

The Putney Prolonged Disorders of Consciousness Toolkit



A set of practical resources to support the assessment and monitoring of patients in a Prolonged Disorder of Consciousness

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Royal Hospital for
Neuro-disability

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Rationale

Informal assessment

Toolkit is a set of resources to support assessment and monitoring

Set of non-standardised assessments

Aims to support patient-centred assessment in a more flexible way

Supports clinicians to clinically evaluate behaviours in areas of uncertainty



Rationale

Informal assessment

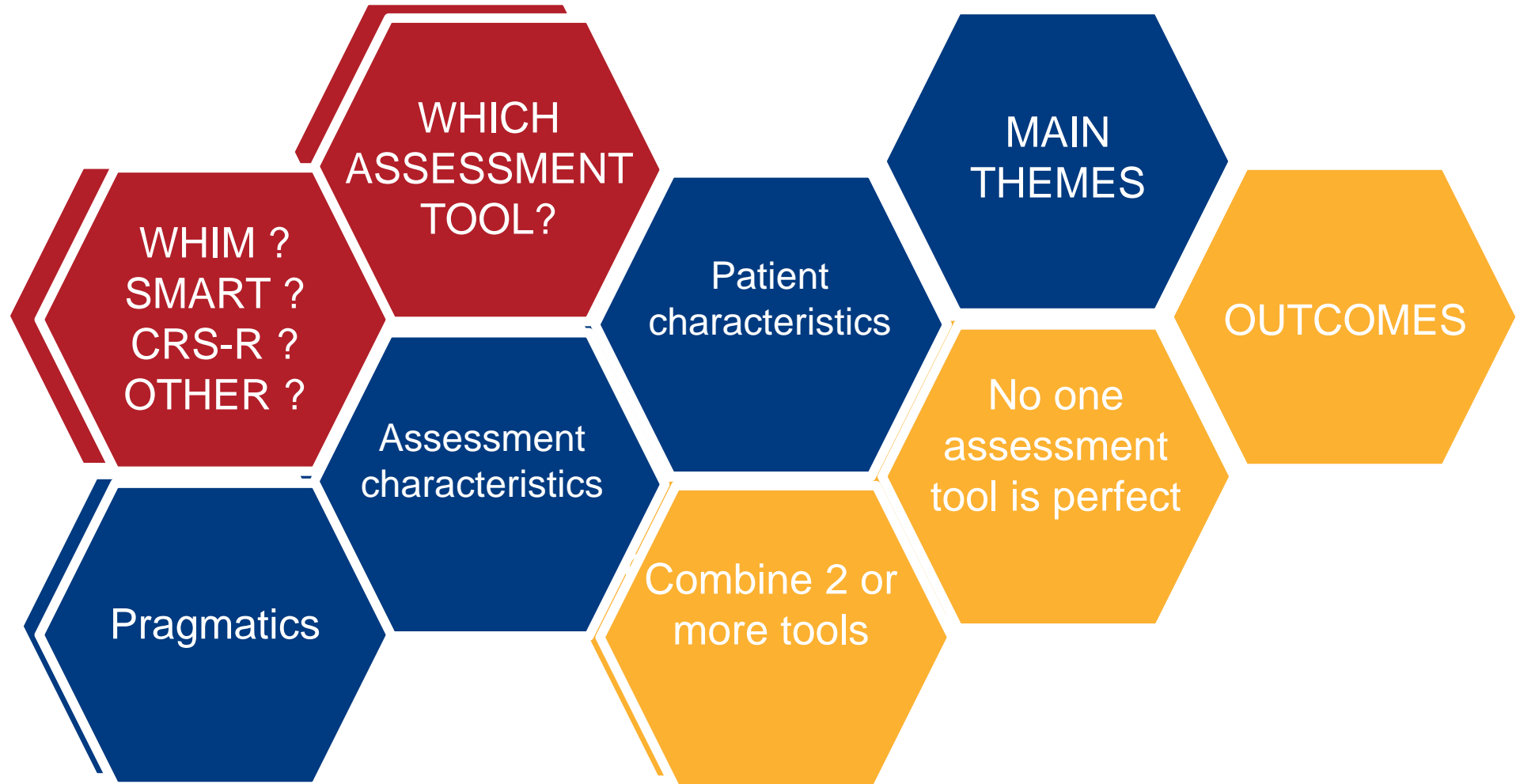
Supports the formal assessment process

Enables clinicians to collect evidence, in a meaningful environment, on behaviours to:

- Support diagnosis
- Support family/carer education
- Identify and signpost the highest level of response that can be further explored



How do we build a picture of a patient in a PDOC?



