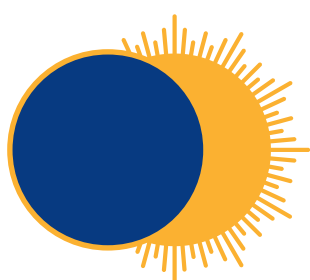




The Putney Prolonged Disorder of Consciousness Toolkit

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

developed at the



Royal Hospital for
Neuro-disability

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Setting the scene

Introduction to the Royal Hospital for Neuro-disability (RHN)

The RHN is a charity, independent from the NHS but working closely with it, to provide the best possible care for people living with neuro-disability.

Established in 1854, the RHN was a prominent Victorian charity receiving support from Florence Nightingale and Charles Dickens. It was the first institution in the UK to care for people living with chronic illness or disability. It was also the first unit set up to assess and look after patients in disorders of consciousness (DOC).

Today the RHN is a respected authority on neuro-disability care. It provides training in neuro-care and research advances into the science of care for people with neuro-disabilities. Its mission is to meet the needs of people with complex disabilities which have arisen from a profound brain injury. This includes those who are deemed to be in a prolonged disorder of consciousness (PDOC).

The assessment and monitoring of individuals in a prolonged disorder of consciousness is complex. As such, the RHN is guided by the Royal College of Physicians National Clinical Guidelines on Prolonged Disorders of Consciousness (2013). These guidelines recommend the use of one or more of the following structured assessment tools:

- **The Wessex Head Injury Matrix (WHIM)** (Shiel A, Horn SA, Wilson BA et al 2000; Wilson FC, Elder V, McCrudden E et al. 2009)
- **The Sensory Modality Assessment and Rehabilitation Technique (SMART)** Gill-Thwaites H 1997; Gill-Thwaites H, Munday R 2004)
- **The JFK Coma Recovery Scale – Revised (CRS-R)** (Seel RT, Sherer M, Whyte J et al 2010; Giacino JT, Kalmar K, Whyte J 2004)

All of these assessment tools are used at the RHN by experienced members of the multi-disciplinary team in the assessment of individuals in a prolonged disorder of consciousness. Indeed the SMART is an award-winning clinical tool, pioneered by Helen Gill-Thwaites MBE at the RHN, along with Ros Munday MBE and Dr Karen Elliott.

In addition to structured assessment tools, the RCP guidelines highlight the critical importance of informal assessments, done over a period of time by specialist teams. It is in this context that experienced staff at the RHN have developed this resource.

The team who developed the toolkit



Susie Wilford

An experienced senior occupational therapist, Susie has worked across specialist disability management and rehabilitation settings. Susie has had a particular interest in working with individuals in a prolonged disorder of consciousness over the past eight years. With leadership and creativity as her core skills, Susie has helped develop and deliver high quality assessment and treatment for individuals in a prolonged disorder of consciousness.



Amy Pundole

Amy Pundole is Clinical Lead Speech and Language Therapist for the Brain Injury Service. She has worked with patients in a Disorder of Consciousness for 13 years contributing to assessment, diagnosis and management. Amy regularly presents at conferences and study days on PDOC and has published papers on Emergence and Assessment. She has recently started a PhD at UCL focussing on how emergence is assessed.



Dr Sarah Crawford

Dr Sarah Crawford is a Consultant Clinical Neuropsychologist and the Professional Lead for Clinical Psychology at the RHN. Her clinical interests include cognition, emotion and behaviour in severe brain injury including PDOC, and providing support for patients' families and their clinical teams. She has published papers on emergence from disorders of consciousness and the psychological needs of patients, families and staff.



Dr Andrew Hanrahan

Andrew has been a Consultant in Neuro-rehabilitation at the RHN since 2014. He is lead consultant for the Brain Injury Service (BIS) and is directly involved in the clinical care of patients in PDOC. His interests span all aspects of the care of these patients and their families. Dr Hanrahan is particularly interested in the practice of decision-making for these patients and their families, within a framework of moral principles, statute, evolving case law and the context in which these patients would otherwise have made decisions for themselves.

Rationale

The 2013 RCP guidelines on prolonged disorders of consciousness (PDOC) emphasise the importance of informal assessment as well as the use of formal diagnostic tools in the diagnosis of PDOC.

The Putney PDOC toolkit is a set of resources to support the assessment and monitoring of patients in a PDOC.

They are a set of non-standardised assessments which have been developed from informal clinical tools used at the RHN by a range of disciplines to support the formal assessment tools already mentioned in the 'Introduction'.

The aim is to support patient centred assessment in a more flexible way and provide a practical resource for clinicians to support evaluation of behaviours in areas of uncertainty, for example tally charts of specific movements.

We have taken the opportunity to consolidate resources developed over the years at the RHN, updated them and plan to make them widely available to clinicians working with patients in a PDOC.

They enable clinicians to collect evidence on each patient's range of behaviours to support diagnosis, educate families and signpost the highest level of response that can be further explored.

The role of optimal stimulation, rest and 'downtime', as well as attention to the immediate nursing and therapy environment is important. A dedicated toolkit can be used in exploring behaviours in different more meaningful environments that mattered to that person now in a PDOC (like outdoors in the garden with sunlight, fragrance and breeze, music, prayer and other enriched micro-environments at the bedside or in their rooms with familiar objects and sounds.)

Areas covered include:

- 24 hour management
- arousal monitoring
- behavioural observations
- emotional responses
- supporting appropriate interactions
- ways to assess and record object use
- assessing and monitoring command following
- assessing response to oral trials
- individual assessment plans
- further ideas for assessing emergence
- ongoing monitoring post assessment
- the use of sensory groups and individual sessions to carry out annual reviews e.g. baking and art groups.

We want to share our resources to save others reinventing the wheel, provide some consistency for assessment across settings and provide ideas that clinicians can develop further.

This resource has been developed and consolidated by staff at the RHN. It is intended to be used by clinical professionals only.

