



Australian Government

**National Health and
Medical Research Council**

N H M R C

**ETHICAL GUIDELINES FOR THE
CARE OF PEOPLE IN POST-COMA
UNRESPONSIVENESS (VEGETATIVE STATE)
OR A MINIMALLY RESPONSIVE STATE**

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1 INTRODUCTION

1.1 AIMS OF THE ETHICAL GUIDELINES

These guidelines aim to contribute to the care of people in a state of post-coma unresponsiveness (PCU) or a minimally responsive state (MRS) by addressing the ethical issues associated with this care, especially the complicated issues that have proved difficult for families, health professionals, courts and tribunals. The guidelines provide an ethical framework to guide decisions in the best interests of people in PCU or MRS, and they offer a basis for reaching consensus among health professionals and families involved in making these decisions. Clear ethical concepts and terminology are essential to ensure that the process of decision-making is transparent, and that its basis and validity can be readily understood, so that those involved are reassured.

The guidelines complement *Post-coma unresponsiveness (Vegetative state): A clinical framework for diagnosis* (referred to in this document as the *Diagnostic Framework*), undertaken by the Health Advisory Committee of the National Health and Medical Research Council (NHMRC) and endorsed by Council in December 2003. That document was concerned solely with the diagnosis of PCU; however, ethical guidelines for the *care* of people in PCU are also relevant to (though not necessarily adequate for) the care of people whose condition may be closely related to or indistinguishable from PCU. This includes people who are in MRS, so the terms of reference for these care guidelines (provided in Appendix 2) have been expanded to include people in MRS.

The guidelines address PCU and MRS following coma, but some of the principles apply also to other conditions associated with unresponsiveness or minimal responsiveness.

The guidelines are intended to assist care providers from a time that is sufficiently after the initial injury so as not to interfere with or influence acute management, but at a point when rapid changes are no longer expected. Usually this is no earlier than one month after the person emerges from coma.

The nature of decision-making changes as the person moves from the acute phase, when the objective is to stabilise his or her condition after trauma (including stroke), to the stage when the person is relatively stable, giving more time to assess, consult and reflect on the nature of longer-term care.

1.2 DEVELOPMENT OF THE GUIDELINES

The guidelines have been developed by an expert working committee of the Australian Health Ethics Committee (AHEC) of the NHMRC. The Working Committee included doctors, nurses, clergy, a social worker, a lawyer, ethicists, and patient and disability representatives (listed in Appendix 3).

To stimulate and invite comment and input, the PCU Working Committee developed an Issues Paper that identified many of the issues involved in the care of people in PCU and, in a targeted consultation, circulated the paper in April 2006 amongst a comprehensive range of possible stakeholders. Submissions were invited from individuals or organisations with experience of PCU, through providing care, having a family member in PCU, or running an organisation that cares for people in PCU. Forty submissions were received, with respondents including families, professional carers, nurses, medical practitioners (including rehabilitation, intensive care, neurology and neurosurgery, paediatrics and palliative care), ethicists, health administrators, therapists, social workers and counsellors, people providing spiritual or pastoral care, professional organisations and colleges, health departments, guardianship and public advocacy bodies, and special interest groups representing carers and people with brain injury.

At this stage, the NHMRC issued revised terms of reference to the Working Committee, stipulating that the guidelines were to take the form of *ethical* rather than care guidelines, but taking into account the clinical, legal and social issues involved. The revised terms of reference are provided in Appendix 2.

The submissions provided valuable input on the ethical, legal, social and clinical issues associated with the care of people in PCU or MRS, which has informed the development of these guidelines.

In line with the revised terms of reference, the guidelines do not deal with the details of care provided to people in a state of PCU or MRS, nor do they provide legal advice or review or make recommendations for law reform. They do acknowledge the differences across Australia in laws that may influence the care of people in PCU or MRS; for example, in research project approval, substitute decision-making, guardianship, advance care planning, refusal of treatment, and negligence. The guidelines do, however, take into account how decisions about care are made and the clinical, social and legal matters involved.

Only very limited data were found on the incidence and prevalence of PCU and MRS in Australia, and on the site of care for people in PCU or MRS. These data are included in Appendix 5.

1.3 PRINCIPLES

The provision of care is an expression of our fundamental humanity and connectedness with others, and of our common sense of obligation to promote good and do no harm. People in PCU or MRS are highly vulnerable because of their total dependence on others. They are owed a particular duty of care to promote their interests and protect them from exploitation, abuse and neglect. That duty is likely to extend over a long period of time.

Decisions about the care of people in PCU or MRS should:

- (a) demonstrate respect for all aspects of human dignity, including the worth, welfare, rights, beliefs, perceptions, customs and cultural heritage of all involved;
- (b) respect, where these are ascertainable, the values, beliefs and previous wishes of the person in PCU or MRS;
- (c) recognise the needs of all those directly involved—including people in PCU or MRS, families, friends, health professionals, and other carers—to be:
 - (i) involved in decisions that affect the person in PCU or MRS;
 - (ii) given accurate and timely information;
 - (iii) realistically educated about the person's situation, care and prospects; and
 - (iv) assisted, when necessary, to deal with their own responses in their particular situations;
- (d) give due regard to justice, particularly in relation to the responsible use of resources. This includes ensuring so far as possible that there is:
 - (i) fair distribution of the benefits of or access to goods and services;
 - (ii) equality of opportunity;
 - (iii) no unfair burden on any members of the community or on particular groups; and
 - (iv) no abuse, neglect, exploitation or discrimination;
- (e) respect the basic rights of people in PCU or MRS, including:
 - (i) the right of individuals to be treated with respect;
 - (ii) the right of individuals to life, liberty, and security;
 - (iii) the right of individuals to have their religious and cultural identities respected;
 - (iv) the right of individuals to self-determination, including by advance care planning or representation;
 - (v) the right to access health care that is appropriate to their needs;
 - (vi) the right of individuals to privacy and confidentiality;
 - (vii) the recognition that human beings are social beings with social needs; and
 - (viii) the right to approach death peacefully;
- (f) give due regard to the rights and duties of those who care for people in PCU and MRS, and the duties of the community both to people in PCU or MRS, and to their carers (family, professional and other); and
- (g) respect the limitations of medical treatment, in relation to achievable goals.

1.4 DEFINING PCU AND MRS

The *Diagnostic Framework* describes PCU as follows:

The term post-coma unresponsiveness (VS¹) may generally be applied to patients emerging from coma in an apparently wakeful unconscious state in which there is:

- a complete lack of responses that suggest a cognitive component;
- preservation of sleep-wake cycles and cardiorespiratory function; and
- partial or complete preservation of hypothalamic and brain-stem autonomic functions.²

The *Diagnostic Framework* recognises that, while PCU as a clinical entity is conceptually well defined, it may be difficult to differentiate from other conditions that follow severe brain damage, which form part of a spectrum of impaired responsiveness. This is 'sometimes due to poor understanding of the assessment criteria, and sometimes due to inherent limitations in assessing the effects of very severe brain damage'.³

Consciousness—the state of awareness of self and the environment—is an inference that observers make from a person's behaviour. There is no positive evidence for lack of consciousness; it can only be inferred from a lack of behaviour that indicates consciousness.

At the severe end of the recognised continuum of brain damage and related levels of consciousness are:

- (a) **Coma**—a state of presumed profound unconsciousness from which the person cannot be roused when examined. Coma is not brain death; some brain function remains, and some or all may be recoverable;
- (b) **Post-coma unresponsiveness (PCU)**—a state or condition in which a person has emerged from coma to the extent that he or she is observed to have sleep/wake cycles over a period of time but no purposeful responses to stimuli. Responsiveness may gradually return in some people, leading to MRS or even better, although improvement may be very slow. Some recovery may be achievable but full recovery is highly improbable; and
- (c) **Minimally responsive state (MRS)**—which may arise when a person has emerged from coma or PCU. There is a minimal level of purposeful response, with discernible but inconsistent evidence of consciousness. Cognitively mediated behaviour occurs often enough or for long enough to distinguish it from reflex behaviour, and the more complex the response, the easier it is to make this distinction. For example, it may take time and repeated observations to be sure whether a simple movement (eg, finger movement, eye blink, eye movement) that is seen occasionally is simply

¹ VS signifies 'vegetative state', a term that has also been used to signify PCU.

² *Post-coma unresponsiveness (Vegetative state): A clinical framework for diagnosis*, NHMRC 2004, p. ix

³ *Ibid.*, p. ix

coincidental or is actually in response to a specific event (eg, to a command to move fingers or to blink eyes). In contrast, a complex response (eg, intelligible words) seen only a few times may be enough to be sure that the person is conscious. There may be a delay between the stimulus and the person's response, highlighting the importance of examining the person for a sufficient time to have confidence in the diagnosis. Establishing a diagnosis might be complicated by factors other than awareness that interfere with responses (eg, sensory or motor deficits, diminished drive, aphasia, apraxia). In MRS, the responses do not indicate a capacity for decision-making.

The *Diagnostic Framework* explained the use of the term 'PCU' in preference to terms such as 'vegetative state':

The term *persistent vegetative state*...[is] widely established in the medical, legal and ethical literature.... In several countries, the terms *vegetative state* or *continuing vegetative state* are used, with the modifier *permanent* applied when there is no prospect of emergence... There are increasing concerns in the literature and the clinical community about these terms and their potential to be misunderstood or to be prejudicial to the care of patients with the condition.... The advantages of [the term PCU] are:

- it usefully excludes unresponsive states that do not follow a period of coma, such as the terminal stages of Alzheimer's disease, or the unresponsiveness seen in developmental abnormalities such as anencephaly;
- it avoids the potentially pejorative term *vegetative*; and
- it has no time-based qualifiers—that is, it could apply as soon as emergence from coma occurs and for as long as the patient remains unresponsive.⁴

Similarly, the term MRS is used rather than 'minimally conscious state' (a term also used in the literature), as responsiveness can be assessed whereas consciousness can only be inferred from the patient's clinical responses.

Coma, PCU and MRS are all quite distinct from **brain death**, where all function of the brain has permanently ceased—that is, the person has died. Breathing is maintained artificially by a mechanical ventilator, the heart keeps beating autonomously for a time, and other organs may continue to function for a time. Brain death is diagnosed by assessing that the underlying cause and the extent of brain injury is such that all brain function has ceased and, after excluding factors that might temporarily suppress brain function, that this cessation is permanent. Over a period of time, the health professionals caring for the patient carefully observe the development and progress of the injury or disease. If it is thought that all brain function has been completely and permanently lost, doctors perform a series of clinical tests to confirm that the loss of function involves the whole brain, including the brain stem (which is involved in vital reflexes like coughing,

⁴ Ibid pp. v-vi

gagging, breathing). If clinical testing is not possible, then brain death is confirmed by imaging to establish absence of blood flow to the whole brain.

'Locked-in syndrome' is a phenomenon that is quite distinct from PCU and MRS. There is specific damage to the brain stem but consciousness and cognition remain intact and the person can only communicate through 'coded' responses, usually eye movements. These guidelines are not intended for people with locked-in syndrome.

1.5 OTHER TERMINOLOGY

In these guidelines:

- Where possible, the word **'person'** is used, rather than 'patient'; however 'patient' is used occasionally where it refers to the obligations of a health professional in relation to a patient, or where it adds clarity.
- The term **'family'** is used broadly to include those closest in knowledge, care and affection to the person in PCU or MRS. This may include the immediate biological family, the family of acquisition (related by marriage/contract), as well as the family of choice and friends (not related biologically or by marriage or contract).⁵ For Aboriginal and Torres Strait Islander peoples, it may also include traditional kinship groups and structures. This broad definition reflects common usage and practice, and the importance of enabling those close to a person in PCU or MRS to be involved in his or her care.
- The term **'clinician'** is used to mean any health professional directly involved in a person's care, including medical, nursing and allied health staff.

⁵ Definition adapted from Canadian Palliative Care Association, *Standards for Palliative Care Provision*, June 1998.

2 DIAGNOSIS AND PROGNOSIS

For people in PCU or MRS, decisions on treatment and care are made on the basis of prognoses that are, at best, imprecise. Of necessity, these decisions are provisional. They need to take into account that changes in the person's condition may be very slow (over years), and that continuing review is essential in the long term. Life expectancy is difficult to predict, and may range from months to decades.

Over recent decades, as medical technology has enabled many more people with severe brain damage to survive, it has become clear that terms such as 'persistent' or 'permanent' are inappropriate. The person's condition may not be static; rather, there may be gradual change, and the person may emerge in time to a state of MRS or better.

While neurological recovery after traumatic brain injury (TBI) can continue for many years, most recovery of useable function occurs in the first two years. Some regulatory bodies that fund TBI therapy programs start to evaluate permanent impairment at 18 months after injury, when the majority of their clients have plateaued in function. At longer times after injury, the person may gain increased function by learning to adapt better to long-term disability.

