

Electronic Annex 2b

Minimum requirements in experience and training of assessors for patients with a prolonged disorder of consciousness

Due to the complexity of this patient group, the significant rates of misdiagnosis in non-specialist referrers, and the requirement for important clinical decisions, it is appropriate to ensure a high degree of competency for the assessors of patients with a prolonged disorder of consciousness (PDOC). This is particularly important for when evaluations are conducted in domiciliary settings including at home, in nursing homes or other care facilities.

As noted in Section 2 of the guidelines, evaluation of the level of consciousness depends primarily on detailed clinical evaluation by professionals who are experienced in the management of PDOC.

The use of validated assessment tools such as the Wessex Head Injury Matrix (WHIM), the Coma Recovery Scale (CRS-R) and the Sensory Modality Assessment and Rehabilitation Technique (SMART) can be used to support that assessment, but should never be used in isolation.

This annex sets out the competency in PDOC assessment at four levels.

- > **Expert PDOC Physician**
- > **Expert PDOC Assessor**
- > **PDOC Assessor**
- > **PDOC Observer**

1 Expert PDOC Physician

An Expert PDOC Physician is a medical consultant in a relevant specialty (usually rehabilitation medicine or neurology). They are members on a register of **responsible, reliable and reputable medical professionals who are expert in all aspects of disorders of consciousness**. These individuals complement the competency requirements for an Expert PDOC Assessor (see below), to **take the lead in specialist clinical management, evaluation and decision-making in patients with PDOC**.

- > They must be competent and proficient in the medical and pharmacological management of conditions arising in patients in a PDOC, including identifying and liaising with relevant other medical specialists, as appropriate.
- > **They may not themselves have all the requirements for an Expert PDOC Assessor (although some will), but they must be able to systematically enquire, collect, collate, interpret and critically analyse the relevant clinical findings and investigations to formulate a PDOC diagnosis, to determine a prognosis and estimate life expectancy.**
- > Specifically, they should have expertise in:
 - **interpreting all clinical investigations**, electrophysiology and brain imaging
 - **undertaking medication reviews**
 - **advising** on the appropriate use of neurostimulants and interpretation of responses to them and **explaining relevant current research** in the field
 - **prognostication and life expectancy**
 - **formulation of an end-of-life care plan** and providing advice on terminal care prescribing.
- > They must be able to explain to family members, staff in simple and credible language, all aspects of care, assessment of PDOC and the conclusions reached.
- > Where necessary they must be able to provide evidence to the courts.

Most of these Expert PDOC Physicians could provide (should they choose to do so) **a second opinion for the withdrawal of life-sustaining treatments**, including clinically assisted nutrition and hydration (CANH), in accordance with the British Medical Association (BMA) / Royal College of Physicians (RCP) guidance, with which they must be fully conversant.

- > They must be able to organise, chair and fairly present a balanced and considered view at complex *best interests* decision-making discussions, meetings with multidisciplinary teams (MDTs), family/friends and commissioners.
- > They must be able to produce a reasonable, balanced and justifiable report summarising their conclusions in an acceptable time frame.
- > They will be required to provide a more detailed statement of their competency and expertise, when doing so.

A full list of essential and desired requirements is included in Table 1.

2 Expert PDOC Assessor

An Expert PDOC Assessor is a clinical professional with substantial and regular experience of PDOC management and assessment (at least five per year).

- > They can perform a detailed clinical evaluation (including at least the CRS-R and WHIM) with appropriate facilitation and the required medical optimisation, the need for which they are competent at identifying.
- > They are also able to interpret the results of the different tools used.

A full list of essential and desired requirements is included in Table 2.

3 PDOC Assessor

A PDOC Assessor has recognised professional healthcare training and/or qualifications. They work under the direct or remote supervision of an Expert PDOC Assessor.

- > They are familiar with the needs of PDOC patients and families.
- > They can distinguish spontaneous and reflex responses from more purposeful, localising or discriminating responses.
- > They understand the importance of detecting some awareness, differentiating between categories of vegetative state (VS) and minimally conscious state (MCS).
- > They have had the relevant training (in the form of competency modules – developed locally and updated periodically) to be able administer the CRS-R and/or WHIM competently.
- > PDOC assessors may work with PDOC Observers who provide information about observed responses, which the PDOC Assessor is then responsible for verifying.

4 PDOC Observer

A PDOC Observer may be a healthcare assistant (HCA) or rehabilitation assistant (RA), or other therapists and nurses working in general non-specialist settings.

- > These individuals have some basic experience in working with patients in PDOC, but not necessarily any formal training.
- > They work under the direct supervision of a trained PDOC Assessor.

Tools such as the WHIM and the CRS-R can be applied by suitably guided PDOC Observers to provide information that contributes to the assessment, but it would be inappropriate for untrained and unsupervised care staff or families to complete a diagnostic assessment in isolation.

Table 1 Minimum requirements of an Expert PDOC Physician

| Category | Essential | Desirable |
|--|---|--|
| Background qualification and training | <ul style="list-style-type: none"> > An Expert PDOC Physician is a consultant in a relevant specialty (usually RM or neurology) > Substantial and regular experience of PDOC management > Specialist training and experience in the management of patients with severe and complex neurological impairments, including those with PDOC | |
| Experience of PDOC assessment | <ul style="list-style-type: none"> > Evidenced experience in working specifically with patients in PDOC > Evidence of experience maintained over time: minimum of 10 patients within the last 2 years | |
| Knowledge and clinical skills | <ul style="list-style-type: none"> > Proficient in the medical and pharmacological management of conditions arising in patients in a PDOC, including identifying and liaising with relevant other medical specialists, as appropriate > Knowledge of current research and practice with patients in PDOC; and be fully conversant with the RCP guidelines > Can interpret the relevant clinical findings and investigations to determine prognosis > Able to advise on the appropriate use of neurostimulants and interpretation of responses to them > Experienced in prognostication and estimation of life expectancy in patients with complex brain injury > Knowledge of the definitions, features and behaviours associated with each stage of the PDOC continuum (VS, MCS and emergence) > Knowledge of the cognitive, communicative, perceptive and motor aspects of complex neurological disabilities and how this impacts on assessment of awareness and management of the individual > Proven competence in the interpretation of assessment tools for PDOC, including the CRS-R, SMART and WHIM | Can provide a second opinion for the withdrawal of CANH according to the BMA/RCP Guidelines. |