24-hour management

This pays attention to recording and fostering regular sleep-wake patterns and creating an environment with light and dark periods.

During assessment it's important to consider the environment and how to ensure the individual is best supported to be able to demonstrate what they are able to do.

Use of a 24-hour management programme sets the scene, providing structure and routine for the individual, staff and family.

This includes:

- Providing regular rest periods, especially after planned care and before therapy sessions. A person in a PDOC may not need to 'rest', but their brains need to remain relatively unstimulated to make the interpretation of responses to stimuli valid and true. Flickers of awareness may be missed.
- Reframing rest as an active, planned intervention and not merely the absence of stimulation.
- Regulating the amount of sensory stimulation. This may be from something as routine as a shower or personal care, hoisting out into a wheelchair or moving them into a common area.
- Providing planned times for assessment/therapy sessions.
- Providing planned times for family to visit. Sometimes an assessment needs to be rescheduled to accommodate the family's need to have their relative alert and aware enough to engage with them socially. This underpins the bio-psycho-social approach to any intervention.
- Supporting families with education and guidance on how they can best support their loved one.
- The 'Weekly Planner' supports the 24-hour management programme.

Help me get a good rest

This is an example extract from our Personal Support Plan which is sent out at discharge, individualised for a specific patient.

Why is it important to get a good rest?

- Following my brain injury it is likely that I will become fatigued very easily.
- To help me be able to do the most for myself and interact as best I can, it is very important for me to have regular rest periods.
- Rest periods are designed to minimise all stimulation and distractions and help me to recharge and get ready for my next interaction.

Tips for helping me get a good rest

The environment

- Make sure all TVs and radios are off and that the rest space is free from noise
- Ensure the room is a good temperature, not too hot and not too cold.
- Dim or turn off the lights.
- Ask my Doctors, nurses and therapists to co-ordinate my schedule, resulting in the least disturbances possible.

Help me to get comfortable

- Make sure to tell me about my rest period and how long it is going to be for.
- Help me to bed or recline my wheelchair (staff can help)
- Check that my arms, legs and head are resting comfortably.
- Make sure that I am not showing any signs of distress or discomfort and check on me regularly during my rest period to make sure I am safe and comfortable.
- Keep touch and other stimuli to a minimum.
- Minimise disturbances like turning me in bed, changing my clothes, giving me feeds and medication through my feeding tube, or taking non-essential observations (like blood pressure, temperature recordings).

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							
9.30			REST PERIOD		REST PERIOD		
9.45							
10.00							
10.15							
10.30			THERAPY ASSESSMENT		THERAPY ASSESSMENT		
10.45							
11.00							
11.15			REST PERIOD		REST PERIOD		
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							WASH
13.45							
14.00		SENSORY ART GROUP		SENSORY MUSIC GROUP			
14.15							
14.30							REST PERIOD
14.45							
15.00							
15.15							
15.30							
15.45							
16.00							
16.15						BACK TO BED	
16.30							

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
17.00	BACK TO BED	BACK TO BED		BACK TO BED			
17.30	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION
18.00							
18.30							BACK TO BED
19.00							
19.30							
20.00							
20.30							
21.00							
21.30							
22.00	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION
22.30							
23.00							
23.30							
00.00							
00.30							
01.00							
01.30							
02.00							
02.30							
03.00							
03.30							
04.00							
04.30							
05.00							
05.30							
06.00							
06.30	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION	MEDICATION
07.00							
07.30							

Seating tolerance: 4 hours.

Special requests:

Arousal

The level of an individual's arousal will vary depending on a multitude of factors. For example it will be intrinsically linked to their brain injury and/or environmental factors. Understanding which factors impact on arousal will be helpful in managing these and therefore enabling the individual to respond to the application of stimuli during assessment.

Arousal can be monitored using the 'arousal monitoring' form during an activity.

To improve arousal, the 'Arousal Facilitation Protocol' from the CRS-R (2004) can be used.

Obtaining and maintaining arousal for even brief periods of time may be difficult to do. Using nociceptive (pain producing) stimuli may be necessary. However, this must always be done in the most effective way, using standard practices, explaining this to other staff and relatives who may be present.

If an individual has poor wakefulness during the day, it is recommended to complete an 'Arousal chart' to identify any wake/sleep patterns e.g. if a patient is awake during the night and asleep during the day (Yelden K, Duport S, Kempny A, Playford ED 2015).

Arousal Facilitation Protocol

Guidelines

1. The goal of this intervention is to prolong the length of time the patient maintains arousal (i.e. eye opening).
2. The protocol is administered anytime the patient is observed to:
 - a. Exhibit sustained eyelid closure AND/OR
 - b. Stops following commands for a period of at least one minute.
3. Re-administer the arousal facilitation protocol when:
 - a. Sustained eye closure re-occurs OR
 - b. Behavioral responsiveness ceases despite sustained eye opening.

Interventions

1. Present deep pressure stimulation unilaterally to the face, neck, shoulder, arm, hand, chest, back, leg, foot, and toes. The muscle should be firmly grasped at its base between the thumb and forefinger. While squeezing the muscle firmly, it should be "rolled" back and forth through the finger tips three to four times. This procedure should be repeated sequentially working from the facial musculature to the toes. The examiner should assure that there are no internal lines, local injuries (e.g. fractures, contusions, decubiti) or systemic complications (e.g. heterotopic ossification) before administering deep pressure.
2. Administer same on contralateral side.

Extract from the Coma Recovery Scale – Revised (2004)

Authors: Joseph T. Giacino, PhD and Kathleen Kalmar, PhD

Patient name

NHS number

Arousal monitoring

Use this form to record and monitor a patient's arousal before, during and after an activity.

- Say the patient's name and repeat.
- Gently shake shoulders with both hands.
- If patient does not arouse, use the CRS-R 'Arousal Facilitation Protocol' (Giaciano 2004). See reverse for extract from CRS-R.