The *Diagnostic Framework* recognises that there may be difficulties in diagnosing PCU and distinguishing it from MRS. In particular, it is very difficult to be certain that a person who has sleep/wake cycles is not responding at all, and it is not possible to be certain that the person is unaware, or what level of awareness he or she might experience. In MRS, there may be a delay between a stimulus (eg, touch, light, movement, a voice) and any response, and responses may be ambiguous and difficult to identify. Those who spend longer with the person are more likely to report something that may be interpreted as purposeful. Genuine consideration should be given to the family's observations, as they may spend much time with the person.

Accurate diagnosis of PCU and MRS often takes many weeks or longer—the *Diagnostic Framework* states that the diagnosis should not be considered for a minimum of four weeks after emergence from coma. Figure 1 (page 8), reproduced from the *Diagnostic Framework*, summarises considerations in the clinical diagnosis of PCU.

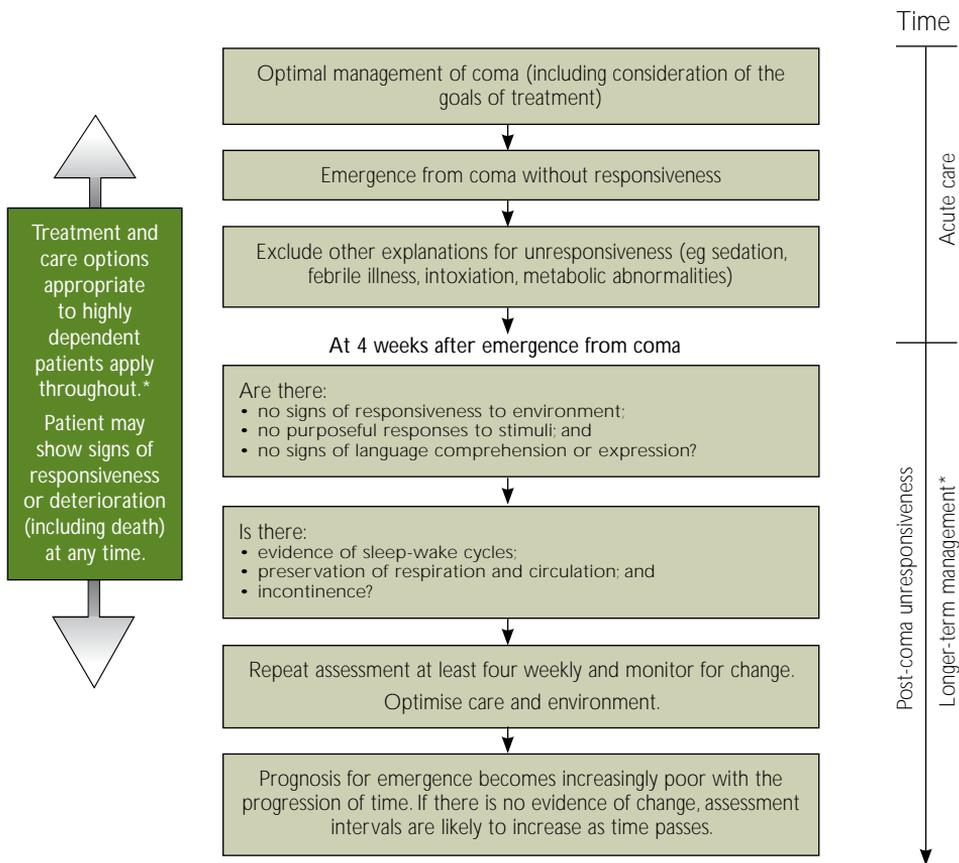
Confidence in the diagnosis usually increases as time passes, and consistency of observations over time helps to build this confidence. Confident diagnosis needs to be distinguished from the *provisional* findings of a single clinical examination – when, for example, a person emerging from coma may be observed to be in PCU or MRS. Similarly, the prognosis for a person with a diagnosis of PCU or MRS becomes clearer only over many weeks or months. **Periodic clinical reassessment is essential.**

The likelihood of some recovery varies according to the severity of the brain damage. As noted in the *Diagnostic Framework*, the research evidence is very limited and difficult to interpret. In general, however, experience suggests that **there is a low probability of functional improvement for people in a state of PCU and MRS, and the longer the person remains in PCU, the lower the chance of improvement.** The likelihood of significant improvement is lower for people whose PCU is of non-traumatic origin.

There are few data available to indicate whether different types of care or intervention make a difference to prognosis.

At the same time, it is not unheard of for people who have been in PCU or MRS for some years to emerge from a severely incapacitated state to a state of functioning where, although still dependent, they are able to participate actively in their own lives and with others.

FIGURE 1: Considerations in diagnosing post-coma unresponsiveness⁶



* Decisions about the treatment of highly dependent patients (including decisions about withholding or withdrawing treatment and the continuing provision of artificial nutrition and hydration) should be informed both by what, if anything, is known about their wishes and by a broad consideration of their best interests, and should reflect the best contemporary standards of care for people who are highly dependent.

In all instances the question is never whether the patient's life is worthwhile, but whether a treatment is worthwhile.

⁶ from *Post-coma unresponsiveness (Vegetative state): A clinical framework for diagnosis*, NHMRC 2004, page xii

3 GOALS AND RANGE OF CARE

The goals and range of care for people in PCU and MRS provide context for the guidelines in the chapters that follow.

3.1 GOALS

A person in PCU or MRS is in a relatively stable state of severe disability and any recovery of function is likely to be very slow. The overall goals of care here are twofold:

- to provide the best possible care and achieve the best possible outcomes for people in PCU or MRS, within the severe constraints of their condition and the available resources; and
- to affirm, support and respect the family in their chosen role in that care.

This entails:

- (a) assisting the person to maximise any naturally occurring recovery and build on this to improve his or her function;
- (b) supporting the person socially, emotionally and spiritually as well as physically;
- (c) supporting the family physically, socially, emotionally and spiritually;
- (d) minimising deterioration and maintaining the person's life, health and remaining function; and
- (e) anticipating and relieving possible pain or discomfort.

3.2 RANGE OF CARE

People in PCU or MRS may be receiving any of the following types of care:

- (a) general and specialist medical care, including the prevention and management of complications, administration of antibiotics, and palliative care;
- (b) general and specialist (rehabilitative) nursing care, including assessment, prevention and therapeutic management of integument (skin), elimination, oral health, nutrition and hydration, and tracheostomy/ventilation; and the assessment and management of pain;
- (c) physiotherapy (including joint/muscle and chest therapy), occupational therapy (assessment and facilitation of responsiveness, including use of technology, and maintenance of muscle and joint mobility), speech pathology (assessment and management of swallowing and communication), and dietetics;
- (d) psychological, counselling and spiritual care;
- (e) other modalities, such as music therapy, diversional therapy, recreation therapy, massage, or some complementary or alternative approaches;
- (f) care provided by the family and others, such as continuing prescribed therapies, personal care (eg, hairdressing, manicure), conversation and reading to; and
- (g) other specific modes of care, stimulation or rehabilitation.

3.3 BEST PRACTICE CARE

Best practice care for people in PCU or MRS is individualised, holistic and patient-centred care. It recognises that people in PCU or MRS are part of a family, and of society.

Best practice care requires a high standard of coordinated physical, medical, allied health and psycho-social support, delivered with compassion and respect by a specialist team of health professionals working in partnership with the family.

Best practice includes:

- (a) ongoing review of the person's health and neurological function;
- (b) ongoing, sensitive two-way communication between clinicians and family;
- (c) advance care planning;
- (d) continuity of care and care providers, and seamless transitions between programs and settings;
- (e) provision of support, information and, where necessary, bereavement care to family and other carers;
- (f) interpreter services;
- (g) access to respite care; and
- (h) maintenance of records in the long-term.

Volunteers and attendant carers provide a wide range of services throughout health care, and have the potential to play a significant role in the care of people in PCU or MRS and the support of their families.

People in PCU or MRS may be cared for in a range of different settings. After stabilisation in the acute hospital, the next stage in treatment and care may be a rehabilitation facility, residential care, supported community care, or home. Some people may access only one of these options. Others may move through a number; for example, a person may transfer to a rehabilitation facility and then to residential care, a community house, care at home, or to shared care between home (eg, for weekends) and another care site.

Decisions about the site of care for a person in PCU or MRS may affect not only the prospects of improvement, but whether deterioration is prevented.

For instance, without adequate medical and physiotherapy care, a person in PCU or MRS may deteriorate and develop contractures that compromise care and lead to life-limiting conditions such as respiratory failure and muscle and joint problems. If the person subsequently recovers some cognitive function, such complications can increase the level of physical disability.

Sites of care, and decisions about the site and level of care, are discussed in Section 6 'Sites and Levels of Care' (page 29).

4 RESPONSIBILITY AND PROCESS FOR DECISION-MAKING

4.1 INTRODUCTION

Each competent person has the right to consent to or refuse medical treatment; however people in PCU or MRS are unable to exercise their rights in person. Consent to interventions or withdrawal of life support will, therefore, be the responsibility of third parties—in these guidelines, the term ‘representative’ is used.⁷

This raises a number of ethical issues, including those involved in determining:

- (a) who holds responsibility for such decisions, how such a person is appointed, and the nature, limits and exercise of that person’s responsibility;
- (b) the role of the previously expressed wishes of the person in PCU or MRS. These may be documented in a non-specific way that guides rather than directs, documented formally in a specific way that has greater legal weight (by statute or common law), expressed informally by others to whom the person has previously made known his or her wishes, or constructed hypothetically based on what others believe the person would have wished; and
- (c) the exercise of the professional duty of care of health professionals involved.

4.2 REPRESENTATIVES

When a person becomes unable to make decisions, another person will have the role of representing that person. There are three ways in which someone may become a ‘representative’:

- (a) the representative was appointed by the person before he or she became incapable of making decisions about his or her medical treatment;
- (b) the representative is appointed by a court or tribunal after the person has become incapable of making such decisions; or
- (c) the representative has legal authority conferred automatically by statute, for example, as the person’s spouse, carer, other next of kin or close friend.⁸

In practice, decision-making is usually by consensual agreement among family, friends and carers, but in cases where there is disagreement that cannot be resolved, approaches should be made to the relevant legal authority or representative.

⁷ Sometimes the terms ‘substitute decision-maker’ or ‘agent’ are used in some jurisdictions.

⁸ The order of priority of legal representative varies from jurisdiction to jurisdiction, and local advice in relation to State and Territory law needs to be sought. This person is referred to in some jurisdictions as the ‘person responsible’.

A representative is responsible for making decisions in the person's best interests. To do so, the representative must be adequately informed about the person's circumstances and treatment options, and his or her values, beliefs and previous wishes. Clinicians have an important role in ensuring that adequate information is available.

It is possible that a health care team member may be concerned that a representative is making or proposing to make a decision that is not in the best interests of the person in PCU or MRS. In most jurisdictions the actions of a representative may be reviewed by a court or tribunal. Health professionals and other concerned people should ensure that such review takes place if, in their view, a representative is not fulfilling his or her role responsibly, or is making decisions not in the person's best interests.

4.3 TREATING CLINICIAN OR TEAM

Working in partnership with the family, clinicians have the responsibility for determining the clinical options, and discussing these with and seeking consent from the person's representative (see Section 4.2 on previous page).

Decisions about care must be made in the person's best interests. They are best made jointly with the person's family and carers, after taking into account:

- (a) the availability of, access to and responsible use of health resources; and
- (b) the extent to which the family is involved in providing care, and the family's needs in relation to the burdens that care may place on them.

The success of shared decision-making hinges on early, open communication, including acknowledgement of uncertainties in diagnosis and prognosis.

4.4 DETERMINING 'BEST INTERESTS'

Assessment of a person's best interests in relation to a care decision must take into account:

- (a) the person's values, beliefs and critical interests;
- (b) the person's previously expressed wishes, to the extent that they can be ascertained, and whether the present circumstances correspond to the situation that the person imagined when expressing or recording those wishes;
- (c) the wishes of a nearest relative or other family members, if it can be confidently assumed that the family's wishes are aligned with the person's interests;
- (d) the benefits and burdens of treatments, and the consequences to the person if the treatment is not carried out, having regard to the level of confidence about prognosis at the time a decision is made;
- (e) the relative merits of any other treatment options; and
- (f) the nature and degree of the risks associated with the treatment and/or with those options.

There is sometimes a tension over the meaning of ‘best interests’ in the context of PCU and MRS, especially if what is judged by clinicians to be in the person’s best interests in a medical sense differs from what the person’s representative considers to be in the person’s best interests in the light of a broader range of considerations. For example, the clinical view may be that a treatment would be beneficial, but the person may have clearly expressed a wish not to undergo such treatment. Alternatively, health professionals may view as clinically risky something that the family considers is in the person’s overall best interests (eg, experiencing soft foods or drinks that the person used to enjoy). These matters are generally resolved by ongoing discussion (see Section 5.9 ‘Role of and support for families and other carers’, page 26). It may also be the case that a representative may request interventions considered by the clinicians to be inappropriate or ineffective (see Section 5.7 ‘Misunderstanding and conflict’, page 24).

