
Electronic annex 2a

Full formal clinical assessment of people with PDOC

These recommendations apply to any formal comprehensive clinical evaluation of someone with a prolonged disorder of consciousness (PDOC).

The diagnostic assessment process should follow a structured approach and should consider:

- **causation**; what evidence is there relating to the reasons for the prolonged unawareness?
- **primary neurological pathways**; is there evidence that they are sufficiently intact to allow evidence of awareness to be detected?
- **awareness/responsiveness**; what is the behavioural evidence concerning level of awareness?

Causation

It is essential to establish that there is a known cause for the PDOC, and that there are no reversible or treatable causes that are causing or exacerbating the reduced level of consciousness. Occasionally it is difficult to define the precise pathology, but in those circumstances it is still important to establish that there are definite structural changes in the brain.

The following questions should be asked and evidence relating to the questions should be sought and documented.

What is the nature of the underlying neurological damage and dysfunction?

- Is it sufficient to cause the observed clinical state?
- Is it reversible or treatable (eg hydrocephalus or ‘syndrome of the trephined’)?

Are there any additional or alternative causes that might account in part or in whole for the clinical state?

- drugs?
- complications of the original damage?
- other, unrelated disease?

Are any further investigations of causation needed?

These are generally only warranted for treatable or reversible factors.

Primary neurological pathways

The level of awareness of the person is judged on the basis of their behaviour, and behaviour requires (a) some sensory input and (b) some motor output. Thus it is important to establish that the person can receive some sensory input and can have some control over some motor output. For example, although in general primary pathways will be intact, it is always important to consider whether the person has:

- a severe critical illness neuropathy sufficient to limit motor function
- spinal cord damage that reduces or prevents sensory input and/or the opportunities for motor output
- damage to specialised sensory organs (ears, eyes) limiting sensory input.

A **systematic approach** should be used to collect evidence, and one approach to the neurological examination is to ask the following questions:

Is there evidence that an intact primary visual pathway is present?

- Are direct and consensual pupillary reflexes to light present?
- Also consider:
 - is there any response to visual threat?
 - does the person fixate on and track an object moving in their visual field?
 - does the person localise/look at a new object in their visual field?
- Investigations that can be used if there are no pupillary reflexes include visual evoked potentials and electro-retinograms, but these should only be used if essential.

Is there evidence that an intact primary auditory pathway is present?

- Is there a startle or blink in response to sudden loud noise?
- Also consider:
 - does the person wake (open eyes) in response to noise?
 - does the person localise sounds, looking towards sound?
- Auditory evoked brainstem potentials could be used if there is no response to sound, to establish whether or not the primary auditory pathway is intact.

Is there evidence that an intact primary somatosensory pathway is present?

- Are stretch reflexes present?
- Is there any response to painful stimuli (on each limb, and supra-orbitally)?
- Also consider:
 - is there any consistent response to touch or passive limb movement?
 - are there any responses to nursing and other care procedures?
- Electrophysiological measures can be used if evidence is lacking:
 - Nerve conduction studies can investigate peripheral nerves if a neuropathy is suspected.

- Somatosensory evoked cervical or brainstem potentials can also be used to investigate primary sensory pathways including spinal cord function.

Is there evidence that the primary motor output pathways are intact?

- Cranial nerves:
 - are there spontaneous eye movements?
 - is there spontaneous blinking?
 - are there spontaneous facial movements?
 - are there facial movements in response to pain?
 - are there spontaneous jaw movements (teeth grinding, yawns etc)?
 - are there any other movements in response to pain or other stimuli?
- Limbs:
 - are there any spontaneous limb movements?
 - are there reflex movements in response to pain, stretch reflexes etc?
 - can the limbs be moved passively through a range sufficient for movement to be seen?

Is there evidence that the spinal cord is intact?

- does limb pain cause facial or cranial movement?
- does noise cause startle movement in limbs?
- does facial pain or tracheal suction cause limb movement?

Assessing level of responsiveness and awareness

The third aspect of the assessment is to determine the level of responsiveness and awareness. This depends on observations made of behaviour and it is vital to distinguish between the actual behaviour observed and the interpretations made from, or attributions placed on, the behaviour.

Three types of behavioural observations may contribute:

- spontaneous behaviours, not requiring external stimuli
- behaviours occurring in response to normal incidental stimuli
- behaviours occurring when using structured, planned stimuli.

When assessing responsiveness several complementary sources of behavioural observations should be used:

- routine observations recorded within notes, made by staff. Patient records should be reviewed carefully
- observations made by relatives and friends, usually obtained by questioning them, but potentially also recorded by them
- observations made specifically by trained staff using a structured assessment protocol to investigate observed behaviours at rest and level of responsiveness.

A formal structured observational assessment should always be one part of the overall assessment, but it should never be the only part (see main guidelines).

Documentation

Documentation should record observed behaviours, what the patient responded to, how often the behaviour was seen and by whom.

- Whenever a formal diagnostic assessment is undertaken, the responsible clinician or team should document carefully and fully the evidence considered and the reasoning behind the conclusions drawn.

Prepared by Professor Derick Wade on behalf of the *Prolonged disorders of consciousness* Guideline Development Group, September 2012.