Date and time	
Environment	
People present	
Status of patient at start	
Activity carried out with patient	
Number and type of prompts given <small>e.g. verbal, auditory, tactile, noxious or any combination of these.</small>	
Status during activity	
Status at end of activity	
Comments	
Name and signature of therapist	

Date and time	
Environment	
People present	
Status of patient at start	
Activity carried out with patient	
Number and type of prompts given <small>eg verbal, auditory, tactile, noxious or any combination of these.</small>	
Status during activity	
Status at end of activity	
Comments	
Name and signature of therapist	

AROUSAL CHART (24 HOURS)

NB a person with their eyes closed is not necessarily asleep.

Name Date NHS number

TIME - AM	EYES OPEN	EYES CLOSED	TIME - PM	EYES OPEN	EYES CLOSED
midnight			12.00 midday		
00.30			12.30		
01.00			13.00		
01.30			13.30		
02.00			14.00		
02.30			14.30		
03.00			15.00		
03.30			15.30		
04.00			16.00		
04.30			16.30		
05.00			17.00		
05.30			17.30		
06.00			18.00		
06.30			18.30		
07.00			19.00		
07.30			19.30		
08.00			20.00		
08.30			20.30		
09.00			21.00		
09.30			21.30		
10.00			22.00		
10.30			22.30		
11.00			23.00		
11.30			23.30		

Behavioural Observations

To understand what an individual is responding to, it is important to understand what they are doing at rest, when no stimuli have been applied.

During the assessment period, frequent 'Baseline Observations' should be carried out at rest. These will help identify patterns of behaviours and support the multidisciplinary team to be able to confirm with confidence whether a behaviour either is or is not in response to the stimuli applied.

In support of this, 'Eye movement observations' should be carried out where it is difficult to establish if an individual is responding to an eye movement request e.g. blink twice, or look up.

Both the CRS-R, and the SMART in particular, include the completion of behavioural observations. Knowledge and experience of using SMART have assisted in the production of these observational tools.

'Tally charts' can also be used to observe small behaviours that occur at rest and which could be interpreted as being functional e.g. blinking; moving a thumb or facial movements.

Family observations of their relative's responses are also important to take into consideration. These can give us valuable information and areas to explore. Families can be provided with a structured form to record these as shown in the 'Family observations of their relative's responses' form which has been adapted from: Royal College of Physicians. Prolonged Disorders of Consciousness; national clinical guidelines. London: RCP, 2013

Examples of Tally charts for specific behaviours without stimuli

Tally charts are really useful if a patient has small behaviours that occur at rest but could be interpreted as being functional. It is possible that behaviours sometimes occur spontaneously and at other times under voluntary control but looking at the resting pattern helps with

deciphering this. It is useful to ask families to complete this task with you, particularly if they are interpreting behaviours as meaningful. Repeat this at different times and in different positions e.g. bed/chair.

Blinking

Observe for 2 minutes and score on tally chart each time behaviour is seen – you may need to tweak dependent of behaviours seen for specific patient

Single fast blink	Single slow blink	Double blink	Multiple fast blink

Small movements eg of left big toe

Observe for two minutes

Slow raise	Fast twitch	Lowered

Facial movements

Observe for two minutes

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

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

Note: each column equates to 15 seconds.














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 patient was looking straight ahead	
4		Right eye  Left eye  Tick the centre of the circle if the patient was looking straight ahead	
5		Right eye  Left eye  Tick the centre of the circle if the patient was looking straight ahead	

FAMILY OBSERVATIONS OF THEIR RELATIVE'S REPONSES

Name of patient

Name of person completing this form

Question	What were you doing?	What did they do?	Date and time observed and with whom:
Seeing			
Do they look towards you when you walk into the room?			
Do they follow your movements with their eyes when you walk around the room?			
If you hold up photos, pictures or objects, do they look towards them?			
If you move the picture or object in front of them, do they follow with their eyes (e.g. left to right or up and down)			
Sounds			
Do they turn to you when you say their name? (Try this from both sides of your relative)			
If you play their favourite music do you see any change in their behaviour? (smiling, grimacing, turning towards or away from the sound)			
What do they do if you play music they don't like?			
Do they follow spoken instructions? (Only ask them to do things that you know they can do at rest)			
Touch			
Do they react when you touch them? (Please describe what they do)			
Is there a difference between light and firm touch? (e.g. try stroking versus squeezing their arm)			
Smell (patients with a tracheostomy may not be able to smell as there is little or no air going through the nose)			
Do they react to different smells (e.g. their favourite perfume or toiletries)			

Question	What were you doing?	What did they do?	Date and time observed and with whom:
Movement			
Do they move towards an object – (e.g. try to touch it)			
Do they hold objects in the right way (e.g. hold a pen or comb correctly)?			
Do they try to use the object in the correct way?			
Do they make a clear movement when you ask them to? (e.g. thumbs up or wave)			
Communication			
Do they show different responses to different people?			
Do they smile in response to a joke/grimace or moan to something unpleasant?			
Do they try to indicate a preference or yes/no using gestures, heads nods/shakes or words?			
Do they attempt to respond to a greeting? (eg say 'hi' or 'goodbye' with an exaggerated wave.) What do they do?			
Wakefulness/arousal			
Is there anything that appears to keep them more awake or alert?			
Is there anything that appears to make them more tired or drowsy?			
Other			

Adapted from: Royal College of Physicians. Prolonged Disorders of Consciousness; national clinical guidelines. London: RCP, 2013.

Emotional responses

Patients in PDOC can show a wide range of behaviours that are usually linked with emotions, such as tears, grimacing, smiling and so on. We cannot ask them directly how they are feeling because they cannot give us a self-report about their mood. However, people around them, particularly family members or carers, often become concerned that the patient might be experiencing negative emotions such as sadness, pain or even depression. Understandably, they may wish some kind of treatment to be given, such as anti-depressant medication.