4.5 RESPECTING THE PERSON’S WISHES

The role of the person’s previously expressed wishes, in the context of PCU or MRS, is to inform decision-making and assist those making decisions to ensure that those decisions reflect the person’s own values and priorities. In reality, the effect is likely to be to influence the process towards more or less intervention, within the range of what is considered reasonable care.

The clinicians retain the ethical responsibility for ensuring that whatever care is provided serves identified medical goals, and that treatment options are neither futile nor unreasonably burdensome (see Section 6.2.2, page 35, for discussion of futility and burden).

The weight that is given to a person’s wishes will depend at least in part on how those wishes are expressed and recorded, and how specific they are to a particular treatment or set of circumstances. For example, more weight would ordinarily be given to written expression rather than oral, or to wishes that deal with a specified set of clinical circumstances.

Where a person has indicated refusal of a particular treatment, the weight given to those wishes will depend on a consideration of:

- (a) what was intended by the refusal;
- (b) the person’s circumstances when the refusal was made, including competence and state of mind, what he or she understood, whether the refusal was freely given, and whether the person had expressed suicidal ideation;
- (c) the circumstances for which the person intended the refusal to apply and whether the present reality reflects that understanding; and
- (d) the evidence for and level of knowledge of the person’s wishes.

Clinicians have an ethical responsibility to be satisfied, to the best of their capacity, that the evidence of a patient's previous wishes is sufficiently reliable to be taken into account.

A person's wishes with respect to refusal of a particular treatment, if informed and made competently and freely, should be respected if the current circumstances reflect what the person envisaged.

4.6 ADVANCE CARE PLANNING

Advance care planning describes the process by which a person seeks to provide advance guidance or instructions about how health care decisions are to be made for that person, if and when he or she becomes unable to make such decisions.

In determining the wishes of a person in PCU or MRS, the existence of advance care planning is helpful to families, clinicians and other carers.

After a person is in PCU or MRS, advance care planning can also be undertaken by the person's representative.

The process of advance care planning may involve nothing more than discussion with family, friends, health professionals or other carers; it may include the formal appointment of a representative; and/or it may include a formal record of values and wishes.

Values and wishes may be recorded in several ways:

- (a) The person's health professional may (and usually would) keep his or her own notes of what has been said and review them regularly in the light of changing circumstances.
- (b) The person may prepare a statement of general principles about what he or she would like done in the future.
- (c) The person may prepare a specific plan for care, or specify treatment that he or she does or does not want, immediately or in the long term.
- (d) The person may issue an advance care directive that may be considered to be more binding and may, in some jurisdictions, have legal status in that respect.

4.7 ADVANCE CARE DIRECTIVES

An advance care directive is a set of instructions for a person's future health care, to be carried out in the event that he or she is unable to make decisions. It is intended by the person to be binding, that is, more than a statement of his or her wishes. Often it specifies circumstances in which certain types of treatment are not to be applied. In some jurisdictions, advance care directives can have a legal status requiring compliance by caregivers in relation to refusal of treatment.

To apply an advance care directive, the clinician needs to be satisfied that the directive applies to the actual circumstances of the person's condition and care.

This may depend on whether the circumstances are of the type the person envisaged when issuing the directive.

Where a directive is binding but a clinician is concerned that compliance is not in the person's best interests, or if the clinician thinks there is now information available that would have influenced the person to make a different decision, the clinician should seek advice from the Office of the Public Advocate or Guardian (for contact details, see below), or seek legal advice. Depending upon the jurisdiction, it may be possible to obtain a ruling from a court or tribunal on the validity of the directive. Questions to be considered may include whether, at the time, the person was adequately informed, competent, and not acting under duress.

4.8 VULNERABILITY

People in PCU or MRS are particularly vulnerable members of our community. Because they are unable to communicate, they can be at risk of abuse, neglect or exploitation from people in positions of trust. Abuse does sometimes occur. It may be financial, physical, emotional or sexual, and may come from professionals, family, paid carers, or others.

People in PCU or MRS have a right to protection and care. Any suspicions of mistreatment should be reported immediately. If the person is in an institution, in the first instance concerns should be raised with management. If the person is being cared for at home, various government agencies can help, including the police, the department for community services in your State or Territory, or the Office of the Public Advocate or Guardian (depending on the nature of the suspected mistreatment).

New South Wales

Office of the Public Guardian
1800 451 510

Queensland

Office of the Adult Guardian
1300 653 187

Western Australia

Office of the Public Advocate
1300 858 455

Australian Capital Territory

Office of the Public Advocate
(02) 6207 0707

Victoria

Office of the Public Advocate
1300 309 337

South Australia

Office of the Public Advocate
1300 066 969

Tasmania

Office of the Public Guardian
(03) 6233 7608

Northern Territory

Office of Adult Guardianship
(08) 8922 7343

5 COMMUNICATION, TEAMWORK AND SUPPORT

Post-Coma Unresponsiveness and Minimally Responsive State—A guide for families and carers of people with profound brain damage provides information for families and carers to accompany these ethical guidelines.

It is suggested that the health care team offer this guide to families and carers when a provisional diagnosis of PCU or MRS is first made, so that it is available to them throughout discussions about diagnosis, prognosis and care, including possible changes in the level of care.

5.1 INTRODUCTION

Optimal care for people in PCU and MRS is achieved through teamwork, by a coordinated multidisciplinary team of health professionals working in partnership with the family.

Ongoing, sensitive two-way communication among staff and between families, staff and other carers is fundamental to this.

Communication is the basis for achieving the consistency and depth of understanding that is needed to make ethical decisions about care, and is particularly important given the uncertainty inherent in any prognostic predictions for a person in PCU or MRS (see Section 2 'Diagnosis and Prognosis', page 7).

There are ethical issues in:

- (a) how a person's prognosis and likely pathway, and the uncertainty inherent in these predictions, is communicated;
- (b) how differences of opinion are respected and decisions made;
- (c) maintaining a central focus on the person in PCU or MRS and his or her best interests, throughout a process that is often emotionally difficult as well as ethically complex; and
- (d) who is given information about a person's medical condition.

5.2 WHO SHOULD BE INVOLVED?

It is usually presumed that communication will involve those involved in the person's care and close family members.

If there is disagreement about who should receive information about the person, the matter should be referred to the person's representative (see Section 4.2, page 11).

The representative's consent is also required for communication with people who are not family or not involved in the person's care (eg, lawyers, insurers, case workers). Such communication needs to respect the person's privacy and be in accord with his or her best interests.

Communication between acute, rehabilitation and disability services is important so that health professionals involved in the care of people in PCU and MRS not only have comprehensive information on individual patients, but also know the services available and where the best outcomes for particular patients can be achieved.

5.3 COMMUNICATION AND THE PERSON IN PCU OR MRS

It is not possible to be certain that a person in PCU or MRS is unaware, or what level of awareness he or she might experience.

As a matter of caution and respect, all dealings with people in PCU or MRS should be conducted on the basis that they may be aware.

For example, always explain what is happening, include the person when talking with others in his or her presence, and be aware of what should and should not be said in the person's presence, and its possible effect.

5.4 COMMUNICATION WITH THE FAMILY

Severe brain damage in a family member or friend is devastating and, as discussed above, prognosis is characterised by uncertainty. **The success of shared decision-making hinges on early, open and ongoing communication between health professionals and family, including acknowledgement of uncertainties in diagnosis and prognosis.**

Clinicians involved in the care of a person in PCU or MRS should provide information and education to families and other carers gradually and progressively, in a way that evolves with the family's ability to adapt to and comprehend the circumstances.

There needs to be a willingness to discuss the circumstances openly, with ongoing opportunity for family and other carers to ask questions and express their ideas and concerns. Clinicians need to be alert to families' and other carers' level of understanding and expectations, and to the amount and depth of information they are ready for. Discussion should be an iterative process, allowing families to digest and adjust to difficult information at their own pace.⁹

Clinicians have an obligation to communicate their assessment of the person's condition, care needs and prospects in a way that is both accurate and easily understood. They should be clear about what is known and what remains unknown about the person's condition and prospects, the generally slow rate of any improvement after severe brain injury, and the inherent uncertainty of any prognosis.

Information-giving needs to be consistent and questioning encouraged. Consistency involves collaboration between members of the treating team.

Communication must always be two-way, with active listening on the part of clinicians and an open exchange between clinicians and families. Each brings to the consultation different information, options and understanding, which are important for achieving the best possible care for the person in PCU or MRS. Allowing opportunity for discussion is as important as giving and receiving information.

Those providing care need to be aware of the potential power differential between professionals and family, and take steps to minimise its effect.

It is important not to make cultural assumptions, but to approach each person and each family situation as unique and to clarify individual needs (see Section 5.5 'Communication, care and culture', page 22).

5.4.1 Features of effective communication

Features of effective communication include:

- (a) identifying families' and other carers' current knowledge, understanding, preparedness to receive information, and information needs at the time;
- (b) sensitivity to the emotional nature of discussion about levels of care;
- (c) respect for patient, carers and family members;
- (d) opportunities for family members and other carers to ask questions and express doubts and concerns;
- (e) use of open-ended questions;

⁹ See *Communicating with Patients: Advice for Medical Practitioners* (NHMRC 2004); *General Guidelines for Medical Practitioners on Providing Information to Patients* (NHMRC 2004); and *Making Decisions about Tests and Treatments: Principles for better communication between healthcare consumers and healthcare professionals* (NHMRC 2005). All are available online at <http://www.nhmrc.gov.au>

- (f) listening to family members' and other carers' understanding of the person's condition, prospects and care options, their hopes, and their difficulties in providing care and support;
- (g) clarifying any lack of understanding, using terms and concepts that the family and other carers understand; and
- (h) being alert to responses that may indicate denial or blocking of information, and responding with care and respect.

5.4.2 Formal consultation with family and other carers

Whenever assessments are made, discussion between the health care team and the family will occur. On occasion, these will constitute formal meetings. Formal meetings may be initiated by the family or the clinicians.

In arranging a meeting, the circumstances and needs of the family need to be taken into consideration (see Section 6.4 'Rural and remote populations', page 38).

Clinicians need to come to the meeting well prepared. They need to have reviewed the patient's records, discussed his or her circumstances with each of the health professionals involved, and drawn conclusions about diagnosis and prognosis. The information needs to be up-to-date and consistent, with areas of remaining uncertainty clearly identified.

In considering major decisions such as moving from one level of care to another, extra care is needed. The style of consultation, the timing and the setting need to be planned beforehand, to enable clear and open communication and discussion and to ensure that involved health professionals, family and other carers are able to participate in decisions.

The discussion needs to be open to exploring medical, cultural, spiritual, and existential issues.

Families should be given written information to back up and extend what is discussed.

5.4.3 Discussing prognosis and care options

The uncertainty and unreliability of diagnosis and prognosis is likely to be a strong feature in discussions between the health professionals and the family. **Whenever diagnosis and prognosis are discussed, the lack of certainty and the difficulty of living with uncertainty should be acknowledged.** It is important to be neither overly optimistic nor overly pessimistic.

Information needs to be given in a setting, manner and pace that gives the family the best opportunity to understand, absorb, adjust to and accommodate it.

Health professionals need to be sensitive to the impact of information; maintaining open, two-way communication with the family. Written information enables families more time to absorb and adjust to the situation, and oral information should be supported by written information that is relevant to the situation of the person in PCU or MRS, and to the needs of the family.

Where possible, decisions about care options should be based on evidence of effectiveness. Such evidence may be limited or non-existent, particularly in the case of non-medical modalities of care, including alternative and complementary therapies. Discussion of these issues with families needs to be open and supportive, and families need to feel validated in their efforts to do all that is reasonable and possible for the person in PCU or MRS. At the same time, claims for effectiveness and cure, and the financial and emotional costs attached, may be major issues in relation to complementary and alternative approaches. Focussing on what is reasonable and necessary with measurable outcomes is a sound approach.

Clinicians have a responsibility to assess whether or not a treatment could be harmful (physically, emotionally, socially and/or financially) and to guide and work with the family in their decision-making.

Clinicians need to explain to families in advance that there are occasions when, after a treatment has been tried for a reasonable time without sustainable benefit, it may need to be withdrawn, although this may result in an apparent deterioration in the person's condition.

Making judgements about acceptable risk can be difficult, and often there is no single right answer—whether, for example, a person should be given the opportunity to taste and swallow something he or she is known to have enjoyed (eg, tea, ice-cream), although there is considered to be significant risk of aspiration. The guiding principle is what is in the person's best interests. Such decisions are best made in partnership with the family, respecting the family's previous knowledge of the person and the risks he or she would have been prepared to take (see Section 4.4 "Determining 'best interests'", page 12).

5.4.4 Discussing changes to the level of treatment or ceasing a treatment

The goals of current and proposed treatments need to be made clear to family and carers.

