimed to ascertain the degree of consensus amongst expert SLTs regarding SLT best practice for patients in PDOC, to inform the future development of SLT guidelines.

#### **Methods & Procedures**

A two round modified Delphi technique was used. Participants were recruited from major trauma centres and neurorehabilitation units in England, and national SLT clinical excellence networks. To participate SLTs had to be working on neurosciences, neurosurgery or neurorehabilitation wards that treat adult PDOC patients, or have three or more years' experience of working with PDOC. The Round 1 questionnaire was developed from the RCP PDOC guideline and from existing research literature. It included ratings of statements regarding SLT best practice using Likert or temporal scales, with optional written justifications/comments and opportunities for participants to suggest additional statements. The percentage agreement amongst participants was calculated for each Round 1 statement. Written justifications for views were analysed using content analysis. The Round 2 questionnaire contained both quantitative and qualitative feedback from Round 1, allowing participants to reappraise their views. The final degree of consensus was then calculated after completion of both rounds.

#### **Outcomes & Results**

Forty SLTs completed Round 1, with 36 completing Round 2 (90% response rate).

Consensus was achieved for 87% (67/77) of statements regarding best practice on a variety of topics including communication, tracheostomy, dysphagia, and oral hypersensitivity. They represented assessment, management and service delivery components of SLT practice.

#### Conclusions & Implications

Sixty-seven best practice statements were created. The statements provide a useful starting point for the creation of SLT guidelines to support best practice. They also have the potential to be used to advocate for the provision of SLT services for patients in PDOC. Future studies should focus on whether the expert opinion generated here can be borne out in experimental research.

#### **What this paper adds**

What is already known on this subject

Despite SLTs being listed as key members of the multidisciplinary team working with patients in PDOC, there is insufficient information to guide SLTs' clinical practice when working with this client group.

#### **What this study adds**

To our knowledge, this is the first published Delphi study on SLT best practice for patients in PDOC. It is also one of only a small number of studies that addresses SLT for this patient group. A high degree of consensus was found in most areas resulting in a set of 67 SLT best practice statements for patients in PDOC.

Clinical implications of this study

The best practice statements generated here provide a useful starting point for the creation of SLT guidelines to support best practice. They also have the potential to empower SLT departments to advocate for SLT input for this client group.

## Introduction

What are prolonged disorders of consciousness?

In the United Kingdom (UK), disorder of consciousness is the overarching term used to describe three states – coma, vegetative state (VS) and minimally conscious state (MCS) (Royal College of Physicians (RCP) 2013). 'Prolonged' in this context means persisting for more than four weeks after sudden onset brain injury (RCP 2013), and thus the term prolonged disorders of consciousness (PDOC) does not tend to include coma as they usually only last a few weeks (NHS Choices 2018).

Although PDOC can occur in paediatric brain injury patients, this paper focuses on adults as it was felt that assessment and management of the paediatric population may differ significantly.

VS is a state of wakefulness without awareness. Patients in VS may display spontaneous or reflexive movements but none of these movements has any intent (RCP 2003). MCS is a state of wakefulness with inconsistent but reproducible signs of awareness (Giacino *et al.* 2002). Behaviours consistent with awareness include gestural/verbal 'yes/no' responses, intelligible verbal output and purposeful or discriminating behaviour (Giacino and Kalmar 2005). Patients are considered to have emerged from PDOC if, on two consecutive occasions, they are able to demonstrate functional object use, discriminatory choice making or accurately answer yes/no questions (RCP 2013).

Although there is no national database of patients in PDOC, in the UK it is estimated that there are between 4,000-16,000 patients in VS, and three times that many in MCS (Parliamentary Office of Science and Technology 2015).

### Impact of PDOC

The impact of PDOC on families of patients in PDOC, and on the National Health Service (NHS) is considerable. Research shows that there is a clinically significant psychological impact on families of patients in PDOC with high levels of depression, anxiety and grief

(Moretta *et al.* 2014, Soeterik *et al.* 2017). Despite being a small group, PDOC patients also place a large financial burden on the NHS. Formby, Cookson and Halliday (2015) report that an average patient in persistent VS costs the NHS £90,000 annually.

## SLT and PDOC

The focus of this study is on the role of SLTs working with patients in PDOC. There is limited guidance regarding SLT and PDOC, both from published guidelines and research.

The most relevant national guideline is the RCP PDOC guideline (RCP 2013) and it refers to a variety of topics relevant to SLTs (see Table 1). However, it does not provide detail on what exactly SLT assessment or management should entail.

Table 1 here.

**Table 1.** Summary of SLT topics from RCP PDOC guideline (RCP 2013)

Topics referred to in RCP guideline	Area of SLT practice
Saliva management	Dysphagia
Ability to feed orally / swallowing therapy	Dysphagia
Management of oral reflexes / desensitisation of the mouth	Oral reflexes / oral hypersensitivity
Ability to use augmentative and alternative communication	Communication
Advice regarding communication and interaction	Communication
Level of interaction and responsiveness	Communication
Tracheostomy management and decannulation	Tracheostomy

Given the known issues with conducting clinical research into rare conditions, such as, recruitment and funding (Griggs *et al* 2009), there are very few high-quality studies regarding PDOC and consequently current recommendations are largely based on expert opinion.