There are some measurement tools that have been suggested as possible ways to measure and monitor these types of behaviours. These include the Signs of Depression Scale in PDOC (RCP, 2013) and the Nociception Coma Scale (Schnakers et al, 2010; Chantelle et al, 2012). Our psychologists prefer a more individualised approach that avoids words such as 'depression' and 'pain' (which we cannot assess directly) and focuses instead on behaviours (which we can).

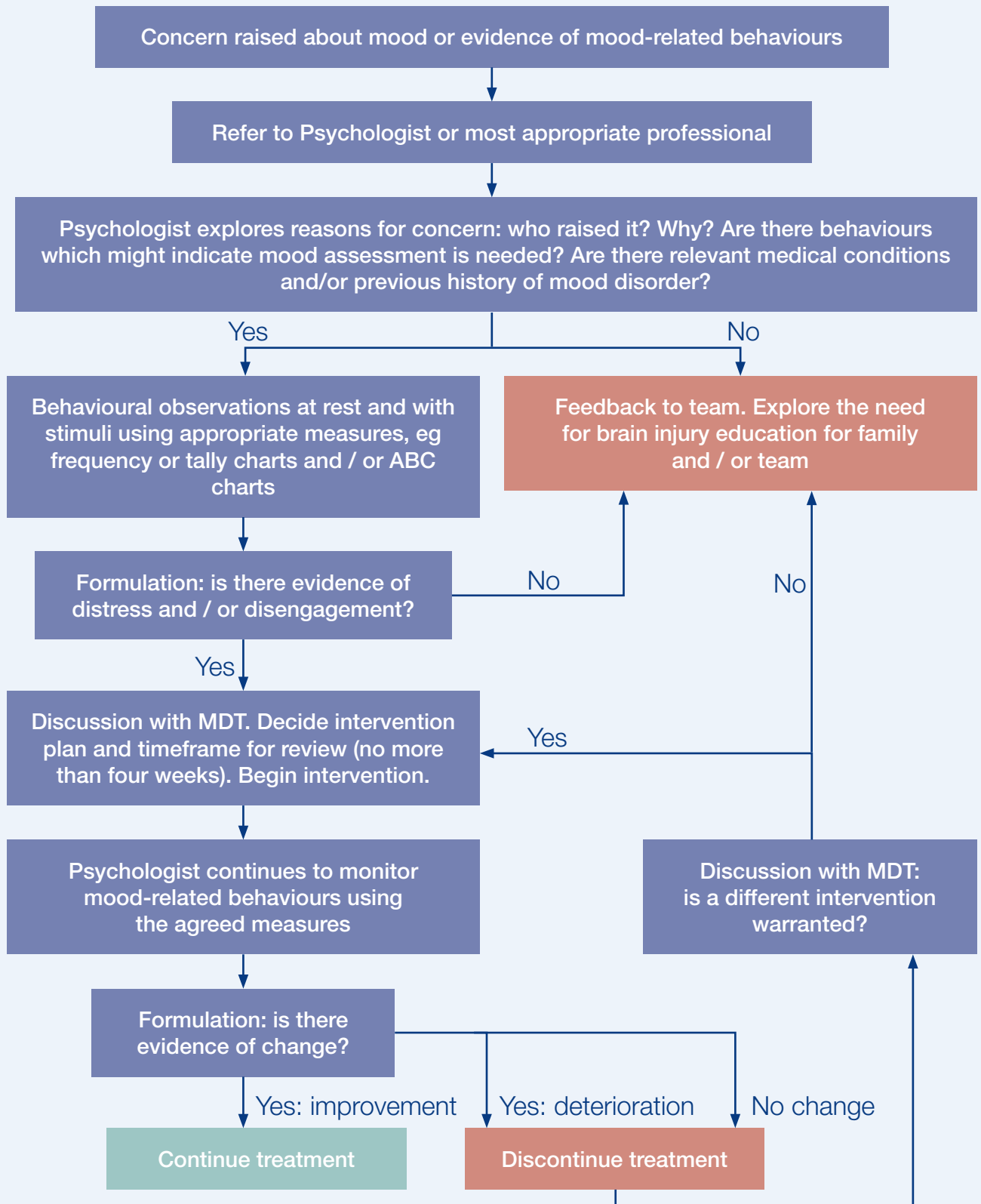
We recommend that the flowchart overleaf is followed whenever concerns are raised about possible low mood. This enables mood-related behaviours to be measured before, during and after treatment so that there is clear evidence of whether or not a treatment has had an effect. It allows for the possibility that behaviour may sometimes deteriorate with treatment – e.g. the patient may show evidence of sedation/withdrawal of engagement.

High frequency behaviours can be monitored using measures such as tally or frequency charts (see examples in Behavioural Observations section earlier in the toolkit). Low frequency behaviours can be monitored using measures such as a simple ABC chart (example follows).

Interventions may include pharmacological treatments such as anti-depressants or neuro-stimulants. A non-pharmacological approach with this client group is likely to consist of behavioural activation.

These patients are not able to engage with talking therapies, but may benefit from a 'behavioural activation' approach. This is a simple intervention for depression which involves helping people engage with enjoyable activities. For patients in a PDOC, this may involve taking them to different environments, eg the gardens, or involving them in sensory groups. (See section on Monitoring.)