Decisions to change levels of treatment (see Section 6.2 'Making decisions on levels of care', page 33) should reflect an assessment of whether current treatment is likely to achieve the goals set for it and whether the benefits or prospective benefits of treatment are outweighed by its burdens. Families and carers need to be aware that if the answer to either of these questions is 'no', a change in the level of care may be indicated.

In making a decision to change the level of care, it needs to be clear that this is not an abandonment of either the patient or the carers, but rather an option for a level of care that is more appropriate to the person's condition at the time. The emphasis always needs to be on what care is to continue, especially when some options are being withdrawn.

5.5 COMMUNICATION, CARE AND CULTURE

There may be cultural differences in relation to receiving and discussing information about illness, disability, death and dying, and making decisions. A number of groups have particular needs and expectations in relation to care of a person in PCU or MRS. These include:

- Aboriginal peoples and Torres Strait Islander peoples (see Section 5.5.2, page 23);
- the many groups within Australia's multicultural society who have specific cultural and linguistic needs (discussed below, Section 5.5.1);
- people of different religious affiliations;
- children in PCU or MRS and their families (see Section 5.6, page 23); and
- people in rural and remote areas (see Section 6.4, page 38).

5.5.1 Culturally and linguistically diverse communities¹⁰

People bring to any exchange their own attitudes and beliefs, some of which arise from their cultural and linguistic background. In the context of PCU or MRS, these inevitably influence how both families and health professionals respond.

It is vital that health professionals be sensitive to these cultural issues; that they do not leap to stereotyped conclusions, but rather seek to learn about the beliefs and needs of the particular person and family.

It is important for health professionals to find out whom they should be addressing (individuals or groups) when discussing a patient's condition. If not sure, then ask.

In most cultural groups, the family has traditionally been the main source of security, assisted at times by social and religious groupings. Rituals have often provided a structured pattern of behaviour and given comfort, particularly in situations of stress, loss and grief. Migration from the country of birth cuts off many support systems, increasing the sense of helplessness in times of need. Many immigrants have retained their traditional community support and settled in close proximity to each other, but subsequent generations are not necessarily prepared to follow this pattern.

¹⁰This section draws on Palliative Care Australia's *Multicultural Palliative Care Guidelines* (1999), developed by Andrew Taylor and Margaret Box based on wide-ranging consultation with culturally and linguistically diverse communities

Where a family is not comfortable using English, they must have access to a professional, independent interpreter. Consideration of gender and social strata in the choice of interpreter is important. Social strata in many ethnic communities are strongly adhered to, and an interpreter from a different social stratum may be seen as an insult. In some societies and with some conditions, information conveyed from a man to a woman or vice versa would be considered highly improper.

Cultural Competency in Health: A guide for policy, partnerships and participation (NHMRC 2006) provides a discussion of this subject.

5.5.2 Aboriginal and Torres Strait Islander peoples

Consideration of care for Aboriginal and Torres Strait Islander peoples in PCU or MRS must take into account the principles and values of Aboriginal and Torres Strait Islander cultures. Death and dying issues are discussed in *Companion Guide: Providing culturally respectful palliative care to Aboriginal people in South Australia* (Government of South Australia, 2006, www.pallcare.asn.au/aboriginalcaresa.php). There is also a discussion of Aboriginal and Torres Strait Islander values in *Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research* (NHMRC 2003). Aspects to be respected in working with Aboriginal and Torres Strait Islander people in PCU or MRS and their families include:

- religious beliefs about the person's spirit;
- obligations, respect and responsibilities between family groups;
- additional components of care to be negotiated;
- family members staying in the room, especially for younger people;
- sensitive, plain language conversations about the person's condition and options available (prognosis); and
- options for members of the extended family to be involved, to foster trust and greater understanding of the condition.

Interpreters may be essential to minimise misunderstanding and to enable conversation between health professionals and family.

5.6 CHILDREN

PCU or MRS in a child poses particular challenges in relation to the family's involvement, concerns and grief, as well as the impacts on people in the child's broader environment.

Where a child is in a state of PCU or MRS, the intensity of issues can be magnified, not only for parents but for all those involved in the child's care. For parents, in addition to the grief at the effective loss of their child, there is loss of hopes and dreams, and a sense of responsibility and possibly culpability.

There may be a desire and willingness to care for the child at home. There is also often a family and community expectation that parents will take on this care. As with adults, the burden of care is significant and ongoing. Health professionals are under the same obligations to respect and address the needs of the family (see Section 5.9 'Role of and support for families and other carers', page 26). In that respect, health professionals have an obligation to consider the impact of care at home on the child's siblings.

Health professionals' obligation to optimise continuity of care and advocate for the child or young person in PCU or MRS is especially pertinent during the potentially difficult transition between child and adult services.

5.7 MISUNDERSTANDING AND CONFLICT

Most disagreements can be prevented by early, sensitive and ongoing communication to achieve consensus and clarity on the care plan and goals. There may, however, be times when opinions about optimal care for the person in PCU or MRS differ between staff and family, between family members, or between members of staff.

5.7.1 A proactive approach

Involving family members and carers in the decision-making process requires that they be listened to and have their questions answered. Information given should be consistent and realistic, and should not seek to be more confident than the evidence allows. Helping families to find ways to live with this uncertainty is important, especially if some family members feel the need to 'do something' to achieve certainty by actions that may be precipitous or futile, or by withdrawal of treatment. **Setting goals for care and for future assessment of care is important in averting or negotiating future conflicts.**

Some people in PCU may show frequent signs of what appears to be distress (eg, through contorted bodily or facial movements), though it is often unclear whether these responses reflect distress or involuntary movement, and whether possible distress could be alleviated. This can be very upsetting for families, and for staff.

Families can misinterpret or exaggerate the importance of small improvements (real or apparent) in motor function or response. These may give rise to false hopes. They may also lead to requests for futile treatment. Such issues should be responded to sensitively.

Where there is difference of opinion within a family, mediation may be required.

5.7.2 Second opinions

If the family and/or others do not accept the clinical opinion, or if they want confirmation of the clinical opinion provided, an independent second opinion should be offered. A second opinion may assist in overcoming misunderstanding and conflict, or the family may simply believe a second opinion is a good idea or good practice. In all of these cases a second opinion is warranted.

A clinician giving a second opinion should be from another hospital, given that the family needs to be satisfied that the second opinion is independent. The person's hospital or facility can suggest a number of options. The family is free, however, to reject these suggestions and choose another suitably qualified person. The person providing the second opinion should make time to explain his or her findings in person to the family and allow opportunity for questions.

5.7.3 When clinical opinions differ

There may be times when opinions about optimal care for the person in PCU or MRS differ among clinicians. Acute care professionals may have different perspectives from those engaged in rehabilitation, as they have different objectives and time frames, and use resources differently. There may also be differences of opinion between those who are more closely involved with a patient on a day-to-day basis and those who assess the patient less frequently.

It is essential to good communication that clinicians are of one mind when they come to talk to the family. Conflicting information and advice are not helpful. Health professionals have an obligation to seek and, where possible, provide consistent advice, which includes all options that the family should consider. The leadership responsibility would seem to rest at a practical level with the clinicians who are most directly involved on a day-to-day basis.

5.8 RECORD KEEPING

Adequate, accurate and comprehensible record keeping is an important part of good communication, including records of the nature of any discussions that have taken place among team members or between team members and family or other carers. Copies of advance care planning documents should be included in the person's record.

Clinicians should ensure that written documentation is transferred with the person in PCU or MRS between sites of care (including home), to ensure that care is not compromised. This may take the form of comprehensive summaries and/or photocopies of important sections of the medical record. Families may be encouraged to keep a diary of care, or care manual.

Given the nature of PCU and MRS, records may need to be kept longer than usually required, to inform the person's care over his or her lifetime.

Subject to the relevant privacy legislation, the person's representative has a right to access the person's records. The method of access and the process involved varies between jurisdictions and facilities.

5.9 ROLE OF AND SUPPORT FOR FAMILIES AND OTHER CARERS

Families can make a very positive contribution to the care of people in PCU and MRS, as they are the people with the knowledge of the person's personality, values and preferences before the injury. The care that families provide needs to be in the context of a specialised team approach, and families require specialised care and support.

Health professionals need to be sensitive to and responsive to the high levels of stress that caring can lead to for families, whether that care is delivered at home or in an institution.

Support for families entails:

- (a) assessing the situation on an ongoing basis;
- (b) seeking and advocating for adequate professional and other support for the family. This may require liaison with government and/or private agencies;
- (c) exploring respite care possibilities and/or possible changes to the site of care, where necessary;
- (d) taking into account the potentially complex effects on families and the person when and if that person emerges from PCU or MRS; and
- (e) respecting and seeking to address the family's burden of care with a sufficient level of resourcing and support including psychological care.

Where families choose to be involved in care, staff caring for the person in PCU or MRS (eg, in a nursing home) need to help and support families in this, and make them feel welcome and valued.

Some families may choose to play a substantial role in the person's longer-term care, and may be pivotal in determining the quality of that care. For others, this may be neither feasible nor desirable. Families describe a wide range of roles they may take on, for example, specific carer, legal guardian and decision-maker, advocate, lay therapist and case manager, practical support, and more. **Health professionals have an obligation to affirm families in the roles they choose, to provide them with ongoing, active support and care** in these often difficult and unfamiliar roles, and to understand and be aware of the difficulties and unfamiliarities families may face.

At the same time, many families find there are also strongly positive aspects to caring for the person, and this needs to be acknowledged by health professionals.

The person in PCU or MRS and/or the family or carers often face financial hardship, resulting both from loss of income (of the person and/or the family) and from care expenses. Health professionals need to be aware of funding that is available, and advocate for adequate and coordinated financial support for the care, equipment and accommodation required.

5.10 SUPPORT FOR HEALTH PROFESSIONALS

Involvement in the care of people in PCU or MRS raises a number of issues for health professionals and non-family carers (paid or volunteer), including:

- (a) the psychological and physical impact of working with people in PCU or MRS;
- (b) support and psychological and spiritual care for people doing this work; and
- (c) education for direct-care staff and other professionals involved in caring for people in PCU or MRS.

Health professionals caring for people who are severely brain damaged may find the level of care required very demanding, particularly when combined with the demands of supporting families. It is acknowledged that there is a risk of 'burnout' in health professionals.

Health professionals have an obligation to be responsive to the burden placed upon colleagues. They also have an obligation to people in PCU or MRS, to ensure that the health professionals providing care are sufficiently trained and competent to deliver that care optimally, and are supported in their care delivery.

6 SITES AND LEVELS OF CARE

6.1 PHASES AND SITES OF CARE

Care of a person with severe brain injury may go through a number of phases. **Decisions about the site of care may determine the intensity and range of services available, which affects not only the prospects for improvement, but whether deterioration is prevented.**

As well as affecting the person's physical well-being, the site of care may have a significant impact on the person's psychosocial, spiritual and emotional well-being, which can be seriously compromised if the person is left in isolation.

6.1.1 Initial phase

Initially, a person with severe brain injury is admitted to an acute hospital. The focus is on managing and stabilising the medical condition. Many patients will die during the acute phase, either due to the brain injury or associated complications or because treatment is withdrawn.¹¹

When a person's condition appears relatively stable, usually several weeks after the emergence from coma, an assessment may be made that, as a result of injury, the person is in a state of PCU or MRS and any improvement is likely to be slow. Such a diagnosis should not be made until at least four weeks after emergence from coma. Once it has been made, the treating team should discuss with the family all of the options for the person's continuing care.

A decision must be made about whether intensive treatments will be continued or scaled down, or whether such treatments may be either futile or overly burdensome, given the nature of the condition.

The next site for care may be a rehabilitation facility (where available), residential care (nursing home), supported community care or home. Some people may access only one of these options; some may move through a number; some may move from acute care to residential care, for a period of assessment and monitoring to assess whether more active rehabilitation is appropriate. The appropriate next site of care is not always available.

6.1.2 Rehabilitation

Rehabilitation is aimed at optimising the person's ability and function, physically, psychologically, socially and spiritually. It involves a multi-disciplinary team that may include a rehabilitation medical consultant, physiotherapist, occupational therapist,

¹¹ See Myburgh JA, Cooper DJ, Finfer SR, Venkatesh B, Jones D, Higgins A, Bishop N, Hignett T, and the Australasian Traumatic Brain Injury Study (ATBIS) Investigators for the Australian and New Zealand Intensive Care Society Clinical Trials Group, 2008. Epidemiology and 12-month outcomes from traumatic brain injury in Australia and New Zealand. *Journal of Trauma* (in press).

rehabilitation nurses, speech pathologist, music therapist, diversional therapist, social worker, chaplain, neuro-psychologist, dietitian, other specialists and the general practitioner. An exercise and care program is developed for the individual to promote and stimulate activity and response. Discharge planning for the next stage of care is started as soon as the person is admitted to rehabilitation. That next stage might be within a supported community house, residential care or the person's home.

People who are slow to recover from brain injury may need some level of rehabilitation care for long periods of time as progress, though evident, may take years.