24 hour management

- **Recording and fostering regular sleep-wake patterns**
- **Creating an environment with light and dark periods**
- **Consider the environment in all contexts**
- **How to ensure the individual is best supported to be able to demonstrate what they are able to do**



24 hour management

- Weekly planner
- ‘Help me get a good rest’ guidelines
- Arousal monitoring
- Arousal chart (24 hours)

Weekly planner: [patient name] Ward: [ward name]

Please space therapy sessions throughout the day as much as possible. w/c 16 July 2018

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
8.00							
8.15	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION
8.30							
8.45			WASH		WASH		
9.00							
9.15			REST PERIOD		REST PERIOD		
9.30							
9.45							
10.00							
10.15							
10.30			THERAPY ASSESSMENT		THERAPY ASSESSMENT		
10.45							
11.00			REST PERIOD		REST PERIOD		
11.15							
11.30							
11.45						WASH	
12.00							
12.15	SHOWER	WASH		SHOWER			
12.30						MEDICATION	MEDICATION
12.45							
13.00	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	REST PERIOD	
13.15	REST PERIOD	REST PERIOD	BACK TO BED	REST PERIOD	BACK TO BED		
13.30							
13.45							WASH
14.00		SENSORY ART GROUP		SENSORY MUSIC GROUP			
14.15							
14.30							REST PERIOD
14.45							
15.00							



Behavioural Observations

- Need to understand what the patient is doing at rest when no stimuli have been applied

BASELINE OBSERVATIONS

Name Date NHS number

Environment Time

Observe the patient in a quiet room without any stimuli for five minutes. You can see the patient in bed or a chair. Make sure the whole of the patient's body is visible.

Instructions

Observe the patient for 15 seconds. Write a brief description of each behaviour observed eg eyes open; mouth twitch; and place tick(s) in column (1) to indicate you saw the behaviour. Write what you see – don't worry about using jargon. Continue observing for 15 second periods, ticking any behaviours already observed and indicating any new ones, until five minutes is complete.

Description of behaviour	Frequency of behaviour																			
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20



Behavioural Observations

Eye Movement Observations

- Tally of number of blinks
- Direction of the eyes
- Observations

Tally Charts

Facial movements

Observe for two minutes

Raise corners of mouth (as if smiling)	Twitch right cheek	Lower eyebrows (as if frowning)	Eyes up

EYE MOVEMENT OBSERVATION

Name Date NHS number
 Environment Time

Instructions

Observe eye movement for 5 minutes as follows:

- Use a stopwatch/timer and observe eyes for 1 minute. Record what you see in the chart below by doing a tally of number of blinks and drawing directional arrows on the eyes showing where the patient was looking.
- Repeat 5 times until 5 minutes have been observed.
- You can record for 5 minutes and fill in the chart by watching the video back after.

Minute	Number of times blinked (tally)	Eye movement	Observations e.g. long time between blinks
Example		Right eye Left eye Tick the centre of the circle if the patient was looking straight ahead	This patient looked straight ahead, up, to his left and upper left. He blinked 4 times in one minute. (Make a note if there are any distractions such as a loud noise; direction of their gaze normally; or no movement.)
1		Right eye Left eye Tick the centre of the circle if the patient was looking straight ahead	
2		Right eye Left eye Tick the centre of the circle if the patient was looking straight ahead	
3		Right eye Left eye Tick the centre of the circle if the	