Flowchart for exploring mood-related concerns in patients in PDOC



ABC chart: low-frequency emotion-related behaviours

Name NHS number

Antecedents	Behaviour	Consequences
<p>Time and date. What was happening just before the behaviour occurred? Where did it happen? Who was involved? Did something specific trigger the behaviour?</p> <p>Time: Date: </p> <p>Your name: </p>	<p>Give as full a description as possible of the behaviour. How long did it last for? How would you describe the intensity of the behaviour?</p>	<p>What did you or others do? What impact did this have on the behaviour? Did something specific stop the behaviour? What behaviour did the patient show next? Did the behaviour recur within a short time? (specify length of time)</p>
<p>Time: Date: </p> <p>Your name: </p>		
<p>Time: Date: </p> <p>Your name: </p>		

Supporting appropriate interactions

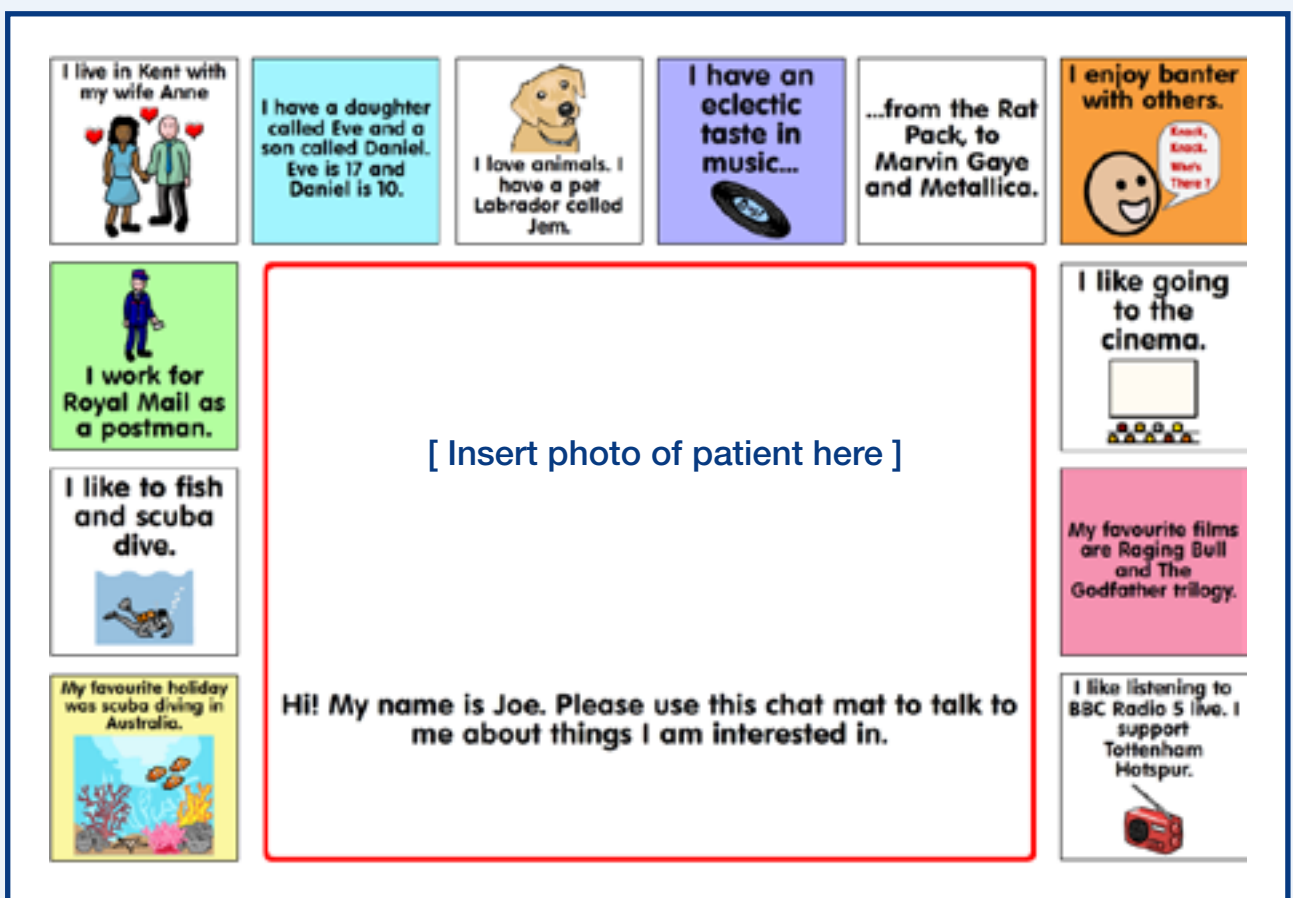
While a patient in a PDOC may not be able to reliably communicate with us, it is vital that we provide them with a motivating and interventional environment to promote communication wherever possible.

To enable all staff to interact with our patients in a humanising way, each patient has a 'Chat Mat' and 'Communication Passport'. These are kept with them at all times and hung on their wheelchair.






The 'Chat Mat' provides some key personal information about family, likes, taste in music and so on. The 'Communication Passport' gives information to carers on how best to communicate with the patient. Examples of the 'Communication Passport' are shown for patients in a MCS and VS.

In addition, guidelines for staff on how to 'Help me fill my free time' are used to support staff and families on how best to interact with their patient/relative and what to look out for in terms of changes in presentation.

Chat mat example



Communication passport – minimally conscious state



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 ChatMat 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

Side one

<p>If you have any questions please contact Speech and Language Therapy on extension</p>	<div style="border: 2px solid black; padding: 10px; margin: 0 auto; width: 80%;"> <p>Communication Passport</p> </div> <p>Name:</p> <p>Ward:</p>
--	---

Side two

Communication passport – vegetative state

	How to help me communicate
	I cannot express my needs reliably by any means; please make choices which are in my best interests
	Explain clearly what you are going to do before helping me
	I have a Chat Mat which tells you about me and my interests. This will help you to know what to talk to me about.

Side one

<p>If you have any questions please contact Speech and Language Therapy on extension</p>	<div style="border: 2px solid black; padding: 10px; margin: 0 auto; width: 80%;"> <p>Communication Passport</p> </div> <p>Name:</p> <p>Ward:</p>
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Side two

Help me fill my free time

Since my brain injury my ability to interact with my environment and others has changed.

Below are some guidelines with helpful tips on how to engage with me.

Tips for spending time with me

Always introduce yourself to me and tell me what we are going to do.

Say my name and observe what I do. Try this on my right and left side.