The aims of rehabilitation programs for people in PCU or MRS are to maintain a level of function, to prevent deterioration due to immobility, to monitor neurological improvement, and to assist the individual to build on any improvement to function. The person is likely to remain dependent on care for daily needs.

Rehabilitation for people in PCU or MRS can involve:

- (a) physiotherapy to maintain muscle tone, prevent contracture and improve posture;
- (b) speech pathology addressing issues relating to swallowing and communication;
- (c) sensory stimulation programs;
- (d) medication to improve arousal and decrease agitation; and
- (e) occupational therapy to consider splinting and the provision of aids and equipment to assist carers.

This care may be delivered in a specialist rehabilitation facility, or it may be provided by the rehabilitation team in residential care or the person's home, or patients may move over time between these sites as the level of rehabilitation care changes.

In the early stages, the individual is generally passive during most therapy, but if improvement occurs, the person may become an active participant. **The intensity and goals of therapy must be regularly monitored.** In many cases, ongoing 'therapy' is carried out in the longer term by non-professional carers who have been instructed by health professionals.

Decisions may need to be made about what limits, if any, should be placed on such a program if, after a reasonable period, an individual shows no evidence of improvement and prospects for improvement become less likely. In these cases decisions on therapy are often influenced by the availability of resources and consideration of cost and benefit. Intensive rehabilitation has significant cost and should be evaluated at regular intervals to assess whether there are reasonable prospects of benefit, bearing in mind that slow recovery is possible over many years. The rehabilitation team is also involved in specifying long-term care needs for individuals in PCU or MRS, including the need for maintenance therapy.

6.1.3 Maintenance care

Maintenance care continues when there is little or no expectation of further improvement in function. Therapy during this phase is intended to maintain an existing level of function, health and well-being, and to help carers to provide optimal care. For example, prevention or treatment of contractures assists the provision of nursing care.

Decisions need to be made about the level of maintenance rehabilitation and care that is appropriate to the person's needs (decisions on withdrawal of aspects of maintenance care are discussed in Section 6.2.4, page 36).

Maintenance care may be delivered in various settings, and should involve:

- the delivery of nutrition and hydration;
- comprehensive care to maintain health and well-being;
- physical therapy to prevent contractures and maintain muscle tone, with therapists, other health professionals and carers working together to maintain level of function;
- ongoing review for any improvement; and
- anticipating and treating infections and symptoms that appear distressing.

6.1.3.1 Residential (nursing home) care

Many people in PCU and MRS are cared for in residential care. Generally, residential care lacks the range of facilities needed by younger people and available in rehabilitation facilities. The nursing home may be unable to deliver the medical and other therapies, such as physiotherapy and speech pathology, or the level of nursing care needed by someone in PCU or MRS. Such care is important both to support any prospect of improvement and to prevent deterioration.

There are, however, some residential care facilities that provide the range of care needed for people in MRS and PCU.

People in PCU have no need of many of the facilities that are provided in a nursing home, including kitchen and catering facilities, lounge and recreational facilities. Their needs are quite different, and placement in nursing home care, while perhaps convenient or sometimes the only option, may thus be a misuse of resources.

As a community we have an ethical obligation to address this misallocation of resources for people, such as those in PCU or MRS, for whom any recovery will be very slow. This has been recognised in the United Kingdom, France and Italy, where specific resources have been made available for specialist care facilities for people with severe acquired brain injury, targeting services to the actual needs of this client group.

6.1.3.2 Community house

A community house accommodates about 4-5 people with similar disabilities, who require supervision, are dependent for some or all of their care, and are unable to perform the tasks required for day-to-day living (eg, showering, dressing, eating). Trained staff are on duty 24 hours a day, with a house coordinator managing the house. Each resident has his or her own program, facilitated by the house staff, which includes social outings, shopping and leisure activities.

It is possible to provide adequate care for someone in PCU or MRS in supported community care, provided that arrangements can be made for the necessary specialised therapy and there is regular review by a medical rehabilitation consultant.

6.1.3.3 Care at home

Care at home is delivered by family and others.

Decisions about care at home must take into consideration whether adequate care can be provided in that environment. Health professionals have an ethical obligation to consider the impact of such care on families and households.

Experience with the 'Acquired Brain Injury: Slow To Recover' program in Victoria highlights the very high stress levels reported by families who care at home for a person with severe brain damage. Questions to be addressed with the family include: under what circumstances should a family take on the physical, social, economic, psychological, and personal burden that caring for a person in PCU or MRS entails?

The home may need to be modified for wheelchair access and hygiene requirements. Family members may be trained to provide some of the therapies needed, but it is likely that outside carers will also be needed. **The family is likely to need significant support to maintain the intensity of care required for someone in PCU or MRS. Part of the treating team's ethical responsibility is to ensure that arrangements are in place for that support.**

Sometimes a trial period of care at home may enable the family to realise the demands of care and assess whether they have the capacity to meet those demands in the longer term.

Families need sensitive support as they grapple with the possibility of not being able to manage the care of their family member at home.

6.1.4 Palliative care

Palliative care is provided when a person has a life-threatening illness and requires specific attention to symptom control as well as end-of-life issues. However it is important to counter any misperception in the community that palliative care is concerned with bringing about death.

Palliative care has a role outside of the immediate context of the end of life, particularly in incurable or prolonged illness. It is therefore appropriate to refer people in PCU and MRS for palliative care consultation when symptom control is difficult or withdrawal from overly burdensome life-sustaining treatment is being considered.

Palliative care comprises a multi-disciplinary range of services to support the person and his or her family physically, socially, emotionally and spiritually. This holistic care will continue throughout the person's illness and, in the form of bereavement support, after the person's death.

Though people in PCU or MRS are usually in a stable condition, they are prone to life-threatening medical complications. They may also be capable of suffering pain or discomfort, although it may not be possible to establish this. Health professionals therefore need to minimise any possible discomfort and respond to signs that might indicate distress. If burdensome treatments are withdrawn, it is essential that health professionals emphasise the ongoing commitment to care that is palliative and supportive.

It may thus be necessary to seek a palliative care consultation for people in PCU or MRS, not only to relieve distressing physical symptoms, but also for independent review of the social, emotional and spiritual aspects of care, and of the family and carers (professional and other), including grief and bereavement support.

6.2 MAKING DECISIONS ON LEVELS OF CARE

Justice in the allocation of resources recognises that the needs of individuals vary. Those who are affected by profound illness or disability have different needs from those who are well and able. The resources of any community are finite and need to be used effectively and efficiently. Consideration of the resources required for people in PCU and MRS is relevant to ethical judgements about the levels of care warranted in circumstances of high dependency, especially when the need is prolonged, the prospect of benefit to the individual is slight, and the burden of care is great (see Section 5.4.4 'Discussing changes to the level of treatment or ceasing a treatment', page 21).

6.2.1 Basis for decision-making

After diagnosis of PCU or MRS is confirmed, there may be a number of points at which clinicians need to decide whether to initiate a treatment or to continue, reduce or increase the level of treatment.

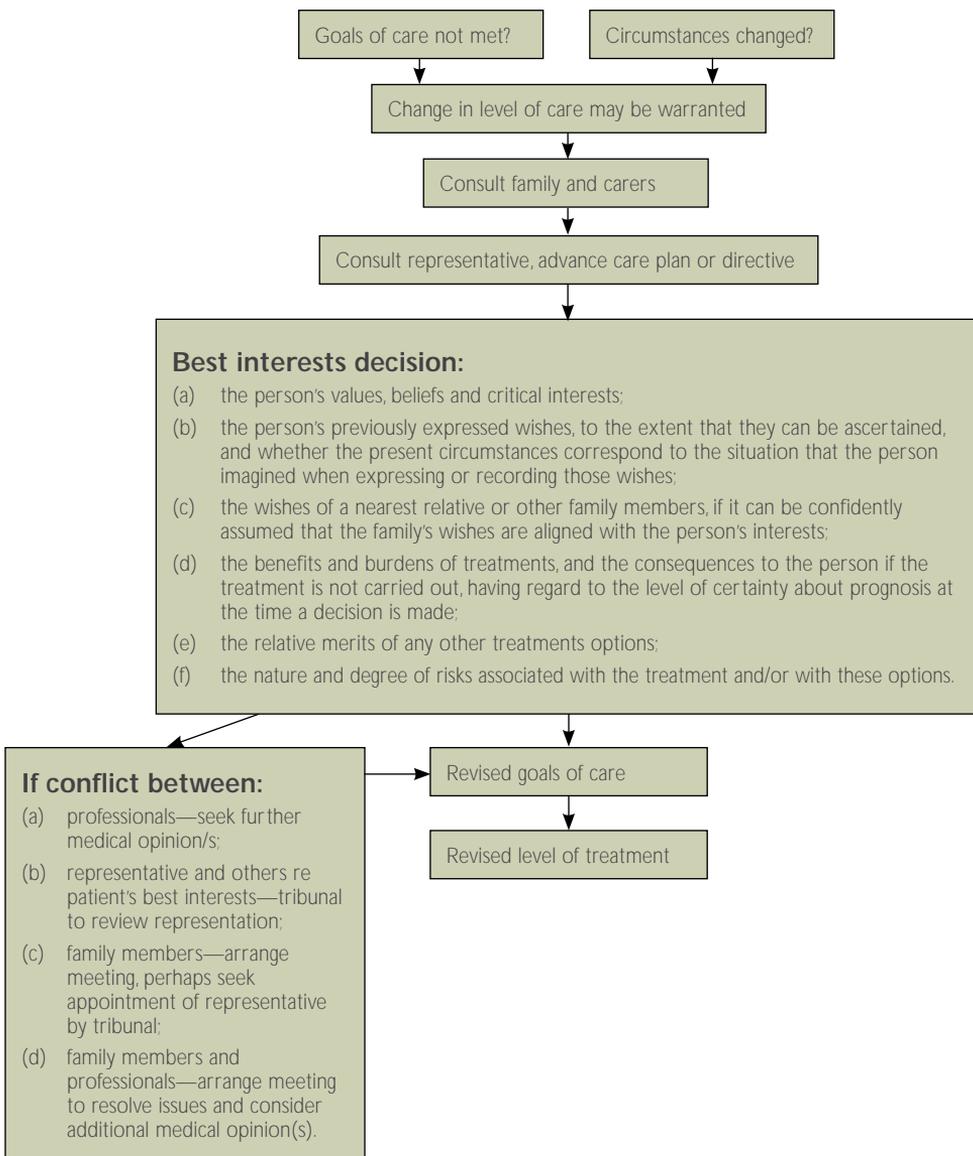
These decisions need to be based on the person's best interests and a clinical assessment of the likely benefits and relative burdens of each treatment option, and made in consultation with the family, carers and representative. It is important that decisions about the best interests of a person in PCU or MRS are not affected by the emotional responses of family, carers and others and their sense of being burdened.

Where possible, decisions about care should be based on evidence of effectiveness, but such evidence may be limited or non-existent, particularly in the case of non-medical modalities of care, including therapies perceived as 'alternative' or 'complementary'.

As discussed earlier (see Section 5.4.3 ‘Discussing prognosis and care options’, page 20), high levels of treatment or care may involve significant burden to the community and its resources. Clinicians need to explain to families in advance that there are occasions when, after a treatment has been tried for a reasonable time without sustainable benefit, it may need to be withdrawn, although this may result in some deterioration in the person’s condition.

Figure 2 sets out a process for revising clinical decisions.

FIGURE 2: Revising treatment decisions – a sequence



6.2.2 Burdensome and futile treatment

It is always necessary to consider whether a treatment or intervention may be overly burdensome or futile.¹²

Benefits of treatment may include:

- (a) slowing down the progress of disease;
- (b) sustaining the person's life;
- (c) reducing disability and improving health; and
- (d) relieving the person's distress or discomfort.

Burdens of treatment include distress and suffering to the patient. Decisions about treatment may also need to take into account the impact for the family and community.

Overly burdensome treatment is distinct from a level of care for health and life that carers may be regarded as obliged to provide.

Treatments may be judged to be overly burdensome when the burden of treatment for the patient is disproportionate to the likely benefits. Whether a particular treatment is overly burdensome is determined by assessing and balancing the risky, intrusive, destructive, exhausting, painful or repugnant nature of the treatment, against its benefits or chance of success.¹³

Such decisions are informed by the patient's and family's particular circumstances, their experience of illness and its remedies, and their culture, beliefs and preferences. These decisions may also need to take into account the burden or cost of the treatment and the availability of resources for the family and/or community.

'Futile' is used in medical practice to mean many different things. Its use is ambiguous and may in fact obscure, rather than clarify, the nature of the decision being made. For that reason in these guidelines the more limited Macquarie Dictionary definition is adopted: 'incapable of producing any result; ineffective; useless; not successful'.

Treatment is futile only if it produces no benefit to the patient. Futile treatment ought neither be continued nor initiated. Artificial nutrition and hydration (ANH) is futile if it fails to sustain the person or bring comfort. Circumstances may develop in which the delivery of ANH becomes overly burdensome and may be withdrawn. This is discussed in Section 6.2.4 (page 36).