There is little research literature that specifically relates to SLT and PDOC, and what does exist is often methodologically limited. A small number of studies focus on dysphagia, and specifically the use of instrumental swallowing assessment and appropriateness of therapeutic feeding (having small amounts of oral intake for therapeutic purposes) in this population (Brady *et al.* 2006; 2009, O'Neil-Pirozzi *et al.* 2003). However, drawing

conclusions about dysphagia management from these studies is hampered by small sample sizes, insufficient detail regarding therapeutic feeding volumes and absence of longer-term follow-up. Nevertheless, the evidence suggests that conducting instrumental swallowing assessments is possible for some patients in PDOC.

One study investigated SLTs' assessment and management of oral hypersensitivity of patients in PDOC (Millwood *et al.* 2005). Whilst it provides evidence that oral reflexes and their sequelae are a common problem for patients in PDOC, as it is a descriptive study it provides minimal evidence regarding SLT best practice. This study also mentions the use of Facial-Oral Tract Therapy (FOTT) as part of their SLT intervention. FOTT is a complex, multifaceted intervention (Hansen and Jakobsen 2010) that can be used with patients in PDOC as it does not involve active participation by the patient (Hansen, Engberg and Larsen 2008). It was created by Kay Coombes and is reported to follow principles of the Bobath concept (Seidl and Westhofen 2007). However, evidence for the approach is limited (Kjaersgaard, Nielsen and Sjölund 2014) with few English language papers on the topic and study designs that limit the ability to draw conclusions regarding FOTT's effectiveness (e.g. Seidl and Westhofen 2007; Konradi *et al.* 2015). Despite this FOTT is regarded as a popular technique in neurorehabilitation in many European countries (Hansen and Jakobsen 2010).

Lancioni and colleagues have published prolifically on the use of high-tech augmentative and alternative (AAC) by people in PDOC (e.g. Lancioni *et al.* 2010; 2011; 2014). However, all studies are case studies or case series, with a high level of personalisation of the technological devices and a wide variation in length and frequency of intervention.

Furthermore, whilst some results of interventions used were found to be statistically significant there is a lack of consistency in statistical significance testing. Despite these issues the studies do indicate the importance of considering the use of high-tech AAC as part of SLT assessment and management of patients in PDOC, since some patients may be able to utilise these devices. It is notable that there are no studies regarding the use of low-tech AAC with patients in PDOC.

Some studies have focused on the criteria for emergence from MCS. Overall, both the research studies (Nakase-Richardson *et al.* 2009, Schnakers *et al.* 2015) and the one narrative review (Pundole and Crawford 2018) raise important points about difficulties with assessing emergence from PDOC, for example, the potential impact of aphasia on ability to demonstrate emergence. In terms of best practice, although the RCP PDOC guideline (RCP 2013) has recommendations regarding what constitutes emergence, there are some areas left unspecified and evidence suggests that SLTs should consider a wide range of factors that influence patients' ability to demonstrate emergence when planning assessments.

Finally, it is noteworthy that whilst there is some evidence and guidance to support SLT best practice in the weaning of patients with a tracheostomy (e.g. NCEPOD 2014, Pryor *et al.* 2016, Speed and Harding 2013) there are no studies that specifically relate to the tracheostomy management of patients in PDOC although recent evidence suggests that level of consciousness may not be a factor that predicts the ability to wean (Enrichi *et al.* 2017, Perin *et al.* 2017).

The information available to SLTs regarding best practice for working with patients in PDOC is clearly limited. Expert opinion, gathered in a scientific manner, on the topic is also lacking. Consequently, this study aimed to acquire clinically useful information by gaining expert SLT opinion through utilising a modified Delphi technique (Keeney, Hasson and McKenna 2011).

## Aims and Objectives

### **Aim**

To ascertain the degree of consensus amongst expert SLTs regarding SLT best practice for patients in PDOC

### **Objectives**

- To ascertain the degree of consensus amongst expert SLTs, through use of a modified Delphi technique, on SLT best practice for patients in PDOC regarding:
  1. Assessment
  2. Management

### 3. Service delivery

- To inform the future development of SLT guidelines for working with PDOC patients

## **Methods**

### **Design**

The Delphi technique is a research method that aims to ascertain the degree of consensus on a topic (Keeney, Hasson and McKenna 2011). It usually comprises two or more rounds of questionnaires sent to a group of 'experts' with controlled feedback provided from the previous round. A modified Delphi technique was used. Modifications here included replacing the qualitative first round with a questionnaire and to stop the Delphi process after two rounds, which is common due to frequent poor response rates in studies with more rounds (Keeney 2015). Both quantitative and qualitative feedback from the first round questionnaire were provided to help inform participants' responses in the second round questionnaire.

### Sampling and recruitment

Participants were recruited using purposive, snowball sampling. Delphi study participants are expected to be 'experts', although agreement is limited as to how this is defined (Baker, Lovell and Harris 2006). The criteria used here were: SLTs currently employed in static posts on neurosciences, neurosurgery or neurorehabilitation wards that accept adult PDOC patients and SLTs not currently working in these areas but with three or more years' experience of working with adult patients in PDOC as a regular part of their caseload.