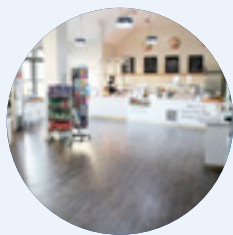
When interacting with me it is important to consider:

- The environment
- Levels of stimulation (balance stimulation with rest periods)

Interact with me in a **range of environments** to give me the best chance to respond eg:



Garden



Café



Quiet space

Leisure	<p>Look at photos or watch a video with me. Allow me time to look at the picture/video before you start talking. Try not to touch me at the same time.</p> <p>Listen to my favourite music with me and observe my reaction.</p>
Daily Activities	<p>Gently wipe my face with a damp cloth.</p> <p>Bring along things to smell e.g. toiletries, perfumes/aftershave and talk to me about them. E.g. 'This is your favourite perfume'.</p> <p>Gently massage my hand and ask me to 'move your fingers'.</p>

Things to look out for:

- Do I open my eyes to look at the objects you are showing me?
- Do I follow the objects if you move them from right to left and back again?
- Do I look towards the smell or the hand/foot you are massaging?
- Do I turn towards the sound of the music?

Help me fill my free time

Help me fill my free time

Stimulation and rest periods

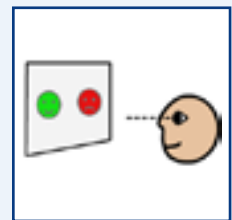
- Too much stimulation can be tiring.
- Always focus on one sensory area at a time to avoid over-stimulation.
- It is important for me to have regular rest periods without any stimulation. You can still spend time with me during these times.
- When I am resting, spend time watching me in a quiet environment and observe my movements and behaviours. I might do different things at rest than when I am doing an activity.



Changes in my presentation

If you observe me doing the following this would suggest a change in my presentation:

- Following spoken or written commands
- Following an object or person with his eyes ('tracking')
- Looking to an object to command from a choice of two



If you think that I am consistently responding to a particular activity, it would be helpful to inform the rest of the team working with me.

Functional use of objects

Some patients are not able to demonstrate what they are best able to do through standardised assessments. Carrying out sessions which involve the use of every day familiar objects should be considered to give them the best chance possible to show what they can do.

Keeping a record of this will help build a picture of:

- which objects have been trialled
- how they held and manipulated the objects (do they hold/manipulate them in a way that accommodates their size/shape)
- what they did with the object

This will be useful in evaluating consistency over time and will identify if any change is happening. In addition this can be used to evidence emergence (see 'Assessing for Emergence').

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 trialled	How does he/she hold and manipulate the object?	Comments (include any facilitation given)
<div style="display: flex; justify-content: space-between; padding: 5px;"> DDMMYY </div>				
<div style="display: flex; justify-content: space-between; padding: 5px;"> DDMMYY </div>				
<div style="display: flex; justify-content: space-between; padding: 5px;"> DDMMYY </div>				
<div style="display: flex; justify-content: space-between; padding: 5px;"> DDMMYY </div>				
<div style="display: flex; justify-content: space-between; padding: 5px;"> DDMMYY </div>				

Command following

The following are 'Top Tips' for individualised assessment of whether a patient can follow commands.

- Make sure you pick the right command.
- Choose a movement that the patient is able to make.
- Look at your results from behavioural observations and check that you don't use a movement that occurs frequently at rest without a stimulus. You won't know if they are following your command or doing it spontaneously.
- If the patient is unable to move any of their limbs you can assess eye movements. However, make sure you assess eye movements at rest first so that you know what happens spontaneously.
- Check response to spoken and written commands in case the issue is with vision/hearing.
- Allow plenty of time for a response (count to 20 in your head) as the patient may have slower cognitive processing so it takes longer to respond.
- If you are not seeing a response try repeating the command in a different way e.g. 'give me a thumbs up' instead of 'move your thumb.'
- If you don't see a response try modelling yourself with gestures. A patient with aphasia or cognitive impairment may not be able to understand or remember the command without a visual prompt.
- Record correct responses, no responses and timely responses that are inaccurate. Timely but inaccurate responses could be due to language or cognitive impairments or that a patient is unable to move the body part requested so responds in the best way they can.
- When you are interpreting your findings, think about the frequency of responding compared with the frequency of spontaneous movements. For example, a patient who lifts their leg 8/10 times to command, but rarely lifts the leg spontaneously, is likely to have genuinely understood the instruction. In contrast, a patient who lifts their leg 2/10 times after your command, but also frequently lifts the same leg when no commands have been given, is unlikely to be responding to your instruction.

Basic one step commands

Name Date NHS number
 Environment Time

Presentation: Auditory Written

Examples:

Stimulus	Observations (eg response time, correct response/no response/timely but inaccurate response)
Open your eyes.	
Close your eyes.	
Look at _____. (e.g. ceiling)	
Look at _____. (e.g. window)	
Move your _____.	
Wiggle your fingers.	
Make a frown.	
Raise your eyebrows.	
Give me a smile.	
Open your mouth.	
Close your mouth.	
Poke out your tongue.	
Give me a cough.	
Say 'ah'.	
Turn your head.	
Squeeze my hand.	
Let go of my hand.	



Response to oral intake

The 2013 RCP PDOC guidelines consider oral feeding a form of sensory stimulation which might elicit behaviours and it may provide useful additional evidence of awareness and interaction in some patients.

It provides a multisensory, context based, potentially motivating task which may elicit swallowing behaviours, such as anticipatory mouth opening to a spoon or licking residue from the lips, which are not assessed elsewhere.

It can also provide additional information on interaction, communication and awareness by providing a functional context in which to communicate likes/dislikes (eg by gesture or facial expression), make choices or indicate 'more.'

It provides a meaningful activity which a patient can be involved in with their families to promote social inclusion and interaction as well as a way to monitor for change over time.

Assessment with oral trials should only be carried out by a qualified Speech and Language Therapist. Tastes of food and/or drink will only be continued if it is considered to be in the patient's best interests, and training has been provided by a qualified Speech and Language Therapist to those who will be providing them.