¹² This is an ethical discussion. The legal application of these terms may vary between jurisdictions.

¹³ Historically the concept of 'overly burdensomeness' has been talked of in terms of 'ordinary' and 'extraordinary' means. This traditional principle was intended to draw a distinction between treatment that is not obligatory and care for one's health and life that is obligatory or expected. The distinction has been used differently by medical practitioners and ethicists. Some medical practitioners tended to describe extraordinary treatment as that which is experimental, unusual or not an established therapy; that is, treatment that goes beyond what would normally be the case or established procedure. Others' use of the term seems to have begun in the context of battlefield amputations and whether a person was obliged to undergo amputation in order to prevent death, presumably from gangrene. The basic notions common to both seem to have been an understanding that:

- there are some treatments that, owing to their risky, intrusive, destructive, painful or repugnant nature, or their low chance of success, may be judged to be overly burdensome and thus not appropriate;
- there is a level of care for health and life that we are obliged as patients to accept or as carers to provide or offer; and
- these decisions are relative to the particular patient's circumstances and his or her own experience of illness and its remedies.

6.2.3 Resuscitation issues

Discussion of whether cardiopulmonary resuscitation is to be attempted in the event of respiratory or cardiac arrest is helpful in determining the level of intervention and resources to be made available and what steps are to be taken in urgent circumstances. The discussion must be documented.

Such decisions are a level of care issue, and need to be discussed between health care staff, family and representative in the same way (see Section 5.4.4 'Discussing changes to the level of treatment or ceasing a treatment', page 21). The issue is whether intensive treatments are warranted.

There is a difference between a person who has a cardiac arrest as a result of an underlying condition from which there is little chance of recovery, and a respiratory arrest that results from an easily reversible cause, such as a temporary obstruction of an airway. In the former case, attempts to resuscitate are likely to be futile. However, clearing an obstruction and subsequent resuscitation may be easily achieved and likely to be successful and ought to be attempted unless the means of doing so are overly burdensome.

6.2.4 Withdrawal of aspects of maintenance care

Where unresponsiveness, or even minimal responsiveness, is prolonged, the question may be raised whether it is warranted to continue treatment for a person for whom significant improvement is considered improbable, or whether the person has any capacity to benefit from maintenance treatment, other than mere survival.

In considering these questions, the impact that prolonging the person's life may have on the lives of the family is not relevant.

A person in PCU or MRS may be affected by other conditions, or his or her condition may deteriorate. Complications may also develop in relation to delivering some elements of maintenance care. For example, tube feeding may cause aspiration and recurrent respiratory infection; or a percutaneous endoscopic gastrostomy tube (PEG) may cause excoriation or gut inflammation. People who are minimally responsive may show signs of discomfort.

As with any decisions about the treatment of people who are highly dependent, **decisions about withholding or withdrawing treatment and the continuing provision of artificial nutrition and hydration should be informed by a consideration of the person's best interests, including what, if anything, is known about his or her wishes; and should reflect the best contemporary standards of care for people who are highly dependent.** The question is never whether the person's life is worthwhile, but whether a treatment is worthwhile.

While the presumption is generally to continue maintenance care, complications may lead to some aspects of that care being considered overly burdensome and those aspects of care may be withdrawn after careful consultation with the family and representative. This should be regularly reviewed with families. The person's previously expressed wishes are relevant to a judgement of the burdensomeness of a treatment, and must be considered. Others not involved in the decision, but involved in the care of the person, need to be informed about the reasons for the decision.

In making a decision in the person's best interests (see Section 4.4 "Determining 'best interests'", page 12), families should understand that the removal of maintenance care that has become futile or overly burdensome is an acceptance of the severity of the person's condition, and not an abandonment of the person.

The decision to withdraw maintenance care, and the person's subsequent death, may raise complex grief and bereavement issues for families. Whenever such a decision is contemplated, specialist bereavement care should be offered to families and should be available throughout, including after the person's death. The offer needs to be sensitive to the nature of the family and the resources available to them.

6.3 RESOURCE ALLOCATION AND SITES OF CARE

People in a state of PCU or MRS require specialist care initially, and lifelong medical, nursing, allied health or other care. Existing health and long-term care funding arrangements are generally insufficient to care adequately for profoundly brain-injured people who do not receive compensation (from employment or road traffic compensation funding) or other financial coverage. The high dependency of people in PCU and MRS means that inpatient and residential care services are unable to provide long-term clinical care and accommodation that is adequate and age-appropriate. In some States there are programs (eg, the Victorian 'Acquired Brain Injury: Slow to Recover' program) that have gone some way to addressing this issue.

There are issues of equity and justice in the allocation of resources at all levels—individual patient, hospital, and health system—for the care of people in PCU or MRS. In particular, a justice issue is raised by the wide gap between the level of care available to compensable patients compared to non-compensable patients.

The absolute number of people in PCU or MRS in Australia is thought to be relatively small, so the economic impact for governments and insurance agencies of providing adequate support for their care and for their families is likely to be relatively insignificant. Health professionals should be mindful of this in their advocacy for adequate care for people in PCU or MRS.

There are also ethical issues to be resolved about the most effective and efficient use of resources for the long-term care of people in PCU and MRS, whether through a combination of specialist facilities and in-home assistance, or in generalist nursing homes or acute care hospitals.

Other models of care might be considered. In France, for example, there are specialised centres for the care of people in PCU. Such centres do not need many of the facilities provided in rehabilitation centres and nursing homes, such as catering facilities, but place emphasis on physiotherapy and occupational therapy, services that may not be as intensively available in a nursing home or rehabilitation service.

The site of care and resources available will be important factors in the ability to provide optimal care. Other factors to be taken into account include:

- the provision and timing of regular reassessment and appropriate response to any improvements in the person's condition (eg, a change of diagnosis from PCU to MRS, potential for slow stream rehabilitation);
- access to respite care; and
- geographical access for families to visit (particularly for rural and remote families).

6.4 RURAL AND REMOTE POPULATIONS

For families in rural and remote areas who have someone in PCU or MRS, there may be particular challenges in relation to service delivery, access to services and optimal care, and family access to sites of care. While it may be beneficial for a person to be at home with his or her own community, local care and professional support may be very limited or unavailable. The site of care may be at significant distance and involve logistic difficulties for a family wanting to remain involved in the care. Overall consideration of the person's care may result in the judgement that it is in the person's best interests to be closer to family and community even if services may be less available.

Health professionals need to be aware of the additional burdens on rural and remote families, and to work with families to resolve these issues in the best way possible for both family and patient – for example, planning review meetings well ahead at times to suit families' travel schedules, regular teleconferencing, providing a nominated contact person readily available by phone, comprehensive information sent by mail, and organisation of local respite.

These issues are even more pressing for rural and remote Aboriginal and Torres Strait Islander communities, for whom sense of self is strongly related to sense of location and land, and core beliefs are grounded in the person's land (see Section 5.5.2 'Aboriginal and Torres Strait Islander peoples', page 23).

7 EVIDENCE, DATA AND FURTHER RESEARCH

Research in PCU and MRS is subject to ethical guidelines to ensure that people in PCU or MRS are not exploited in any way, nor are they deprived of the benefits of involvement in research. In March 2007, the NHMRC released the *National Statement on Ethical Conduct in Human Research*, which provides for research on unconscious people. This is available online at www.nhmrc.gov.au/ethics/human/ahec/guidelines/index.htm.

The *Diagnostic Framework*, in its literature review, made clear that there is little high quality evidence available to inform care for people in a state of PCU or MRS. Furthermore, the Working Committee's activities have highlighted the lack of PCU and MRS incidence and prevalence data in Australia. The *Diagnostic Framework* recommended establishment of a nationally coordinated coma register¹⁴, which could be extended to include related conditions such as PCU and MRS.

¹⁴ from *Post-coma unresponsiveness (Vegetative state): A clinical framework for diagnosis*, NHMRC 2003, page p. 5

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APPENDIX I • GLOSSARY OF TERMS AND PHRASES

ABI	Acquired brain injury
ABS	Australian Bureau of Statistics
Advance care directive	A set of instructions for a person's future health care to be carried out in the event that he or she is unable to make decisions. It is intended to be binding. In some jurisdictions advance care directives have a legal status requiring compliance by caregivers.
Advance care planning	The processes by which a person seeks to provide advance guidance or instructions about how health care decisions are to be made for him or her, if and when he or she becomes unable to make decisions.
AHEC	Australian Health Ethics Committee
AIHW	Australian Institute of Health and Welfare
AROC	Australian Rehabilitation Outcomes Collaboration
autonomy	The decision-making capacities of individuals, usually expressed or understood as self determination. An autonomous person is self-governing. A patient, not a medical practitioner, must decide on his or her medical treatment. To give effect to this, there is the combined duty of disclosure and obligation to obtain consent to intervention. Respect for autonomy may also be expressed as a right to refuse treatment.
beneficence	Seeking to act in a way that is beneficial. This may involve balancing benefits against risks, burdens and costs.
best interests	Assessment of a person's best interests in relation to a treatment decision must take into account <ul style="list-style-type: none"> • the person's values, beliefs and critical interests; • the person's previously expressed wishes, to the extent that they can be ascertained, and whether the present circumstances correspond to the situation that the person imagined when expressing or recording those wishes; • the wishes of a nearest relative or other family members, if it can be confidently assumed that the family's wishes are aligned with the person's interests; • the benefits and burdens of treatments, and the consequences to the person if the treatment is not carried out, having regard to the level of confidence about prognosis at the time a decision is made; • the relative merits of any other treatment options; and • the nature and degree of the risks associated with the treatment and/or with those options.

brain death	A state in which all function of the brain has permanently ceased—that is, the person has died. Breathing is maintained artificially by a mechanical ventilator, the heart keeps beating autonomously for a time, and other organs may continue to function for a time. Brain death is diagnosed by assessing that the underlying cause and the extent of brain injury is such that all brain function has ceased and (after excluding factors that might temporarily suppress brain function) that this cessation is permanent. Over a period of time, the clinicians caring for the patient carefully observe the development and progress of the injury or disease. If it is thought that all brain function has been completely and permanently lost, doctors perform a series of clinical tests to confirm that the loss of function involves the whole brain, including the brain stem (which is involved in vital reflexes, eg, coughing, gagging, breathing). If clinical testing is not possible, then brain death is confirmed by imaging to establish absence of blood flow to the whole brain.
carer	Any person who provides care to a person in PCU or MRS, whether paid or unpaid.
clinician	Any health professional directly involved in a person's care, involving medical, nursing and allied health staff.
coma	A state of presumed profound unconsciousness from which the person cannot be roused when examined. Coma is not brain death; some brain function remains, and some or all may be recoverable.
consent	The act of assenting to a proposed course of action or inaction. In medicine it is usually the case that—unless it is an emergency—consent must be adequately informed.
critical interests	Those matters of conviction or opinion, whether articulated or not, that are particularly important in an individual's life.
cultural and linguistic diversity (CALD)	Refers to the wide range of cultural groups that make up the Australian population and Australian communities. The term acknowledges that groups and individuals differ according to religion and spirituality, racial background and ethnicity as well as language. The term 'CALD background' reflects intergenerational and contextual issues, not just migrant experience. ¹⁵
death	The final cessation of the integrated functioning of the body. Integrated functioning is a characteristic of living beings. Death is observed to have occurred when there is irreversible loss of brain function or irreversible cessation of circulation.
dignity	A complex notion incorporating respect for the worth of the individual as a member of the human family. It is thus an attribute of the kind of being who can normally make autonomous, rational choices, and it involves respect for that person's autonomy. Dignity thus combines respect for a person (inviolability), respect for his or her rational choices (autonomy), and respect for his or her privacy. An individual who has diminished capacity to make rational choices retains dignity through membership of the human family.

¹⁵ *Cultural Competency in Health: A guide for policy, partnerships and participation*, NHMRC 2005

duty of care	An obligation to be careful in the actions that a person takes. The duty is owed to all those whom the person should reasonably foresee will be affected by his or her actions. Broadly speaking, it is the moral or legal obligation that one person owes to another, either simply because the other is a fellow human being or because the person stands in a particular relationship to the other that gives rise to specific obligations.
duty of disclosure	The ethical obligation to disclose information about medical treatment that requires meeting an objective test (where the patient is informed of the usual risks associated with the treatment), and a subjective test (where the patient is provided with the particular information he or she has sought about the treatment).
family	Those closest to the person in knowledge, care and affection. This includes the immediate biological family; the family of acquisition (related by marriage/contract); and the family of choice and friends (not related biologically or by marriage/contract). ¹⁶
FIM	Functional Independence Measure, widely used in rehabilitation to assess level of independence across 18 items. The possible total score ranges from 18 (lowest possible) to 126 (highest possible).
formal meeting	A pre-planned, structured meeting between health care team and family, to discuss care, goals and progress.
futile treatment	Treatment is futile only if it produces no benefit to the patient (ie, does not slow down the progress of disease, sustain the patient's life, reduce disability and improve health, or relieve the patient's distress or discomfort). Treatment ought not to be continued or initiated if it is futile.
health professional	All of those in the health disciplines who may provide information and advice, but are not necessarily in a relationship of clinical care with the person in PCU or MRS.
ICD-10	International Statistical Classification of Diseases and Health Related Problems, 10th revision, used internationally as a standard method for classifying disease, as a basis for epidemiology and health management.
ICU	Intensive Care Unit
incidence	The number of new cases of a particular condition or disease over a specified time period; usually given per 100,000 population per year.
justice	Justice as a virtue is the recognition of the needs of others and the inclination to respect their needs based on common humanity. As a normative principle it means ensuring that there is fair distribution of the benefits of or access to goods and services, equality of opportunity and access, no unfair burden on any members of the community or on particular groups, and no exploitation or discrimination.