SLTs were identified through telephoning the Lead SLT at all English adult major trauma centres and neurorehabilitation units that accepted adult PDOC patients. If willing, they were sent an invitation email, with the participant information sheet and questionnaire attached, which included a request to pass the email onto their team. SLTs were also approached via email through relevant UK-wide SLT Clinical Excellence Networks.



## Questionnaire Development

### **Round 1 Questionnaire**

The Round 1 questionnaire was developed from the SLT topics identified in the RCP guideline (RCP 2013), and a review of the literature. This is in keeping with recommendations from the Delphi literature, which supports Round 1 being compiled from pre-existing information (Tolsgaard *et al.* 2013).

The questionnaire used Timmer, Unsworth and Taylor's (2015) approach of framing best practice around what participants deemed ideal given adequate staffing, resources and equipment. It contained a section on participant demographics and three sections (assessment, management and service delivery) with statements to be rated regarding SLT best practice. Keeney (2015) recommends that, to reduce bias, researchers should allow participants to generate their own ideas. Therefore, the questionnaire gave options for commenting on the wording of statements and suggesting new statements.

Five-point Likert scales were used as these are typically used in Delphi studies (Keeney, Hasson and McKenna 2011), with additional scales used for specific statements as required e.g. frequency scales for how often an intervention should be conducted.

### **Piloting**

The Round 1 questionnaire was piloted on a convenience sample of three SLTs with experience of PDOC from a local NHS trust. Small changes were made to the questionnaire after each pilot participant had completed it. Amendments including rewording statements to increase comprehensibility, two additional statements and format changes.

### **Round 2 Questionnaire**

The Delphi technique is an iterative approach therefore the Round 2 questionnaire was based on the responses from the previous round with modifications made accordingly (Keeney, Hasson and McKenna 2011). These included removing statements that received

100% agreement, amending some statements based on Round 1 analysis, and adding new statements suggested by participants.

For statements that remained the same, the Round 2 questionnaire also contained a summary of justifications that participants gave for their Round 1 rating, including justifications for divergent views as recommended by Murphy *et al.* (1998).

Copies of the Round 1 and Round 2 questionnaire can be found in the Supporting Information (see S1 and S2).

## **Data Analysis**

### **Quantitative**

Quantitative data from both questionnaires were coded and entered into Microsoft Excel before being analysed using SPSS version 24 (IBM Corp. 2016). Coding and data entry were hand checked for a random sample of 10% to ensure it was in keeping with recommendations for levels of data accuracy (Hammond *et al.* 2014).

The percentage agreement for each statement was calculated after each round. A 75% threshold for consensus was chosen as this was recommended by Timmer, Unsworth and Taylor (2015) based on a review of the occupational therapy Delphi.

Consensus was deemed to have been reached if  $\geq 75\%$  of participants:

- Agreed (strongly agree and agree) or disagreed (strongly disagree and disagree), for statements using a Likert scale
- Selected the same response (e.g. '2 weeks'), for statements using a non-Likert scale

The percentage of participants selecting each response option was also calculated for all statements in Round 1. This information was then included as feedback in the Round 2 questionnaire, along with the individual participant's previous ratings. Participant demographic characteristics were analysed using descriptive statistics.

## **Qualitative**

Although there is no universally agreed approach to qualitative analysis, content analysis is typically used to analyse qualitative data in Delphi studies (Keeney, Hasson and McKenna 2011). Miles, Huberman and Saldaña's (2014) approach to qualitative content analysis was adopted for this study. This involves first cycle coding, pattern coding, jottings and assertion and proposition development.

Before the analysis commenced, irrelevant comments (e.g. comments regarding current practice rather than best practice) or comments without full explanation (e.g. 'if appropriate' without explanation) were removed.

Content analysis for the whole data set was undertaken by the first author. The second author independently conducted content analysis for three out of 45 statements. Both authors agreed on the themes and very minor differences regarding wording were discussed and agreed upon together.

## **Ethical Approval**

The study was reviewed by the university faculty Research Ethics Committee and a favourable ethical opinion was given. Local NHS Trust Research and Development approval was also granted.

## **Results**

### **Participant Demographics**

Forty SLTs completed the Round 1 questionnaire and 36 of these completed Round 2 (90% response rate). Of those completing both rounds, the median years' experience of PDOC was 6 years (interquartile range: 6.8). Over half of participants (55.6%) had worked with PDOC in more than one clinical setting and over two-thirds (69.4%) had completed formal training regarding PDOC since qualifying. Further details can be found in Table 2.

For statements regarding tracheostomy, only the views of SLTs who independently managed patients with tracheostomies were obtained (32/40 participants in Round 1 and 30/36 in Round 2).

Table 2 about here.

**Table 2.** Descriptive statistics for the demographic information collected in Rounds 1 and 2. Figures are frequencies and percentages unless otherwise stated. n=40 for Round 1 and n=36 for Round 2 unless otherwise stated.

