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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  - Monitoring
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?

**WHICH ASSESSMENT TOOL?**

- WHIM?
- SMART?
- CRS-R?
- OTHER?

**Assessment characteristics**

**Pragmatics**

**MAIN THEMES**

- Patient characteristics
- No one assessment tool is perfect
- Combine 2 or more tools

**OUTCOMES**

No one assessment tool is perfect

Combining 2 or more tools

**Royal Hospital for Neuro-disability**
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)
Behavioural Observations

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

**Eye Movement Observations**
- Tally of number of blinks
- Direction of the eyes
- Observations

**Tally Charts**

<table>
<thead>
<tr>
<th>Facial movements</th>
<th>Facial movements</th>
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<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Raise comars of mouth (as if smiling)</td>
<td>Twitch right cheek</td>
</tr>
<tr>
<td>Lower eyebrows (as if frowning)</td>
<td>Eyes up</td>
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</table>

**EYE MOVEMENT OBSERVATION**

**Instructions**
- Observe eye movement for 3 minutes as follows:
  - Use a stopwatch/timer and observe the 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.

**Tally Charts**

<table>
<thead>
<tr>
<th>Minute</th>
<th>Number of times blinked (tally)</th>
<th>Eye movement</th>
<th>Observations e.g. long time between blinks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example</td>
<td></td>
<td></td>
<td>This patient looked straight ahead, up, to his left and upper left. He blinked 6 times in one minute. [Make a note if there are any detractions such as a fixed gaze, direction of their gaze normally or no movement.]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Minute</th>
<th>Number of times blinked (tally)</th>
<th>Eye movement</th>
<th>Observations e.g. long time between blinks</th>
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<tr>
<td>1</td>
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<td>2</td>
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<tr>
<td>3</td>
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</tbody>
</table>
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:

1. **Concern raised about mood or evidence of mood-related behaviours**
   - Refer to Psychologist or most appropriate professional

2. **Psychologist explores reasons for concern: who raised it? Why? Are there behaviours which might indicate mood assessment is needed? Are there relevant medical conditions and/or previous history of mood disorder?**
   - **Yes**
     - Behavioural observations at rest and with stimuli using appropriate measures, eg frequency or tally charts and/or ASC charts
     - Formulation: Is there evidence of distress and/or disengagement?
       - **Yes**
         - Discussion with MDT. Decide intervention plan and timeframe for review (no more than four weeks). Begin intervention.
       - **No**
         - No change
         - Formulation: Is there evidence of change?
           - Yes: improvement
             - Continue treatment
           - Yes: deterioration
             - Discontinue treatment
     - **No**
   - **No**
     - Feedback to team. Explore the need for brain injury education for family and/or team
     - Discussion with MDT: Is a different intervention warranted?
     - **Yes**
       - Continue treatment
     - **No**
       - Discontinue treatment

This flowchart is for educational purposes by the Royal Hospital for Neuro-disability.
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

Hi! My name is Joe. Please use this chat mat to talk to me about things I am interested in.
<table>
<thead>
<tr>
<th>How to help me communicate</th>
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</thead>
<tbody>
<tr>
<td><strong>I cannot express my needs reliably by any means; please make choices which are in my best interests</strong></td>
</tr>
<tr>
<td>Explain simply who you are and what you are doing before you help or move me</td>
</tr>
<tr>
<td>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</td>
</tr>
<tr>
<td>Try giving me simple questions and commands to work on my understanding—see if I am able to respond</td>
</tr>
<tr>
<td>Look out for me watching and tracking things—show me familiar objects, photos, and pictures</td>
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</tbody>
</table>

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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

<table>
<thead>
<tr>
<th>Date</th>
<th>Environment / positioning</th>
<th>Objects trialed</th>
<th>How does he/she hold and manipulate the object?</th>
<th>Comments (include any facilitation given)</th>
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</thead>
<tbody>
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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

PDQG swallowing assessment

1. Environment and Context
   - Comments around the patient’s positioning, slackness, the location of assessment and any people who are present/teaching, medical or medication changes (e.g., chemotherapy).

2. Saliva management status
   - Medications prescribed, drooling, pooling saliva only, or trachea.

3. Modified or-o-meter assessment
   - Comments on symmetry, mouth opening, oral hygiene, spasms or baseline movements. Rate of spontaneous swallows. Abnormal reflexes (e.g., bitter, tongue thrust, tooth grinding).

4. Pre-oral Stage assessment
   - Visual focus on item, tracking, reaching/localizing, choice making or discrimination, response to small, following a command in context, holding cup/arrow 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 stimulator).
     - Sucking place their (or your) finger side-on intermaxillary teeth and suck for sucking.
     - Smooched (press the upper lip in the centre, look for a puckering of the lips).
     - Chewing (press lower mouth together and tongue depressor/finger).
   - Check for hypersensitivity, consider oral stimulation to prepare for intake.
   - Tilt with patient’s own finger clipped in food/drink.

Anticipatory mouth opening, response to touch of sip/cup, appropriate mouth shape, lips closure, initiating the sip, initiation of oral transit, forming and controlling the bolus.

Conclusions
- Did the patient show awareness during the trials, if so how?
  - Engagement with task, indicating preferences or additional responses. Active oral control versus oral reflexive patterns to move bolus. Swallow safety.

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

Speech and Language Therapy PDQG swallowing assessment for repeated assessments

<table>
<thead>
<tr>
<th>Name</th>
<th>NHS number</th>
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<table>
<thead>
<tr>
<th>Date</th>
<th>Date</th>
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<table>
<thead>
<tr>
<th>Environment and Context</th>
<th>Date</th>
<th>Date</th>
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<table>
<thead>
<tr>
<th>Saliva Management Status</th>
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<th>Date</th>
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<table>
<thead>
<tr>
<th>Modified or-o-meter Assessment</th>
<th>Date</th>
<th>Date</th>
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<thead>
<tr>
<th>Pre-oral Stage Assessment</th>
<th>Date</th>
<th>Date</th>
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<table>
<thead>
<tr>
<th>Oral Stage Assessment</th>
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<th>Pharyngeal Stage Assessment</th>
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<thead>
<tr>
<th>Conclusions and Plan</th>
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Individual Assessment Plans

<table>
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<tr>
<th>Individual assessment plan one</th>
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<tbody>
<tr>
<td>Name ________________________</td>
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<tr>
<td>Complete each of the sections below:</td>
</tr>
<tr>
<td>Assessor</td>
</tr>
<tr>
<td>Date</td>
</tr>
<tr>
<td>Time</td>
</tr>
<tr>
<td>Environment</td>
</tr>
<tr>
<td>Position</td>
</tr>
</tbody>
</table>

Great 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

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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

<table>
<thead>
<tr>
<th>Week</th>
<th>Programme outline</th>
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<tbody>
<tr>
<td>Prior to week one</td>
<td>• Screening form completed by MDT</td>
</tr>
<tr>
<td>Week one</td>
<td>• Staff planning</td>
</tr>
<tr>
<td></td>
<td>• Information given to family</td>
</tr>
<tr>
<td></td>
<td>• First group</td>
</tr>
<tr>
<td>Weeks 2 – 4</td>
<td>• Groups 2 – 4</td>
</tr>
<tr>
<td></td>
<td>• Individual sessions</td>
</tr>
<tr>
<td>Weeks 5-6</td>
<td>• Results collated</td>
</tr>
<tr>
<td></td>
<td>• Summary report</td>
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<tr>
<td></td>
<td>• Actions identified and an action plan put in place</td>
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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?
Contact details

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