¹⁶ Canadian Palliative Care Association, *Standards for Palliative Care Provision*, June 1998.

minimally responsive state (MRS)	A state that may arise when a person has emerged from coma or PCU. There is a minimal level of purposeful response, with discernible but inconsistent evidence of consciousness. Cognitively mediated behaviour occurs often enough or for long enough to distinguish it from reflex behaviour.
NHMRC	National Health and Medical Research Council
non-maleficence	Avoiding causing harm.
post-coma unresponsiveness (PCU)	A state or condition in which a person has emerged from coma to the extent that he or she has sleep/wake cycles, but there are no observable purposeful responses to stimuli.
prevalence	The proportion of people in the population who have a particular condition or disease, at a certain point in time.
quality of life	A term used with respect to assessing the outcomes of interventions. It may be used in a formal way, engaging methods of scoring patient disability, discomfort and preferences.
representative	A person's representative is responsible for making decisions in the best interests of that person, when the person becomes unable to make his or her own decisions competently. The representative must be adequately informed about the person's circumstances and treatment options, as well as about his or her values, beliefs and previous wishes. The representative may be appointed previously by the person; appointed by a court or tribunal after the person became incapable; or have legal authority automatically, as the person's spouse, carer, other next of kin or other person specified in the applicable legislation.
respect	Respect for human beings is recognition of each individual's intrinsic worth or value as a person. This is often referred to as their inherent human dignity. Respect requires having due regard for welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective. It involves protecting the privacy, confidentiality and cultural sensitivities of individuals and communities (see Dignity, above).
right to refuse treatment	The right to refuse treatment is implied by the moral and legal obligation to obtain consent. In some jurisdictions it is also explicit in statute. However, it is also a right that may continue to be exercised after a person has previously consented, for example, that treatment be discontinued
rights	For the purposes of this document, 'rights' refers to moral rights, and not legal rights. A moral right is an entitlement or justifiable claim. It is often expressed as a relation between the right-holder and that to which he or she is entitled, such as a person's right to health care or housing or freedom of speech. However, the expression of a right also implies that there is a person or institution in duty bound to respect or grant that to which the right-holder is entitled.
TAC	Transport Accident Commission of Victoria
vegetative state (VS)	A term, sometimes qualified further by the terms 'persistent' or 'permanent', which is also used to describe the condition of post-coma unresponsiveness. ¹⁷

¹⁷The *Diagnostic Framework* noted concern about the term 'vegetative state', and adopted the term PCU because it avoids any pejorative implications of 'vegetative'; it excludes unresponsive states that do not follow a period of coma (eg, late stages of Alzheimer's disease), and it has no time-based qualifiers. See Section 1.4 'Defining PCU and MRS', page 4.

APPENDIX 2 • TERMS OF REFERENCE

The terms of reference as revised in 2006 are as follows:

The PCU Working Committee will provide advice to the Chief Executive Officer (CEO) of the NHMRC about the care of people with post-coma unresponsiveness—diagnosed in accordance with NHMRC’s *Post-coma unresponsiveness (Vegetative state): A clinical framework for diagnosis* (2004)—and people in a minimally responsive state.

This advice will take the form of draft ethical guidelines. In developing the draft guidelines, the Working Committee will:

1. Examine the ethical, legal, social and clinical issues associated with the care of people in PCU and MRS from their perspectives, the perspectives of those who care for them, and those of their family members or guardians.
2. Consider the best available evidence, including relevant international guidelines.
3. Undertake public consultation in accordance with the *National Health and Medical Research Council Act 1992* and have regard to all submissions received.
4. Determine the need for additional documents for either the community and/or carers.
5. Provide regular progress reports to AHEC and to the CEO.
6. Present the final draft guidelines to AHEC for consideration.

APPENDIX 3 • WORKING COMMITTEE MEMBERSHIP

DEVELOPMENT OF ISSUES PAPER

Name	Membership category and relevant experience
Rev Prof John Morgan (Chair)	AHEC member; Warden, St John's College, University of Queensland; Academic Fellow, Faculty of Medicine, University of Queensland; Director, Australian Institute of Ethics and the Professions, University of Queensland; Past President, Australian Association for Professional and Applied Ethics
Ms Margaret Bramwell	Senior Social Worker, Intensive Care Unit, Royal North Shore Hospital; Member, Australian Trauma Society; Member, Australian Association of Social Workers
Dr Kerry Breen	AHEC Chair June 2003 to June 30 2006; Director of Gastroenterology, St Vincent's Hospital Melbourne, 1978-1992; President, Medical Practitioners Board of Victoria, 1981-2000; President, Australian Medical Council 1997-2000
Ms Diane Chamberlain	Australian College of Critical Care Nurses representative; Clinical nurse specialist (critical care); Senior Lecturer, Flinders University, South Australia; Vice President, Australian College of Critical Care Nurses (South Australian Branch)
Mr Julian Gardner	Guardianship; Guardian of Last Resort in Victoria; barrister and solicitor of the Supreme Court of Victoria; Chair, Ethico-legal Committee of Respecting Patient Choices Project
Dr Peter Greenberg	Consultant physician with an interest in evidence-based clinical practice; NHMRC Health Advice Committee member 2002-2006 (Chair 2006); Physician, Department of General Medicine and Principal Fellow, University of Melbourne Faculty of Medicine, Dentistry and Health Sciences, at the Royal Melbourne Hospital
Ms Michele Kosky	Consumer representative; NHMRC member; Executive Director, Health Consumers' Council, Western Australia; active in women's health; Executive Director, Western Australian AIDS Council, 1987-1994; Member, Australian National Council on AIDS, Hepatitis C and Related Diseases
Prof Linda Kristjanson	NHMRC member; Cancer Foundation Chair of Palliative Care and Director, Western Australian Centre for Cancer & Palliative Care, Edith Cowan University; Director, Centre of Nursing Research, Sir Charles Gairdner Hospital; Director of Hospice Research for Silver Chain Hospice Service, Western Australia
Assoc/Prof William Silvester	Intensive care physician; Intensive Care Specialist, Austin Hospital, Melbourne; Senior Lecturer, The University of Melbourne; Medical Director, LifeGift – Victorian Organ Donation Service; Chairman, National Steering Sub-Committee for Medical ADAPT Training Program; Director, Respecting Patient Choices Program (an Advance Care Planning Program)

Name	Membership category and relevant experience
Mr Noel Spurr	AHEC member; Disabled by polio, awarded the Advance Australia Award and Order of Australia Medal for leadership in the Disabled Rights movement; served 9 years as a Councillor at Nunawading and Whitehorse, including terms as Deputy Mayor and Mayor
Assoc/Prof Nicholas Tonti-Filippini	AHEC member; Consultant Ethicist in private practice and Senior Lecturer (Bioethics), John Paul II Institute, Melbourne; Foundation Director, Bioethics Department, St Vincent's Hospital, Melbourne (1982-90)
Rev Bill Uren	AHEC member; Rector, Newman College, University of Melbourne; formerly Hospital Ethicist, Mater Hospital, Brisbane; has lectured in moral philosophy, moral education and bioethics at universities in Melbourne, Perth and Brisbane; has served on clinical and research ethics committees in hospitals, research institutes, universities and professional bodies
Assoc/Prof John Watson	Neurologist; Associate Professor, Department of Medicine, University of Sydney; Director, Stroke Service, Hornsby and Ku-ring-gai Hospital, Sydney; Neurologist, Sydney Adventist Hospital, Sydney; Chairman, University of Sydney Human Research Ethics Committee
Ms Adelle Whalan	Royal College of Nursing representative; Clinical Nurse Consultant specialising in spinal cord injury rehabilitation and chronic pain management, Olympia Private Rehabilitation Hospital, Victoria; Director of Nursing, Ivanhoe Private Rehabilitation Hospital – Acquired Brain Injury Unit and Victorian Addiction Centre

DEVELOPMENT OF THE GUIDELINES

Name	Membership Category
Assoc/Prof Nicholas Tonti-Filippini (Chair)	AHEC member; Consultant Ethicist in private practice and Senior Lecturer (Bioethics), John Paul II Institute, Melbourne; Foundation Director, Bioethics Department, St Vincent's Hospital, Melbourne (1982-90)
Ms Margaret Bramwell	Senior Social Worker, Intensive Care Unit, Royal North Shore Hospital; Member, Australian Trauma Society; Member, Australian Association of Social Workers
Ms Diane Chamberlain	Australian College of Critical Care Nurses representative; Clinical nurse specialist (critical care); Senior Lecturer, Flinders University, South Australia; Vice President, Australian College of Critical Care Nurses (South Australian Branch)
Dr Mark Deuble	Palliative Care specialist; Staff specialist, Princess Alexandra Hospital; Director, Wesley Hospital Palliative Care Service; Member, Palliative Care Queensland; Fellow, Australasian Chapter, Palliative Medicine

Name	Membership Category
Mr Julian Gardner	Guardianship/lawyer; Public Advocate and guardian of last resort in Victoria (2000-07); Chair, Ethico-legal Committee of Respecting Patient Choices Program (2003-07)
Rev Dr Gerald Gleeson	AHEC member/religious expertise; Parish Priest of Summer Hill in Sydney; previous board member, Sisters of Charity Health Service; Research Associate, Plunkett Centre for Ethics in Health Care, St Vincent's Hospital; teacher of philosophy, in particular ethics, at the Catholic Institute of Sydney
Dr Peter Greenberg	Consultant physician with an interest in evidence-based clinical practice; NHMRC Health Advice Committee member 2002-2006 (Chair 2006); Physician, Department of General Medicine and Principal Fellow, University of Melbourne Faculty of Medicine, Dentistry and Health Sciences, at the Royal Melbourne Hospital
Ms Michele Kosky	Consumer representative; Member, NHMRC; Executive Director, Health Consumers' Council, Western Australia; active in women's health; Executive Director, West Australian AIDS Council, 1987-1994; Member, Australian National Council on AIDS, Hepatitis C and Related Diseases
Rev Prof John Morgan	Ethicist; Warden, St John's College, University of Queensland; Academic Fellow, Faculty of Medicine, University of Queensland; Director, Australian Institute of Ethics and the Professions, University of Queensland; Past President, Australian Association for Professional and Applied Ethics
Assoc/Prof John Olver	Rehabilitation physician; Director of Rehabilitation, Acquired Brain Injury Programme Coordinator, Epworth Hospital; Honorary Clinical Associate Professor, Department of Medicine, Monash University; Previous President of Australasian Faculty of Rehabilitation Medicine; Chair of International Affairs Committee, Australasian Faculty of Rehabilitation Medicine
Assoc/Prof William Silvester	Intensive care physician; Intensive Care Specialist, Austin Hospital, Melbourne; Senior Lecturer, The University of Melbourne; Medical Director, LifeGift – Victorian Organ Donation Service; Chairman, National Steering Sub-Committee for Medical ADAPT Training Program; Director, Respecting Patient Choices Program (an Advance Care Planning Program)
Assoc/Prof John Watson	Neurologist; Associate Professor, Department of Medicine, University of Sydney; Director, Stroke Service, Hornsby and Ku-ring-gai Hospital, Sydney; Neurologist, Sydney Adventist Hospital, Sydney; Chairman, University of Sydney Human Research Ethics Committee
Ms Adelle Whalan	Royal College of Nursing representative; Clinical Nurse Consultant specialising in spinal cord injury rehabilitation and chronic pain management, Olympia Private Rehabilitation Hospital, Victoria; Director of Nursing Ivanhoe Private Rehabilitation Hospital – Acquired Brain Injury Unit and Victorian Addiction Centre

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NHMRC STAFF

Julie Taylor	To July 2007
Tess Winslade	May 2006 – April 2007
Alice Knight	From April 2007

APPENDIX 4 • GUIDELINE DEVELOPMENT PROCESS

In developing and issuing guidelines, the National Health and Medical Research Council (NHMRC) and its principal committees are obliged under the *National Health and Medical Research Council Act 1992* (Sections 13 and 14A) to release draft guidelines for public consultation.