<b>Participant demographics</b>	<b>Round 1</b>	<b>Round 2</b>
<b>Area of the care pathway currently working in</b>		
Specialist acute hospital only	10	9 (25.0%)
General acute hospital only	(25.0%)	2 (5.6%)
Hyperacute NRU only	2	1 (2.8%)
NRU only	(5.0%)	15 (41.7%)
Community or specialist nursing home only	2	2 (5.6%)
More than one of the above settings	(5.0%)	7 (19.4%)
	17	
	(42.5%)	
	2	
	(5.0%)	
	7	
	(17.5%)	
<b>Geographical area/s currently working in</b>		
England	38	34 (94.4%)
Wales	(95.0%)	1 (2.8%)
Scotland	1	1 (2.8%)
	(2.8%)	
	1	
	(2.8%)	
<b>Sectors currently employed by</b>		
NHS	33	29 (80.6%)
Charity	(82.5%)	3 (8.3%)
Private	3	1 (2.8%)
Other	(7.5%)	1 (2.8%)
More than one sector	1	2 (5.6%)
	(2.5%)	
	1	
	(2.5%)	
	2	
	(5.0%)	
<b>Current banding</b>		
Band 5	3	3 (8.3%)
Band 6	(7.5%)	6 (16.7%)
Band 7	8	18 (50.0%)
Band 8a	(20.0%)	9 (25.0%)
	19	
	(47.5%)	
	10	
	(25.0%)	
<b>Length of time working as a SLT (years)</b>		

Median (IQR)	12.5 (9.0)	13.0 (8.8)
Minimum: Maximum	1:30	1:30
<b>Length of time working with patients in PDOC (years)</b>		
Median (IQR)	6.0 (6.0)	6.0 (6.8)
Minimum: Maximum	1:22	1:22
<b>Settings worked with patients in PDOC</b>		
Specialist acute hospital only	5 (12.5%)	4 (11.1%)
General acute hospital only	1	1 (2.8%)
Hyperacute NRU only	1 (2.5%)	3 (8.3%)
NRU only	4	7 (19.4%)
Community or specialist nursing home only	4 (10.0%)	1 (2.8%)
More than one of the above settings	8 (20.0%)	20 (55.6%)
	1 (2.5%)	
	21 (52.5%)	
<b>Country where SLT training completed</b>	n=39	n=35
UK	36 (90.0%)	32 (88.9%)
Australia	1	1 (2.8%)
America	1 (2.5%)	2 (5.6%)
	2 (5.0%)	
<b>Teaching on PDOC in SLT qualification</b>		
Yes	1 (2.5%)	1 (2.8%)
No	32 (80.0%)	28 (77.8%)
Do not remember	7 (17.5%)	7 (19.4%)
<b>Attended formal training on working with patients in PDOC since qualifying</b>		
Yes	29 (72.5%)	25 (69.4%)
No	11 (27.5%)	11 (30.6%)
<b>Developed skills/knowledge of working with patients in PDOC in other ways</b>		
Informal on the job training only	11 (27.5%)	9 (25.0%)
Formal on the job training only	1	1 (2.8%)
Other only	1 (2.5%)	3 (8.3%)
More than one of the above	3 (7.5%)	23 (63.9%)
	25 (62.5%)	
<b>Independent management of patients with tracheostomies</b>		
Yes	32 (80.0%)	30 (83.3%)
No	8 (20.0%)	6 (16.7%)
<b>Trained in The Sensory Modality Assessment and Rehabilitation Technique (SMART)</b>		
Yes	13 (32.5%)	11 (30.6%)
No	27 (67.5%)	25 (69.4%)
<b>Trained in Facial-Oral Tract Therapy (FOTT)</b>		

Yes	9	8 (22.2%)
No	(22.5%)	28 (77.8%)
	31	
	(77.5%)	

### Assessment

Consensus was reached in Round 1 for 75% (12/16) of statements regarding assessment of patients in PDOC. Participants generated 250 justifications and comments for analysis.

Themes drawn from content analysis for each statement for all sections (assessment, management and service delivery) of the Round 1 questionnaire can be seen in the Round 2 questionnaire. Examples of codes and themes for all three sections can be seen in the Supporting Information (see S3).

As a result of the Round 1 analysis, one statement was reworded and a further statement was split into two. Eleven new statements on assessment were generated by the participants in Round 1 for inclusion in Round 2.

After Round 2, 85.7% (24/28) statements regarding assessment of patients in PDOC reached consensus. Table 3 shows the percentage agreement for the final statements regarding assessment.

Table 3 about here.

**Table 3.** Final percentage agreement for statements on assessment. Percentage denotes percentage of participants agreeing with statement unless otherwise stated. Statements are

listed in order of percentage agreement. Statements in grey did not reach consensus. n=36 unless otherwise stated.