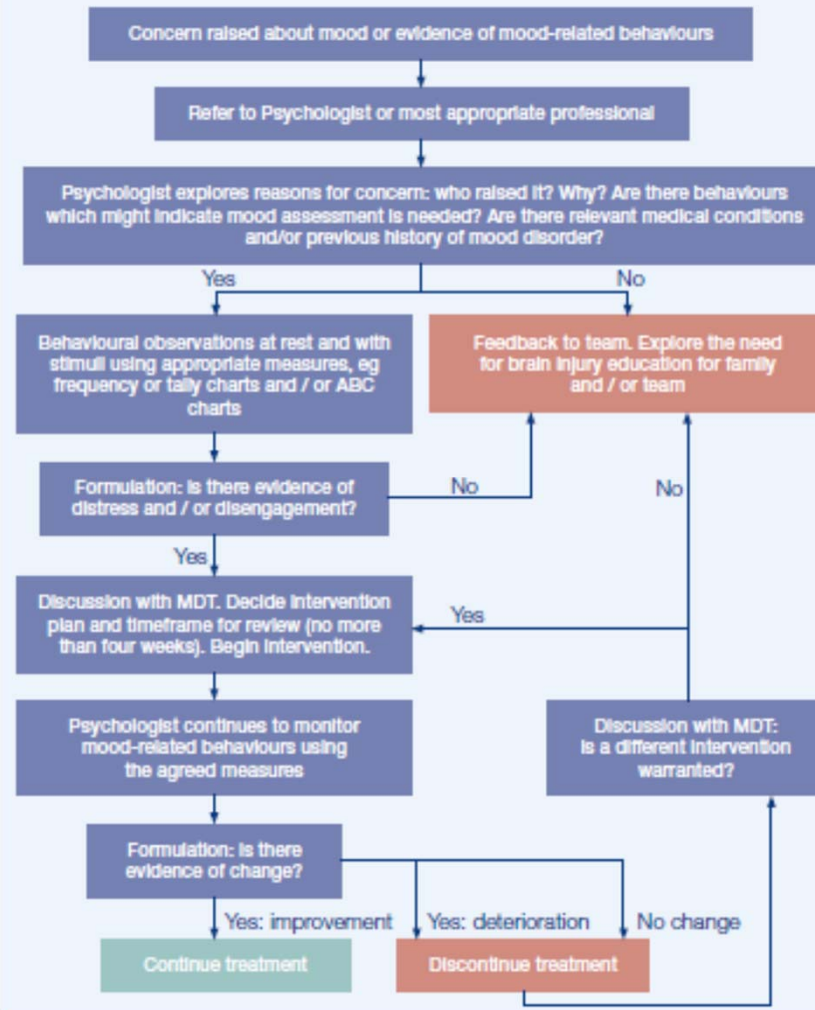
Emotional Responses

- Range of behaviours that are usually linked with emotions, such as tears, grimacing, smiling
- Difficult to score on formal tools
- Individualised approach that avoids words such as 'depression' and 'pain' and focuses instead on behaviours.
- Use a flow chart when team raise concerns about low mood
- Measure behaviours before, during and after treatment (antidepressants/neurostimulants/behavioural activation)



Emotional Responses

Flowchart for exploring mood-related concerns in patients in PDOC












Interactions

- **Lack reliable communication**
- **We set up the environment to promote appropriate interaction/communication wherever possible**
- **Chat Mat – what to talk about**
- **Communication passport – how to talk to me**
- **‘Help me fill my free time’- appropriate leisure activities and how to monitor**








Chat Mat

<p>I live in Kent with my wife Anne</p> 	<p>I have a daughter called Eve and a son called Daniel. Eve is 17 and Daniel is 10.</p>	 <p>I love animals. I have a pet Labrador called Jem.</p>	<p>I have an eclectic taste in music...</p> 	<p>...from the Rat Pack, to Marvin Gaye and Metallica.</p>	<p>I enjoy banter with others.</p> 
 <p>I work for Royal Mail as a postman.</p>	<p>[Insert photo of patient here]</p> <p>Hi! My name is Joe. Please use this chat mat to talk to me about things I am interested in.</p>			<p>I like going to the cinema.</p> 	
<p>I like to fish and scuba dive.</p> 				<p>My favourite films are Raging Bull and The Godfather trilogy.</p>	
<p>My favourite holiday was scuba diving in Australia.</p> 				<p>I like listening to BBC Radio 5 live. I support Tottenham Hotspur.</p> 	



Communication Passport

	How to help me communicate
	I cannot express my needs reliably by any means; please make choices which are in my best interests
	Explain simply who you are and what you are doing before you help or move me
	Sit beside me and talk to me in a calm and relaxed way. Talk about my family and topics of interest see my Chat Mat for ideas
	Try giving me simple questions and commands to work on my understanding –see if I am able to respond
	Look out for me watching and tracking things – show me familiar objects, photos, and pictures



Functional Objects

- **Emergence criteria**
- **Functional assessment with everyday familiar objects**
- **Record which objects trialled, how they are held and manipulated**
- **Do they use the object appropriately**



Using objects

Functional use of objects

Name NHS number

Please complete every session so we can monitor how the patient is using objects.

Try to give him/her at least two objects during a session and help him/her to use them. You may need to start him/her off then see if he/she continues, eg tissue, hairbrush, lip balm, pen, cup with syrup thickened drink. Think about whether he/she holds and manipulates the object in a way that accommodates its size, shape and purpose.

You may need to support the object in his/her hand and start the movement eg bringing the cup up towards his/her mouth.

Date	Environment / positioning	Objects trialed	How does he/she hold and manipulate the object?	Comments (include any facilitation given)
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>				
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Following Commands

- **Used to distinguish VS/MCS**
- **Need individual approach**
- **'Top tips'**
- **Pick right command**
- **Compare to movements at rest**
- **Try rewording or modelling**



Swallowing

- **The 2013 RCP PDOC guidelines consider oral feeding a form of sensory stimulation**
- **Intentional behaviours such as anticipatory mouth opening or licking residue from lips**
- **Additional information on interaction, communication and awareness by providing a functional context in which to communicate likes/dislike/choices/'more'**
- **Little research in this area**
- **Practical ideas for SLTs**
- **What to look for in PDOC swallow assessment**
- **Guidance on clinical reasoning and best interests decision making**



Swallowing



FOR SPEECH AND LANGUAGE THERAPY ONLY

PDOC swallowing assessment

1 Environment and Context

Comments around the patient's positioning, alertness, the location of assessment and any people who are present/feeding, medical or medication changes (craniofacial).