Following the development and dissemination of *Post-Coma Unresponsiveness (Vegetative state): A clinical framework for diagnosis* by the NHMRC in December 2003, a working group of the Australian Health Ethics Committee (AHEC) was formed to develop an issues paper on the ethical issues involved in the care of people in PCU. The working group included doctors, nurses, clergy, a social worker, a lawyer, ethicists, and patient and disability representatives. This issues paper was distributed for targeted consultation in April 2006. From that process, 40 submissions were received from a range of stakeholders. These submissions helped inform the guidelines that were subsequently drafted.

The draft *Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State* and *A Guide for Families and Carers of People with Profound Brain Damage* were released for public consultation in July 2007. A total of 47 submissions were received, including 33 for the Ethical Guidelines and 31 for the Guide for Families, with some respondents addressing both. The submissions were analysed by the working group, with decisions made on each, and the documents revised accordingly. Both documents were presented to AHEC at the 27-28 November meeting. With AHEC's support, the documents were forwarded to Council in December 2007, who endorsed them in early 2008. The CEO formally issued the two documents on 2 May 2008.

APPENDIX 5 • PCU AND MRS IN AUSTRALIA

INCIDENCE AND PREVALENCE: SUMMARY

The incidence and prevalence of PCU and MRS are factors in making decisions about the site and level of care and resource allocation.

It has proven very difficult to identify how many people there are in PCU or MRS in Australia, where they are cared for, and who is involved in their care. There are no data specifically on PCU or MRS, and it is unclear how many patients classified under related diagnostic codes might in fact be in PCU or MRS. Nor is it clear how best to capture these data or through what combination of sources. Sources might include data that include the time of separation from hospital, and/or discharge to nursing home, rehabilitation facility, home, and/or a combination of these.

Hospital data available to the Australian Institute of Health and Welfare do not include specific categories or combinations of categories that might include people in a state of PCU. No specific ICD-10 code exists for 'persistent vegetative state' and related conditions. A range of codes that could indicate the existence of PCU are outlined in Appendix 6.

The Working Committee suggests that people in PCU and MRS might be identified more accurately by flagging all separations from hospital of patients who:

- (a) had a diagnosis of traumatic, hypoxic or other brain injury;
- (b) spent time in ICU in a coma;
- (c) died or were discharged to nursing home, rehabilitation facility (not identifiable in the routinely collected data at the national level) or care at home.

Data from the Australasian Rehabilitation Outcomes Centre (AROC) database suggest that there are probably less than 100 people with the most profound neurological damage in rehabilitation facilities each year (including new and possibly a small number of previously diagnosed patients). However the AROC data collection does not allow the specific identification of people meeting the PCU definition, nor does it capture people who are not admitted to a rehabilitation facility.

Data from the Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers may provide an indication of how many people with profound brain damage are living in a hospital or nursing home, but there is no indication of how many of these people might be in PCU or MRS.

Figures from the Transport Accident Commission of Victoria (TAC) show that over the past 10 years, a total of 42 of their new clients with acquired brain injury (ABI) have been classified as 'minimal function', which, TAC advises, would be equivalent to PCU.

The US Multi-Society Task Force estimated that there are between 10,000 and 25,000 people in a state of PCU in the United States¹⁸. This would equate to 1,000-2,500 people in PCU in Australia; however, there is no evidence of such numbers in Australia.

The section below sets out in more detail the data provided to the Working Committee on the possible incidence and prevalence.

DATA SUGGESTING POSSIBLE INCIDENCE AND PREVALENCE

A search of the **Australasian Rehabilitation Outcomes Centre (AROC)** database to identify patients with brain dysfunction and the lowest level of neurological response (FIM=18) on entry to and exit from rehabilitation facilities identified around 65 episodes per year. AROC collects impairment code data rather than ICD diagnostic code data, and the Functional Independence Measure (FIM) is widely used in rehabilitation to assess level of independence across 18 items. The possible total score ranges from 18 (lowest) to 126 (highest). However, a FIM score of 18 may not indicate PCU as patients with this score would often indicate some level of responsiveness.

The NSW public sector has been very supportive of the AROC collection and it was estimated that in NSW there have been about 50 brain dysfunction *episodes* (rather than patients) a year with FIM 18 entry and exit scores. This would equate to approximately 150 nationally. Given that patients can have multiple episodes over many years, these figures suggest that there are probably less than 100 brain dysfunction patients with FIM 18 entry and exit scores in rehabilitation facilities each year.

Australian Institute of Health and Welfare (AIHW) provided data from the National Hospital Morbidity Database. There are no specific diagnosis codes for PCU; however, the code *S06.05 Intracranial concussive injury - Loss of consciousness of prolonged duration [more than 24 hours], without return to pre-existing conscious level* could, with extended length of stay, indicate cases of PCU due to injury. That is, a possible way of identifying PCU in the database would be to use the code S06.05 and select patients with an extended length of stay. This is based on an assumption that PCU patients would have extended lengths of stay. It does not include loss of consciousness associated with other causes, such as infections or poisoning or diabetes-related hypoglycaemia.

AIHW reports that, in 2003-04, there were 246 separations reported with this code. Length of stay distribution shows most had 'shortish' lengths of stay and therefore may not be PCU, if it is assumed that PCU patients have longer lengths of stay. There were 42 with a length of stay of more than 1 month, and 2 with a length of stay of more than 6 months.

¹⁸ Multi-Society Task Force, 1994. Medical aspects of the persistent vegetative state (1). Multi-Society Taskforce on the Persistent Vegetative State. *New England Journal of Medicine*, 330: 1449–508.

Multi-Society Task Force, 1994. Medical aspects of the persistent vegetative state (2). Multi-Society Taskforce on the Persistent Vegetative State. *New England Journal of Medicine*, 330: 1572–79.

Note that, for rehabilitation purposes, the US categorises traumatic brain injury separately from other types of acquired brain injury. Australia categorises all acquired brain injury together.

The **Australian Bureau of Statistics (ABS) *Disability, Ageing and Carers: Summary of Findings*** provides statistics on people with disability, older people, and carers across Australia. It includes basic demographic and lifestyle information, providing the basis for analysis and further production of figures and trends. It is produced every five years, the most recent being in 2003.

The AIHW Ageing and Aged Care Unit and Functioning and Disability Unit provided a brief analysis of the 2003 disability survey data in the Confidentialised Unit Record Files (CURF). CURFs contain sample data in the form of unit records where the information is not likely to enable the identification of a particular person or organisation. They contain no names or addresses of survey respondents, and may reduce the detail of some items (especially locational data) and make small changes to other items such as income. CURFs provide the most detailed information that can be released from an ABS survey.

The broad category of *head injury/acquired brain damage* merges about 10 subcategories of the ABS survey data such as *traumatic brain injury* and *brain damage from tumour*. Bearing this in mind, in 2003 about 27,930 people with *head injury/acquired brain damage* and *a profound core activity limitation (excluding severe limitations)* were living in cared accommodation. Of these, 5,900 people were in hospitals (people who had been, or expected to be, living in hospitals for three months or more) and 15,600 people were in aged care facilities. These groups might include people with the diagnosis of PCU, but people in PCU cannot be identified from the survey data.

AIHW suggested that, in the absence of information from hospital and nursing home data, some rough estimates might be considered by applying proportions (based on assumptions) to those groups estimated from the *ABS Disability, Ageing and Carers: Summary of Findings* via some investigations into the nursing homes and hospitals.

The **Transport Accident Commission of Victoria (TAC)** advised that clients in a post coma unresponsive state would be equivalent to their severe acquired brain injury (ABI) clients classified as 'Minimal Function'. The functional classifications TAC uses for clients with severe ABI are:

- 1 = Minimal function
- 2 = Conscious but dependent
- 3 = Dependent in most tasks
- 4 = Independent but disabled
- 5 = Independent with mild residual deficits

TAC provided the following table, for the last 10 years, of severe ABI claims with those clients identified as ‘Minimal Function’ identified separately.

Accident year	Minimal function	All others	Total
1995/6	5	39	44
1996/7	3	44	47
1997/8	3	52	55
1998/9	2	53	55
1999/2000	2	71	73
2000/1	9	63	72
2001/2	5	82	87
2002/3	3	91	94
2003/4	5	100	105
2004/5	5	79	84
Total	42	674	716

TAC advised that their current data on where these ‘minimal function’ clients currently reside are not complete; however, around half the clients are in accommodation, and the remainder are living at home.

A prospective study was undertaken in 2000 of adult patients with traumatic brain injury admitted to intensive care units of 16 major trauma centres in Australia and New Zealand over a 6 month period.¹⁹ The patients were followed for 12 months. Four of the 635 patients (1.3%) were in PCU at 12 months.

SITE OF CARE

The Working Committee found only minimal data on where people in a state of PCU or MRS are located.

The Victorian TAC advised that, of their clients with ABI who have been assessed as ‘minimal function’ (equivalent to PCU), around half are in accommodation and the

¹⁹ Myburgh JA, Cooper DJ, Finfer SR, Venkatesh B, Jones D, Higgins A, Bishop N, Hignett T, and the Australasian Traumatic Brain Injury Study (ATBIS) Investigators for the Australian and New Zealand Intensive Care Society Clinical Trials Group, 2008. Epidemiology and 12-month outcomes from traumatic brain injury in Australia and New Zealand. *Journal of Trauma* (in press).

remainder are living at home. Unlike many other personal injury schemes, the TAC does not have caps on attendant care support, so that TAC clients living at home can be provided with up to 24-hour attendant care support. The proportion of TAC clients living at home is therefore likely to be unusually high compared to other schemes.

In 1991, a survey conducted by the Victorian Department of Human Services, based on Commonwealth age and sex data and telephone survey to establish diagnosis, identified 86 nursing home residents under 60 years of age who had ABI, and a further 35 with ABI among long-stay patients in acute hospitals. A 1995 survey²⁰ confirmed these nursing home figures.

²⁰ *Quality and equity in aged care*, Chapter 4: Young people in residential aged care facilities. Senate Committee Report—Community Affairs References Committee, Commonwealth of Australia 2005

APPENDIX 6 • ICD-10 CODING THAT MIGHT INDICATE PCU

The *International Classification of Diseases* (ICD) is the international standard diagnostic classification used to classify causes of death, and diagnoses in datasets relating to hospital admissions and some other health service events. These include the analysis of the general health situation of population groups and monitoring of the incidence and prevalence of diseases and other health problems in relation to other variables such as the characteristics and circumstances of the individuals affected.

The ICD is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and hospital records.

ICD-10 is the current version.

ICD-NA,²¹ an adaptation of ICD-10 that provides a more detailed instrument for coding virtually all recognised neurological conditions, provides a specific code for persistent vegetative state and related conditions. It should be noted that this classification is not used for deaths or hospital morbidity records in Australia – hence detailed categories such as GD96.81 are not available in those datasets.

- Section GD96 – other disorders of central nervous system
 - Subsection GD96.8 – other specified disorders of the central nervous system
 - GD96.81 is reserved for *persistent vegetative states*
 - GD96.82 is reserved for *locked-in syndrome*
 - GD96.83 is reserved for *akinetetic mutism*.

Some other G codes (ie, codes covering long-term conditions) may catch misclassified patients in PCU. For example:

- G47.2, *disorders of the sleep-wake schedule*
- G47.22, *delayed sleep phase syndrome*
- G47.23, *irregular sleep-wake pattern*
- G47.24, *non-24 hour sleep-wake cycle*
- G47.28, *other disorders of the sleep-wake schedule*
- G47.88, *other specified sleep disorders*.

Section G92, toxic encephalopathy, provides

- G92.–0, *early toxic encephalopathy* and
- G92.–1, *delayed toxic encephalopathy*.

²¹Application of the International Classification of Diseases to Neurology, 2nd edition, WHO 1997

The ICD-NA gives two specific examples of double coding:

- G93.1, *anoxic brain damage not elsewhere classified*, plus G96.81, *persistent vegetative state*
- G93.1, *anoxic brain damage not elsewhere classified*, plus R40.2, *prolonged coma*.
- Under section R40, somnolence, stupor and coma, there is
 - R40.2, *coma, unspecified*, which is to be reserved for *unconsciousness not otherwise specified*.

Various T codes may also capture a few people in PCU, although they should strictly have a G code as well as the T code (T codes are used to cover injuries to multiple or unspecified body regions as well as poisoning and certain other consequences of external causes).

Section T90, sequelae of injuries, of poisoning and of other consequences of external causes, includes:

- T90.2, *sequelae of fracture of skull and facial bones*
- T90.5, *sequelae of intracranial injury*
- T90.8, *sequelae of other specified injuries of head*
- T90.9, *sequelae of unspecified injury of head*.
- Section T96 is sequelae of poisoning by drugs, medicaments and biological substances
- Section T97 is sequelae of toxic effects of substances chiefly non medicinal as to source
- Section T98, sequelae of other unspecified effects of external causes, includes
 - T98.1, *Sequelae of other and unspecified effects of external causes*
 - T98.2, *Sequelae of certain early complications of trauma*
 - T98.3, *Sequelae of complications of surgical and medical care, not elsewhere classified*.