<b>Statements regarding assessment</b>	<b>Final % agreement</b>
SLTs should be involved in the completion of formal assessments of the awareness level of patients in PDOC	100
SLTs should work as integral part of an MDT when assessing patients in PDOC	100
SLTs should complete informal assessments of the awareness level of patients in PDOC (n=40)	100
SLT assessment should include observation of the communicative behaviours of patients in PDOC in a range of settings, including with family and friends (n=40)	100
SLT assessment should include observation of the communicative behaviours of patients in PDOC with both familiar and unfamiliar stimuli (n=40)	100
SLT assessment should include assessment of the ability of patients in PDOC to follow commands (n=35)	100
SLT assessment should include assessment of the ability of patients in PDOC to make meaningful choices (n=35)	100
SLT assessment should include assessment of oral hypersensitivity / oral reflexes of patients in PDOC (n=34)	100
SLT assessment should include assessment of the ability of patients in PDOC to manage their oral secretions	100
SLT assessment should include assessment of the ability of patients in PDOC to tolerate cuff deflation and speaking valve (for tracheostomy patients) (n=32)	100
SLTs should model the appropriate approach to assessments of awareness for all involved in a patient in PDOC's care	97.2
SLTs should be involved in the completion of the Wessex Head Injury Matrix for patients in PDOC	97.2
SLTs should gather information from the families/friends of patients in PDOC regarding the patient's specific interests and potentially motivating stimuli	97.2
SLT assessment should include bedside assessment of swallowing of medically stable patients in a minimally conscious state / suspected MCS (if yet to be diagnosed)	97.2
SLT assessment should include assessment of the ability of patients in PDOC to answer yes/no questions (n=35)	97.1
SLT assessment should include assessment of the ability of patients in PDOC to use alternative and augmentative communication (AAC) (n=35)	94.3
SLTs should be involved in the completion of the Coma Recovery Scale-Revised (CRS-R) for patients in PDOC	88.9
In conjunction with the MDT, SLTs should contribute to the assessment of a patient in PDOC's sensation	88.9
In conjunction with the MDT, SLTs should contribute to the assessment of a patient in PDOC's motor responses	83.3
SLTs should be involved in the completion of The Sensory Modality Assessment and Rehabilitation Technique (SMART) for patients in PDOC	83.3
In conjunction with the MDT, SLTs should contribute to the assessment of a patient in PDOC's vision	80.6
SLT assessment should include instrumental assessment of swallowing of patients in PDOC (n=35)	80.0
SLTs working with patients in PDOC should refer to a speaking valve as a one-way valve (n=29)	79.3
SLT assessment should include bedside assessment of swallowing of	77.8

medically stable patients in a vegetative state / suspected VS (if yet to be diagnosed)	
Patients in PDOC are frequently able to tolerate videofluoroscopy (n=31)	70.9 (disagree)
Patients in PDOC are frequently able to tolerate fibreoptic endoscopic evaluation of swallowing (n=28)	60.7
All patients in PDOC should have an instrumental swallowing assessment before commencing oral trials/therapeutic feeding (n=35)	40.0
SLTs should offer cough reflex testing for patients in PDOC	38.9

## Management

There was a high level of consensus regarding SLT management of patients in PDOC in Round 1 with 92.8% (13/14) of statements reaching consensus. Participants produced 164 justifications and comments for analysis resulting in three statements being reworded for Round 2. Ten new statements were also generated by the participants for rating in Round 2.

After Round 2, 95.8% (23/24) of statements had reached consensus. Table 4 shows the percentage agreement for the final statements on SLT management of patients in PDOC.

Table 4 about here.

**Table 4.** Final percentage agreement for statements on management. Percentage denotes percentage of participants agreeing with statement. Statements are listed in order of percentage agreement. Statements in grey did not reach consensus. n=36 unless otherwise stated.

Statements regarding management	Final % agreement
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SLTs should work as integral part of the MDT in the management of PDOC patients	100
SLTs should provide swallowing advice to other professionals regarding patients in PDOC (n=40)	100
SLTs should provide swallowing advice to family/friends of patients in PDOC (n=39)	100
SLTs should provide communication advice regarding patients in PDOC to other professionals (n=35)	100
SLTs should provide communication advice to family/friends of patients in PDOC (n=35)	100
SLTs should provide training to staff and families regarding opportunities for interaction for patients in PDOC (n=40)	100
SLTs should provide programmes to manage oral hypersensitivity in patients in PDOC (n=35)	100
SLTs should be involved in decision making regarding the management of oral secretions of patients in PDOC (n=40)	100
SLTs should consider use of oral trials as part of their management plan for patients in PDOC (n=35)	100
SLTs should be involved in planning tracheostomy weaning of patients in PDOC (n=32)	100
SLTs should be involved in training other professionals about PDOC	100
SLTs should model the appropriate level of stimulation and approach to interacting with patients in PDOC for all involved in their care	100
SLTs should be involved in MDT decision making for patients in PDOC (n=40)	100
SLTs should be involved in best interest meetings	100
SLTs should carefully manage the expectations of family/friends of patients in PDOC	100
SLTs should regularly monitor for changes in communicative behaviours of patients in acute PDOC	97.2
For PDOC patients demonstrating the physical ability to access AAC devices (e.g. switches/eye gaze), SLTs should provide programmes to give patients the opportunity to learn to use AAC	97.2
SLTs should provide information to families regarding disorders of consciousness, monitoring sensation input and guidance on what they can do to help	97.2
SLTs should be involved in mental capacity assessments of patients in PDOC	97.2
SLTs should support families to understand the outcome of mental capacity assessments of patients in PDOC	91.7
SLTs should be involved in decision making regarding the use of botulinum toxin for management of bite reflex	86.1
In conjunction with the MDT, SLTs should be involved in creating sensory stimulation programmes for patients in PDOC	86.1
SLTs should be involved in Court of Protection cases	80.6
SLTs should provide FOTT to patients in PDOC (n=35)	54.3

## Service Delivery

Only one of 15 of statements regarding service delivery reached consensus in Round

1. However, for some statements where participants could select more than one response option, some options also reached consensus. As consensus was not

reached on all options for these statements, this information was used to reword these statements for Round 2.

