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A consensus process to agree best practice for managing physical wellbeing in people with a prolonged disorder of consciousness

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Declaration of interest
SA has a specific interest in outcomes evaluation and has published on the use of Goal Attainment Scaling in this context, as well as standardised measures such as the Arm and Leg activity measures (ArmA and LegA). These tools are freely available. He has received two unrestricted research grants from Ipsen and has received honoraria from Allergan (now abbvie), Ipsen and Merz. He has no personal financial interest in any of the material mentioned in this article.
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Abstract:

BACKGROUND:

Current practice for physical wellbeing of people in a Prolonged Disorder of Consciousness (PDOC) is variable. A scoping literature review identified no agreed standard of care for physical management of those in a PDOC. This study addressed this deficit using a consensus process applied using nominal group technique.

AIM:

The aims of this project were therefore to promote best practice for physical management in PDOC, by identifying consensus for: 1. a pathway of care and 2. current best practice recommendations.

DESIGN:

A consensus process using nominal group technique.

SETTING:

Representation from national, purposively selected, rehabilitation services assessing and managing people in a PDOC in the UK.

POPULATION:

The population to whom the consensus process relates are people in a PDOC, requiring physical management.

METHODS:

An initial meeting (1) with selected clinical experts from national centres was conducted to set terms of reference. A consensus meeting (2) using nominal group technique (n=33) then followed. Experts were initially asked to review systematic review findings reproduced as statements. Following systematic refinement they were then asked to vote on the importance and relevance of statements.

RESULTS:

Following the nominal group process, 25 initial recommendations were refined to 19, which expressed the principles of physical management for people with a Prolonged Disorder of Consciousness. Statements are grouped into ‘acute-care’ (6-recommendations), ‘post-acute care’ (10-recommendations) and ‘long-term care’ (3-recommendations). Across the participants, agreement with the final recommendation statements ranged from 100-61% (n=33-20), 15 of the statements were

supported by 85% or more experts (n=29). In addition, a clinical pathway of care, incorporating the recommendation principles was produced (agreement from 28 experts, 83%).

CONCLUSION:

The recommendations provide a basis for standardising current practice. They provide a standard against which care and effectiveness can be evaluated. An accessible guideline document is planned for publication to enable implementation into practice, supported by online resources.

CLINICAL REHABILITATION IMPACT:

Recommendations have been produced under the headings of 'acute care', 'post-acute care' and 'long-term care'. In addition, a pathway for provision of care interventions has been identified for the physical management of people in a prolonged disorder of consciousness.

Word count: 340

Running Head: Physical wellbeing in prolonged disorders of consciousness

Key words:

Prolonged Disorder of Consciousness, consensus process, nominal group technique, Consciousness

Introduction

Following head injury, for example as a result of trauma after a road traffic accident or hypoxia after cardiac arrest, severe damage to the brain may occur. Such injuries can result in what is known as a 'disorder of consciousness'. Disorders of consciousness include: Coma, which is usually acute and short-term, and prolonged disorders of consciousness, which is unconsciousness lasting more than four weeks. A prolonged disorder of consciousness, can be further sub-divided into vegetative state or minimally conscious state [1]. Vegetative state is characterised by absence of behavioural evidence for self- or environmental awareness [2, 3]. Vegetative state is therefore defined as a state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal - evidenced by sleep–wake cycles and a range of reflexive and spontaneous behaviours. Minimally conscious state is characterised by inconsistent, but reproducible, responses above the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings [1, 4-6]. Minimally conscious state is therefore defined as a state of severely altered consciousness in which minimal, but clearly discernible behavioural evidence of self- or environmental awareness is demonstrated [5-7].

Prolonged disordered of consciousness can occur in two main contexts: Prolonged Disorders of Consciousness (PDOC) following sudden onset acquired brain injury, from which the person may or may not regain consciousness. Alternatively, a Terminal Decline of Consciousness (TDOC) may occur towards the end of life in people with progressive degenerative brain damage (for example due to dementia, Parkinson's disease, or multiple strokes).

People in a Prolonged Disorders of Consciousness are unable to move and have gross motor impairment [3, 8]. Immobility presents known risks to people and this is particularly relevant to those in Prolonged Disorders of Consciousness due to their lack of awareness and inability to self-monitor [5, 8]. If muscles are kept in a shortened position (e.g. with a joint in flexion) it is known that muscle tendon units will shorten and other changes to muscle and tendon structure will also occur resulting in contracture. If this shortened muscle position is further sustained, then contracture and adhesion of other structures such at the joint capsule will also occur [9-11]. Over half of people with stroke have

at least one contracture [12, 13], with the frequency rising to 84% in people with traumatic brain injury [1, 12, 13].

In addition, individuals in a Prolonged Disorders of Consciousness may have disorders such as spasticity or spastic dystonia. Spasticity is defined by the EU-SPASM group as ‘a disorder of sensory-motor control resulting from an upper motor neurone lesion, presenting as intermittent or sustained involuntary activation of muscles’ [1, 14]. If spasticity is also present and left untreated, a vicious cycle may occur, in which unopposed muscle contraction occurs in affected muscle leading to an abnormal limb posture, resulting in soft tissue shortening and further biomechanical changes in the contracted muscles. The presence of spasticity is therefore likely to exacerbate the development of contracture [15].