When carrying out taste assessments, it is vital to weigh up all potential harms and benefits to establish swallow safety. There will be some patients for whom taste trials are not safe. Carry out additional assessments such as Cough Reflex Testing or FEES to inform clinical decision making if appropriate.

It is also important to carefully consider decisions when continuing and extending oral trials by considering a range of questions such as:

- If the patient is managing tastes trials using reflexive movements only, consider whether it is in their best interests to continue and discuss this formally with family and the MDT.
- Could similar information on reflexive/volitional oral behaviours be made from tooth brushing which can also be carried out by family members?
- What is the benefit to continuing if a patient shows no enjoyment in the task even if they can take small amounts safely?
- Are you feeding the patient for nutritional or social reasons?
- Consider carefully the amount that you aim for and why. Is there a benefit to 3 meals a day or is a pot of yoghurt 3 times week with family when they visit going to be more beneficial for the patient to monitor interaction?



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 (cranioplasty).

2 Saliva management status

Medications prescribed, drooling, pooling saliva orally, trache.

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 stimuli)
- Sucking (place their (or your) finger side-on inbetween 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 a single / first assesment

Name Date NHS number
Environment Time

1 Environment and Context

2 Saliva Management Status

3 Modified Oro-motor Assessment

4 Pre-oral Stage Assessment

5 Oral Stage Assessment

6 Pharyngeal Stage Assessment

Conclusions



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			

FOR SPEECH AND LANGUAGE THERAPY ONLY



Speech and Language Therapy PDOC swallowing assessment (example of a specific task)

Name Date NHS number
 Environment Time

Drink used (use a new form for each drink): water juice tea fizzy drink

Task: To give teaspoons of different drinks to assess for evidence of awareness and/or communication behaviours.

Positioning: Prescription wheelchair. Negative tilt to allow for upright positioning.

TASK BREAKDOWN Include facilitation techniques and prompting.	BEHAVIOURS Include all responses during all stages of task.
1 Therapist at eye level with patient	
2 Show patient the drink – (carton/bottle/cup) in the midline “Look at the ……” Pause for response	
3 Move drink to patient’s left, right then back to the middle	
4 Move drink up to patient’s nose and hold for 30 seconds Observe spontaneous responses then say “Smell the drink”	
5 Put cup down and show patient the teaspoon (midline) “I am going to give you a teaspoon of…”	
6 Bring a teaspoon of drink towards the mouth in the midline. Do not touch the mouth ‘here is a spoon’	
7 Touch the teaspoon to the lower lip	
8 Tip the liquid into the mouth	
9 “Show me if you want some more” wait 30 secs “Do you want some more?” wait 30 secs	
10 Repeat numbers 5-10 three times	

Individual assessment plans

Using objects and activities that patients used/enjoyed prior to their brain injury is both motivating and humanising. In addition to the standardised assessments, individual assessment plans can be used to supplement the information being gathered (Day et al. 2017).

An example follows which can be adapted to include whatever interests the patient had prior to their injury and whatever type of stimuli you would like to use (e.g. visual, auditory or tactile).

These can also include any areas of uncertainty to be explored, as explained in the section on 'Behavioural Observations – Tally Charts'. For example, 'Individual assessment plan 1' includes an observation of spontaneous head movement. This particular plan was developed for a patient where it was not clear if he was localising to sound on the left/right or if it was chance that his head rotated in that direction.

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	D D M M Y Y	D D M M Y Y	D D M M Y Y	D D M M Y Y	D D M M Y Y
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					
Play non-preferred music on left					
Auditory: Read a passage from a favourite book / magazine. Note any responses.					
Level of wakefulness					
Record level of wakefulness in session. Record how much stimulus was required to maintain wakefulness					

Carry out five minute observation of spontaneous head movement and record below. Use a noiseless stopwatch.

		Session one	Session two	Session three	Session four	Session five
Minute one	Head position at start					
	Tally of movement towards left					
	Tally of movement towards right					
	Eyes open / closed					
Minute two	Head position at start					
	Tally of movement towards left					
	Tally of movement towards right					
	Eyes open / closed					
Minute three	Head position at start					
	Tally of movement towards left					
	Tally of movement towards right					
	Eyes open / closed					
Minute four	Head position at start					
	Tally of movement towards left					
	Tally of movement towards right					
	Eyes open / closed					
Minute five	Head position at start					
	Tally of movement towards left					
	Tally of movement towards right					
	Eyes open / closed					

Assessing for emergence

The RCP (2013) guidelines propose that emergence can be assessed and measured through demonstration of functional communication or functional object use.

Functional communication

Current guidelines (RCP 2013) suggest the individual should give 6/6 correct yes/no responses on two consecutive occasions.

It should be noted that accuracy can be impacted on by potential language and cognitive impairments, so it's important to ensure relevant professionals are involved (Pundole and Crawford, 2017). The simplest and most relevant questions should be used and consideration should be given to timely but inaccurate responses which indicate some awareness that a question is being asked.

The following pages include assessments of emergence using questions based on:

- Autobiographical information
- Object recognition
- Colour recognition

Functional object use

Current guidelines (RCP 2013) suggest the individual should use at least two different objects on two consecutive evaluations eg bringing a comb towards the head or a pen towards paper. Difficulties can arise due to lack of motor control, language deficits, sensory impairments such as not being able to see or hear or other difficulties related to their brain injury. An example form is included under the 'Functional use of objects' section earlier in this toolkit.

Assessment of emergence – Functional Communication

Autobiographical questions

Current guidelines suggest the individual should give 6/6 correct yes/no responses on two consecutive occasions. Please note accuracy can be impacted by potential language and cognitive impairments, so please ensure the relevant professionals are involved. Use the simplest and most relevant questions. You may wish to consider timely but inaccurate responses as indicating some awareness that a question is being asked.