Participants produced 307 comments and justifications for analysis in this section.

Eleven statements were amended for Round 2 and ten new statements were generated by the participants.

After Round 2, there was a marked increase in the number of statements reaching consensus with 80.0% (20/25) of statements achieving consensus. See Table 5 for the percentage agreement for the final statements regarding service delivery.

Table 5 about here.

**Table 5.** Final percentage agreement for statements on service delivery. Percentage denotes percentage of participants agreeing with statement unless otherwise stated. Statements are listed in order of percentage agreement. Statements in grey did not reach consensus. n=36 unless otherwise stated.

<b>Statements regarding service delivery</b>	<b>Final % agreement</b>
Sessions during an AAC trial for a patient in PDOC should initially be delivered by SLT (in conjunction with OT/PT as needed) followed by involving AHP assistants, nursing staff, family/friends if deemed by SLT to possess the appropriate skills	100
SLTs should provide training to staff, family and friends of patients in PDOC to enable them to be involved in the delivery of AAC programmes	100
SLTs should provide training to staff, family and friends of patients in PDOC to enable them to be complete oral hypersensitivity programmes	100
SLTs should be involved in the creation of MDT guidelines for patients in PDOC	100
There is sufficient training for SLTs on working with patients in PDOC (n=35)	100 (disagree)
Oral hypersensitivity needs of patients in PDOC should be regularly reviewed throughout the pathway	97.2
Oral hypersensitivity programmes for patients in PDOC should be set up by SLT and completed by any person deemed by SLT to possess the appropriate skills	97.2
Oral trials for patients in PDOC should be delivered by an SLT until the patient appears to be stable in their tolerance, before training other members of staff and family to undertake them	97.2
SLTs working with PDOC should have a thorough understanding of relevant national guidelines/policies e.g. Royal College of Physicians Guidelines	97.2
SLTs should work as an integral part of a tracheostomy MDT to facilitate tracheostomy weaning of PDOC patients (n=30)	96.7
The ability of a patient in PDOC to use AAC should be regularly re-explored throughout the patient journey dependent on patient need	94.4
Universities should provide basic teaching on PDOC to student SLTs	94.4
Tracheostomy weaning of patients in PDOC should commence as early as	

possible once the patient is medically stable irrespective of setting (n=30)	93.3
Oral hypersensitivity assessment and intervention for patients in PDOC should commence as early as possible once the patient is medically stable	91.7
There should be a standard competency framework for use by SLTs when training in PDOC	91.7
Assessment and intervention for oral feeding of patients in PDOC should commence as early as possible once the patient is medically stable irrespective of setting	88.9
Patients in a chronic DOC in community settings should be managed by specialist outreach therapy teams	88.9
SLTs should be involved in yearly reviews of patients in chronic DOC	88.9
<b>Statements regarding service delivery continued</b>	<b>Final % agreement</b>
Oral hypersensitivity programmes for patients in PDOC should be delivered: (n=35)	85.7
a. More than once per day	11.4
b. Daily (including weekends)	2.9
c. Daily (weekdays only)	0
d. 3-4 times per week	0
e. 1-2 times per week	0
f. Less than weekly	0
g. Other	0
Assessment and intervention for use of AAC in patients in PDOC should commence as early as possible irrespective of setting	83.3
The frequency of sessions during an AAC trial for a patient in PDOC should be: (n=35)	42.9
a. More than once per day	25.7
b. Daily (including weekends)	17.1
c. Daily (weekdays only)	14.3
d. 3-4 times per week	0
e. 1-2 times per week	0
f. Less than weekly	0
g. Other (R1) / No predetermined minimum frequency (R2)	0
SLTs working with PDOC patients should offer a 7 day service (n=35)	40.0 (disagree)
The minimum frequency of involvement by SLT in tracheostomy weaning of a patient in PDOC, who is actively being weaned, should be: (n=30)	0
a. More than daily	23.3
b. Daily (including weekends)	3.3
c. Daily (weekdays only)	36.7
d. 3-4 times per week	16.7
e. 1-2 times per week	0
f. Less than weekly	20.0
g. No predetermined minimum frequency	20.0
The length of a trial of an oral hypersensitivity programme for a patient in PDOC should be patient dependent but with a minimum length of:	0
a. Less than 1 week	2.8
b. 1 week	33.3
c. 2 weeks	11.1
d. 3 weeks	19.4
e. 1 month	19.4
f. Longer than 1 month	13.9
g. No predetermined minimum	13.9
The length of a trial of the ability of a patient in PDOC to use an AAC device should be patient dependent but with a minimum length of:	2.8
a. 1 week	2.8

b. 2 weeks	25.0
c. 3 weeks	16.7
d. 1 month	19.4
e. Longer than 1 month	22.2
f. No predetermined minimum	13.9