Prolonged disorders of consciousness

| Category | Essential | Desirable |
|---|---|-----------|
| | <ul style="list-style-type: none"> > Able to summarise and clearly explain all assessment findings and investigations to other team members and family/friends > Able to summarise and clearly explain justification for diagnosis and future plans > Undertakes regular <i>best interests</i> decision-making with family/friends > Formulation of an end-of-life care plan and advises on terminal care prescribing as per protocol in the RCP PDOC guidelines (see Section 5b) | |
| General | <ul style="list-style-type: none"> > Excellent communication and reporting skills > Able to interact appropriately with a patient in PDOC and their significant family/friends to support assessment and management of <i>best interests</i> decision-making | |
| For those who provide second opinions for serious medical conditions | | |
| | <ul style="list-style-type: none"> > Able to organise, chair and fairly present a balanced and considered view at complex <i>best interests</i> decision-making discussions, meetings with MDT, family/friends and commissioners > Able to produce a reasonable, balanced and justifiable report summarising their conclusions > Able provide a more detailed statement of their competency and expertise | |

BMA = British Medical Association; CANH = clinically assisted nutrition and hydration; CRS-R = Coma Recovery Scale – Revised; MCS = minimally conscious state; MDT = multidisciplinary team; PDOC = prolonged disorders of consciousness; RCP = Royal College of Physicians; RM = rehabilitation medicine; SMART = Sensory Modality Assessment and Rehabilitation Technique; VS = vegetative state; WHIM = Wessex Head Injury Matrix

Table 2 Minimum requirements of an Expert PDOC Assessor

| Category | Essential | Desirable |
|--|---|--|
| Background qualification and training | <ul style="list-style-type: none"> > Clinical qualification and practice in the field of specialist neurorehabilitation (may be medical, nursing or relevant AHP) > Specialist training and experience in the management of patients with severe and complex neurological impairments, including those with PDOC | |
| Experience of PDOC assessment | <ul style="list-style-type: none"> > Experience in working specifically with patients in PDOC > Evidence of experience maintained over time: minimum of 10 patients within the last 2 years | Experience of over 10 patients per year |
| Knowledge and clinical skills | <ul style="list-style-type: none"> > Knowledge of the definitions, features and behaviours associated with each stage of the PDOC continuum (coma, VS, MCS and emergence) > Knowledge of the cognitive, communicative, perceptive and motor aspects of complex neurological disabilities and how these impact on assessment of awareness and management of the individual > Able to provide physical facilitation for optimal positioning for potential functional ability. Through training, clinical experience or joint working > Able to initiate and set up joint session with other professionals as required > Able to carry out observation, categorise and record behaviours at rest in order to identify what behaviours a patient exhibit without any stimulus > Proven competence in the administration and interpretation of assessment tools for PDOC, including the CRS-R and WHIM > Able to interpret assessment findings to formulate appropriate person-centred goals for subsequent intervention and/or management > Able to summarise and clearly explain assessment findings to other team members and family/friends > Understand the potential impact for the significant family/friends of a patient in PDOC, demonstrated through the assessor's interaction and inclusion of the family/friends in the assessment process | <p>Awareness of current research and practice with patients in PDOC</p> <p>Trained in use of SMART</p> <p>Able to lead on and conduct <i>best interests</i> meetings independently</p> |

| Category | Essential | Desirable |
|----------------|--|---|
| | <ul style="list-style-type: none"> > Able to contribute to <i>best interests</i> discussions about the patient's care > A working knowledge of the RCP PDOC guidelines, and fully conversant with Section 2 | |
| General | <ul style="list-style-type: none"> > Excellent communication and reporting skills. Able to interact appropriately with a patient in PDOC and according to their specific level of functioning > An understanding of the contribution of family/friends to the assessment process > Able to work closely with family and friends by obtaining relevant information from them, including them in assessment, and providing clear explanations of assessment findings | Availability and commitment to undertaking extended and repeat assessment over time |

AHP = allied healthcare professional; CRS-R = Coma Recovery Scale – Revised; MCS = minimally conscious state; MDT = multidisciplinary team; PDOC = prolonged disorders of consciousness; RCP = Royal College of Physicians; RM = rehabilitation medicine; SMART = Sensory Modality Assessment and Rehabilitation Technique; VS = vegetative state; WHIM = Wessex Head Injury Matrix

| Competency statement for the Expert PDOC Assessor | | | | | |
|--|---------------------------|------------|---|---------------------------|----------------------|
| Patient Assessment details | | | | | |
| Name of patient | | | | | |
| Type of assessments completed | | | Number of assessments completed with patient | | |
| Environment(s) for assessment | | | | | |
| Reported responses From | Family/friends | Yes | No | Team members | Yes No |
| | Number interviewed | N= | | Number interviewed | N= |
| Assessor details | | | | | |
| Name of assessor | | | | | |
| Professional Qualification | > > | | | | |
| Statement of competency meeting Expert PDOC Assessor Requirements | | | | | |
| | > | | | | |
| Signed | | | Date | | |

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