Name Date NHS number

Time

Context (eg bed, café, mum present)

Method of yes / no being used

Question	Correct / incorrect or no answer	Comments
Is your name X? (correct)		
Is your brother/sister/mum/dad called X? (incorrect)		
Do you live in X? (correct)		
Is your name X? (incorrect)		
Do you live in X? (incorrect)		
Is your brother/sister/mum/dad called X? (correct)		

Assessment of emergence – Functional Communication

Yes / no object questions questions

Current guidelines suggest the individual should give 6/6 correct yes/no responses on 2 consecutive occasions. Please note accuracy can be impacted on by potential language and cognitive impairments so please ensure the relevant professionals are involved. Use the simplest and most relevant questions and everyday objects. Make sure stimuli are visually, semantically and phonologically distinct. You may wish to consider timely but inaccurate responses as indicating some awareness that a question is being asked.

Name Date NHS number

Time

Context (eg bed, café, mum present)

Method of yes / no being used

Question	Correct / incorrect or no answer	Comments
Is this a pen? (correct)		
Is this a watch? (incorrect)		
Is this a cup? (correct)		
Is this a pen? (incorrect)		
Is this a cup? (incorrect)		
Is this a watch? (correct)		

Assessment of emergence – Functional Communication

Colours

Current guidelines suggest the individual should give 6/6 correct yes/no responses on 2 consecutive occasions. Please note accuracy can be impacted on by potential language and cognitive impairments so please ensure the relevant professionals are involved. Use large cards with blocks of colour. You may wish to consider timely but inaccurate responses as indicating some awareness that a question is being asked.

Name **Date** **NHS number**

Time

Context (eg bed, café, mum present)

Method of yes / no being used

Question	Correct / incorrect or no answer	Comments
Is this red? (correct)		
Is this yellow? (incorrect)		
Is this blue? (correct)		
Is this red? (incorrect)		
Is this blue? (incorrect)		
Is this yellow? (correct)		

Assessment of emergence – Functional Communication

Discrimination

Current guidelines suggest the individual should give 6/6 correct yes/no responses on two consecutive occasions. Please note accuracy can be impacted on by potential language and cognitive impairments so please ensure the relevant professionals are involved.

Use the simplest and most relevant pictures and everyday objects. Use patients' best means to indicate a response (eg eye pointing, gesture).

Use paired items that are phonologically, semantically and visually distant, ie do not use a cat versus dog as these are semantically and visually similar. Do not use cat versus car or bat, as these are phonologically similar.

Use three different picture pairs.

Name Date NHS number

Time

Context (eg bed, café, mum present)

Method of yes / no being used

Everyday items	Colours	People (pick what is relevant for each individual patient)
Cat / scissors	Yellow / red	Mother versus unknown female
Cup / table	Black / green	Father versus unknown male
Spoon / car	Blue / orange	Sister versus unknown female

Example of images used



Monitoring

Monitoring PDOC patients after they are discharged into the community poses challenges that are outside of the remit of this toolkit.

The RCP PDOC Guidelines (2013) recommend that patients are reviewed annually. They provide guidance for families and care staff on what responses to look for to identify if there has been any change.

At the RHN there are a number of PDOC patients who live here.

Staff have developed a process and resources to support the monitoring of patients with the aim of following the recommendations in the guidelines.

Reviews are conducted with all patients in a PDOC annually:

- Patient is seen for a six week period focussing specifically on reviewing their responses (see weekly structure).
- They are seen in either a group setting and/or on a one to one basis for a minimum of four sessions.
 - Two different groups have been set up for the review process. (See 'MDT Annual review of a PDOC patient – groups')
 - One to one sessions may be carried out during sessions such as positioning/postural reviews; reviews of personal care.
- They are seen by all relevant members of the MDT to assess for any changes in current presentation/responses.
- The WHIM is completed on all patients. These can be completed in any of the sessions.
- If the patient previously had a CRS-R, then this is completed in one to one sessions.
- A summary report is completed after the review highlighting any changes in responses.

Annual review structured six-week programme

Week	Programme outline
Prior to week one	<ul style="list-style-type: none"> • Screening form completed by MDT to gain background information to inform the review process.
Week one	<ul style="list-style-type: none"> • Staff planning session to arrange the groups/1:1 sessions. • Information leaflet given to family. • First group takes place.
Week 2 – 4	<ul style="list-style-type: none"> • Groups 2-4 take place. • Individual sessions as required with members of the MDT.
Week 5 – 6	<ul style="list-style-type: none"> • Results are collated. • Summary report completed by the MDT. • Any outstanding actions identified and an action plan put in place.

MDT Annual review of a PDOC patient – groups

The aim of the groups are to provide the patient with opportunities to respond to a range of sensory stimuli within a meaningful and familiar activity.

The two groups used for annual reviews are:

- Sensory art group
- Sensory baking group

All patients are sat in their wheelchair/chair for the group sessions and the groups take place in an appropriate environment. At the RHN this is the art room and the kitchen, but this can be any quiet space. Following review of background information, the most appropriate group for the patient is identified based on previous interests.

Prior to commencement of the group, baseline behavioural observations are carried out to identify behaviours at rest without any stimuli.

Sensory art group

Activities can be varied based on the patient's interests/preferences. For example:

- Using items from the garden such as lavender and leaves
- Using clay and paint

Patients are supported to look at, hear, touch and smell the objects. Responses are recorded and a WHIM is completed. A record of arousal levels are also recorded and whether or not arousal stimulation techniques were used.

Sensory baking group

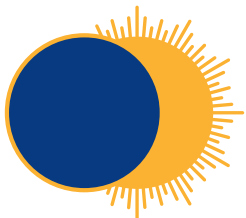
Patients are supported to be involved in the making of a variety of sweet and savoury treats based on their previous preferences. For example:

- Lemon cup cakes
- Chocolate cup cakes
- Chocolate cookies
- Banana muffins

Patients are supported to be involved in the making of the treats. They are given opportunities to look at, hear, touch and smell the ingredients, mixture and final products. Responses are recorded and a WHIM is completed. A record of arousal levels are also recorded and whether or not arousal stimulation techniques were used.

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