## Discussion

The aim of this study was to ascertain the degree of consensus amongst expert SLTs regarding SLT best practice for patients in PDOC. An expert panel of 36 SLTs reached consensus on 67 statements covering assessment, management and service delivery for patients in PDOC. Only 10 statements did not achieve consensus by the end of the Delphi process. Consensus was reached for 85.7% of (24/28) statements regarding SLT assessment, 95.8% of (23/24) statements for SLT management and 80.0% of (20/25) statements regarding service delivery. Overall, there was a high degree of consensus amongst expert SLTs regarding best practice.

The findings and the RCP PDOC guideline (RCP 2013)

Consensus was reached regarding all statements developed by the researcher from the RCP PDOC guideline. Participants frequently referred to it, for example, 'as in the RCP guidance', suggesting that the high degree of consensus on these statements might be due to SLTs in this field having good knowledge of the guideline.

Participants also generated statements that reached consensus relating to areas of the guideline not necessarily considered the role of SLTs, for example, contributing to the assessment of motor function. This suggests that the role of SLTs with this patient group might be wider, and involve more MDT working, than other caseloads.

The findings and key areas of SLT practice

### Dysphagia

SLTs reached consensus on many statements regarding dysphagia assessment, management and service delivery. A particular area of contention between the

literature and the findings, and also between participants, concerned instrumental assessment of swallowing.

Consensus was reached that SLTs should include instrumental assessment in their assessment of dysphagia. However, consensus was not reached regarding whether instrumental assessment is always needed prior to commencing therapeutic feeding. Authors on this topic state that all patients should have an instrumental assessment but provide limited evidence for their view (Brady *et al.* 2006; 2009, O'Neil-Pirozzi *et al.* 2003). It is clear that some SLTs here agree with this, but many disagreed. Some of the common themes relating to this were: the importance of bedside swallowing assessment prior to instrumental assessment; concern over potential delay in commencing therapeutic feeding if awaiting instrumental assessment; and SLTs possessing specialist skills to make judgements regarding need for instrumental assessment.

There was no consensus amongst SLTs regarding the ability of patients in PDOC to tolerate videofluoroscopy or fiberoptic endoscopic evaluation of swallowing (FEES). Some of the common themes relating to this were: difficulties this population have actively participating in instrumental assessment; difficulties with seating and positioning and concern over taking patients off wards for videofluoroscopy. Differences of opinion regarding this may also reflect variation in SLTs' exposure or ability to access FEES.

However, despite this lack of consensus, the quantitative and qualitative analysis suggest that SLTs feel that patients in PDOC tolerate FEES better than videofluoroscopy (60.7% agreement that patients can frequently tolerate FEES compared with 70.9% disagreement that they can frequently tolerate videofluoroscopy). Unfortunately, neither of the studies by Brady and colleagues (2006; 2009) reported how many patients had a videofluoroscopy versus FEES, and therefore this cannot be compared to the available literature.

In terms of SLT best practice, SLTs in this study certainly agreed that instrumental assessment should be a part of dysphagia assessment for patients in PDOC. However, the findings also suggest that a personalised approach may be needed when considering whether a patient is appropriate for an instrumental assessment, and whether therapeutic feeding can be commenced prior to this.

### **Oral reflexes**

SLTs reached consensus on almost all aspects of SLT assessment, management and service delivery relating to this area of practice.

Only two statements related to oral reflexes did not reach consensus. One of these was regarding the minimum amount of time to trial an oral hypersensitivity programme. However, whilst the statement did not reach consensus, 83.2% of participants selected on option which was two weeks or more, and this has the potential to be used a minimum guide.

The only other statement that did not reach consensus on this topic related to the use of Facial-Oral Tract Therapy (FOTT). Whilst FOTT was mentioned in Millwood *et al.*'s (2005) study on patients in PDOC, its effectiveness was not investigated. Furthermore, there is limited evidence for FOTT in general (Kjaersgaard, Nielsen and Sjölund 2014). The common themes regarding FOTT in this Delphi study were: that it is possible to use some FOTT principles without applying all aspects; a concern over lack of evidence for FOTT, and whether it needs to be FOTT itself versus other similar approaches. Since only 22.2% (8/36) of participants were trained in FOTT, this may also have influenced the finding.

### **Communication**

#### Augmentative and Alternative Communication

Consensus was reached regarding some aspects of AAC for patients in PDOC that is complementary to the existing research literature. However, as Lancioni and

colleagues' studies were conducted on patients in non-acute settings, there are elements of AAC service provision which reached consensus that have not previously been discussed in the literature. For example, the importance of assessment commencing as early as possible and ability to use AAC being regularly reviewed throughout the pathway.