2 Saliva management status

Medications prescribed, drooling, pooling saliva orally, trachea.

3 Modified oro-motor assessment

Comment on symmetry, mouth opening, oral hygiene, spasms or baseline movements. Rate of spontaneous swallows. Abnormal reflexes (e.g. bite, tongue thrust, tooth grinding).

4 Pre-oral Stage assessment

Visual focus on item, tracking, reaching/localising, choice making or discrimination, response to smell, following a command in context, holding cup/spoon appropriately, manipulating the object appropriately, using the object, responding to a question, indicating they want food or drink, response to tactile prompt/hand over hand facilitation.

5 Oral Stage Assessment

Check for primitive reflexes:

- Rooting (gently stroke the side of the patient's mouth and look for them turning towards the stimulus)
- Sucking (place their (or your) finger side-on between their lips and look for sucking)
- Snout (tap their upper lip in the centre, look for a puckering of the lips)
- Chewing (depress lower mouth with tongue depressor/finger)

Check for hypersensitivity, consider oral stimulation to prepare for intake.

Trial with patient's own finger dipped in food/drink.

Anticipatory mouth opening, response to touch of spoon/cup, appropriate mouth shaping, lip closure, stripping the spoon, initiation of oral transfer, forming and controlling the bolus. Compare full assistance and hand over hand facilitation. Response to residue on lips (can provide extra residue and verbal/visual/tactile prompts).

Indicating they want more, different responses to different tastes.

6 Pharyngeal Stage Assessment

Swallow initiation and timing, signs of aspiration, airway protection.

Conclusions

Did the patient show awareness during the trials, if so how?

Engagement with task, indicating preferences or emotional response. Active oral control versus oral reflexive patterns to move bolus. Swallow safety.

Plan

- Repeat assessment varying the context or items given.
- Plan an individualised treatment programme.
- Consider instrumental assessments, Cough Reflex Testing / FEES
- Patient best interests – harms versus benefits and pre-injury preferences. Least restrictive options.
- Consider the goal of on-going feeding. Nutrition versus opportunities for social interaction.
- Appropriate quantities.



FOR SPEECH AND LANGUAGE THERAPY ONLY

Speech and Language Therapy PDOC swallowing assessment for repeated assessments

Name NHS number

	Date	Date	Date
Environment and Context			
Saliva Management Status			
Modified Oro-motor Assessment			
Pre-oral Stage Assessment			
Oral Stage Assessment			
Pharyngeal Stage Assessment			
Conclusions and Plan			



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Individual Assessment Plans

Individual assessment plan one

Name NHS number

Complete each of the sections below.

	Session one	Session two	Session three	Session four	Session five
Assessor					
Date	DDMMYY	DDMMYY	DDMMYY	DDMMYY	DDMMYY
Time					
Environment					
Position					

	Session one	Session two	Session three	Session four	Session five
Greet patient with a handshake and 'hello'. Note any responses					
Auditory: present auditory stimuli as detailed below and record any responses.					
Play preferred music choice on right					
Play preferred music choice on left					
Play non-preferred music on right					



Emergence

- **Based on suggestions from RCP guidelines**
- **Yes/no and discrimination tasks using autobiographical information, everyday objects and colours**
- **Items visually, semantically and phonologically distinct**



Monitoring

Annual Reviews

- **6 week programme**
- **Looks at behaviours**
- **Seen in either a group setting and/or 1:1**
- **Minimum of 4 sessions**
- **WHIM completed with all patients**
- **CRS-R if used previously**
- **Summary report**

Week	Programme outline
Prior to week one	<ul style="list-style-type: none">• Screening form completed by MDT
Week one	<ul style="list-style-type: none">• Staff planning• Information given to family• First group
Weeks 2 – 4	<ul style="list-style-type: none">• Groups 2 – 4• Individual sessions
Weeks 5-6	<ul style="list-style-type: none">• Results collated• Summary report• Actions identified and an action plan put in place



Monitoring

Annual Reviews – Groups

- **Activities can be varied based on the patient's interests/preferences**
- **Provides an opportunity for patients to respond to a range of sensory stimuli within a meaningful and familiar activity**
- **Patients supported to look at, hear, touch and smell**

Sensory Art Group

- **Using items from the garden such as herbs/ leaves,**
- **Using clay and paint**

Sensory Baking Group

- **Making a variety of sweet and savoury treats based on previous preferences**



Any questions? Ideas?



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