Some statements regarding AAC did not reach consensus, including the length of a trial of AAC and how frequently an AAC trial should be delivered. Despite this, when grouped together 83.2% of participants selected two weeks or more and 85.7% of participants selected an option that was at least daily on weekdays. SLTs may be able to use that as a minimum guide in their clinical practice. The variation in opinion regarding this may reflect that SLTs consider these facets of service delivery to be patient specific. This is in accordance with Lancioni and colleagues who varied length of time and frequency from participant to participant (e.g. Lancioni et al. 2009; 2014).

## **Emergence**

The word 'emergence' was not specifically used in any of the statements but assessment of areas of communicative behaviour that contribute to the diagnosis of emergence was used. Unfortunately, Pundole and Crawford's (2018) review paper was not published until after Round 1 began, and therefore statements relating to it were not included in the study.

SLTs in this study reached consensus that SLT assessment should include assessment of yes/no, ability to follow commands, and ability to make choices. Consensus on choice making is of particular interest. This is because this method of communication relies less on language and may be useful in determining emergence from PDOC in patients who have concomitant aphasia (Pundole and Crawford 2018).

Overall, consensus regarding topics related to emergence were in line with recommendations from Pundole and Crawford (2018). These authors, however, provide more detail regarding assessment of emergence than was covered in this

study. Therefore, when formulating guidelines or reflecting on clinical practice, their review should be considered, in conjunction with findings here.

## **Tracheostomy**

Prior to this study, there was no literature regarding SLT involvement with tracheostomised patients in PDOC. Consensus was reached on components that correspond to other national guidance, such as, NCEPOD (2014) recommendations regarding SLT contribution to decannulation.

Consensus was also reached that speaking valves should be referred to as 'one-way valves' when working with patients in PDOC. This has not previously been commented upon in the literature or guidance. The reason given for this by participants was that the term 'speaking valve' may result in the inaccurate assumption by staff/relatives that the patient will be able to speak when using it.

There was no consensus regarding the minimum involvement of SLTs in the weaning of tracheostomised PDOC patients. This may be due to differences in opinion regarding how much SLTs should be involved, but also may reflect differences in clinical settings or clinicians' expertise.

## **Strengths and Limitations**

While it was not possible to calculate a response rate for Round 1, the participant numbers were within the appropriate range for a Delphi study (Akins, Tolson and Cole 2005). Furthermore, the response rate for Round 2 was high, at 90%. Overall, the level of engagement in the study suggests that the topic area is one that other SLTs feel is worthy of being researched.

Another key strength was the large volume of qualitative data generated from Round 1 which allowed for detailed qualitative feedback to participants. This is not always a component of Delphi studies and is likely to have resulted in more robust findings, as



changes in participants' views are less likely to be solely the effect of normative pressure (Murphy *et al.* 1998).

Defining an 'expert' is a key issue in Delphi studies, with some researchers expressing concern that not all participants may be sufficiently expert (Keeney, Hasson and McKenna, 2001). It is possible that the criteria for this study resulted in some participants taking part who would not be considered an 'expert'. However, due to the total sample size this is unlikely to have made a significant difference to the findings.

A key limitation of the study was that there was not equal opportunity for consensus amongst statements. The different scales used for the statements regarding frequency and duration meant that there were a varying number of response options, and the responses were not grouped for analysis. This may have affected the opportunity for consensus for those statements, and further consideration of the scales may have been beneficial, particularly those relating to service delivery.

A further limitation is that no opportunity for participants to rank statements in subsequent rounds was offered due to time and funding constraints. In the context of current clinical practice, it may not be possible to implement all aspects of best practice due to for example, staffing or funding issues. Therefore, a further round giving participants the opportunity to rank statements may have been beneficial.

### **Future directions**

Delphi study findings are participants' opinions, therefore, whilst this study provides useful information for SLTs given the dearth of experimental research evidence, it is crucial to utilise it to identify future research.

For any experimental research conducted in this field, it will be important to collaborate nationally and potentially internationally, to ensure sufficient participant numbers to be able to conduct methodologically sound experimental research. Fulfilment of the RCP's

2013 recommendation of a UK database of patients in PDOC would help with this process.

Although this study solely focused on SLT best practice for patients in PDOC, the difficulties with research in this population, and the reliance on guidelines that have not been scientifically formulated, are the same for other professional groups.

Consequently, it may be beneficial for other allied health professionals to complete Delphi studies regarding best practice for PDOC in their own clinical areas. The methodology used in this study could provide a useful basis for this.

Finally, it has hoped that this research could provide the starting point for developing SLT guidelines for working with this patient group, a first step to achieving this might be convening a focus group of SLT experts to rank the statements for importance for inclusion in any future guidelines.

## **Conclusion**

This is the first Delphi study on SLT best practice for patients in PDOC. It is also one of only a small number of studies that addresses SLT for this patient group.

The best practice statements generated in this study provide a useful starting point for the creation of SLT guidelines and a competency framework to support best practice and appropriate training for SLTs. They also have the potential to empower SLT departments to advocate for services for this client group.

The utilisation of the findings of this study has the potential to benefit patients, their families and the NHS by providing more equitable, evidence-based SLT services to patients in PDOC. Future research should focus on establishing whether the opinion of expert SLTs regarding best practice is supported by experimental research.

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