Contractures and spasticity therefore significantly contribute to joint deformities and to other complications such as skin breakdown (pressure injury) and pain [9, 11, 16]. These complications are common and are observed in patients admitted to rehabilitation and long-term services. Pressure ulcer occurrence has been reported to occur in 56% of people in a Prolonged Disorders of Consciousness within the first 6 months of brain injury [9]. Contractures are therefore common in people in a Prolonged Disorder of Consciousness, but incidence and prevalence are not clearly reported in the literature. We know the that immobilisation in a shortened position is a causative factor for contracture and this is exacerbated if the muscle is actively held in a shortened position [11, 17]. Whilst the risk of contracture is high, the time course of the pathophysiological changes is difficult to predict, particularly when spasticity is also present, with resulting difficulty with clinical management [11, 18].

Care and management in this group is therefore important to minimise contracture development and associated complications and pressure ulcers. The need for management in those in Prolonged Disorders of Consciousness starts in the acute phase for those who have a sudden onset acquired brain injury and will need to continue in the long-term.

Posture management:

An important part of rehabilitation and long-term care for people with Prolonged Disorders of Consciousness is a 24-hour posture management programme, including positioning in bed, wheelchairs and other seating. There is limited published literature on the most effective physical management strategies for patients in a Prolonged Disorders of Consciousness, with the majority of literature discussing diagnosis, neuropathology or the assessment of low awareness states.

People in a Prolonged Disorders of Consciousness suffer frequent medical complications secondary to their brain injury and severe physical disability, which can negatively affect health and contribute to complications in care [9]. Regular changes in posture have been shown to alter muscle length, redistribute pressure, facilitate the respiratory system, help in improving alertness and orientation as well as providing comfort [19-21]. Immobility and sustained postures will lead to contracture as previously outlined, a major secondary complication with this group of patients [1, 22].

The evidence for the effectiveness of contracture management with stretch interventions (including positioning) is limited [11, 23, 24]. However, a preventative approach from point of admission is likely to be more effective than restoring muscle length once a contracture is established [1, 10, 11, 25-28].

Despite report of these principles in the literature, our scoping review, identified no clear guidance to clinicians for a programme of physical management and care in Prolonged Disorders of Consciousness, with limited evidence to support practice. The aims of this project were therefore to promote best practice for physical management in Prolonged Disorders of Consciousness, by identifying consensus on: 1. A pathway of care 2. Current best practice recommendations.

Method

Participants:

Guideline Development Group: A guideline development group was established with purposively selected members who had expertise in the clinical management of Prolonged Disorders of Consciousness and/or research publication relevant to the area. The Guideline Development Group membership consisted of three physiotherapists (one clinician, one clinical manager, one clinical academic), one occupational therapist (clinician), one nurse (clinician), one rehabilitation medicine physician/neurologist (clinical academic) and two rehabilitation engineers - clinical scientists (one clinical and one academic).

Wider Consultation Group: The wider consultation group were purposively selected by the Guideline Development Group and had representation of specialist services across the United Kingdom providing clinical care and management to people with a Prolonged Disorders of Consciousness. The group contained: physiotherapists (n= 20), occupational therapists (n= 6), rehabilitation engineers - clinical scientists (2), physician (1) and nurses (n= 5).

Development process:

Two Wider Consultation Group meetings were held. The first meeting (n=34) was used to review systematic review findings and plan a consensus approach, presenting the guideline development group plan for this to the wider group. Thirty-five participants attended the first consultation meeting.

In the first meeting, four discussion groups (three sub-groups had 9 participants and one subgroup had 8) were held to identify clinician priorities for physical management and possible implications for a pathway of care. The outputs were reviewed by the Guideline Development Group and similar statements produced were categorised together. Statements related to a possible pathway of care were also grouped together. These elements were organised and prepared by the guideline development group ready for presentation at the second wider meeting with embedded Nominal Group Process [29].

The Nominal Group Process:

The second meeting used a Nominal Group process to identify a physical management pathway of care and recommendation statements for the management of those in a prolonged disorder of consciousness. Thirty-four participants attended the second consultation meeting.

Nominal Group Technique is a consensus method, initially used in the 1960's as an approach to facilitate effective group decision-making [29]. It has been applied widely in a range of fields including; health and social care. The most common applications have been problem identification, development of solutions, and establishing priorities [29-33]. The technique has been used in nursing to establish clinical consensus of the type required for clinical management [33]. It has also been used in areas of therapy intervention akin to that required for physical management in Prolonged Disorders of Consciousness [34].

The Nominal Group Process (n=34) was used, first to identify a pathway of care, and second to agree recommendations for standards of care. Initial discussions were held in three sub-groups with a facilitator (11 participants in two of the sub-groups and 12 in the third). Each sub-group had a facilitator (Chair). Initial recommendation statements were generated within sub-group and then refined over a further three rounds of iteration, with production of clinical care recommendation statements and refinements to a pathway of care. At each round of iteration, refinements were made to recommendation statements, with like statements or points 'collapsed' into a single item. Similarly, refinements were made to a suggested pathway of care with iterative development at each round.

Integration of group findings:

Following the sub-group process, the outputs from each of the three groups were reviewed by three independent members of guideline development group. A single pathway of care, incorporating comments from all groups was produced. A set of recommendations, with similar recommendations collapsed together, was also produced assimilating all statements from the three groups.

The pathway of care and recommendation statements were voted on by all 35 participants using an online vote recording system called 'Mentimeter' [35]. Each statement was presented in turn to all participants who then anonymously voted using an electronic device (mobile telephone, laptop or tablet computer). At this stage, participants from all three sub-groups, were asked to indicate via 'Mentimeter' if they endorsed the recommendation statements and final pathway of care: Yes, No or Abstain. Final results were recorded and tabulated. Minor corrections or clarifications of wording from participants were accepted at this stage, with possible minor modifications reviewed and incorporated as appropriate by the guideline development group.

Evaluation of evidence supporting the recommendations:

Research evidence for the recommendations, where available, was taken from the scoping analysis, following the nominal group process. Evidence was re-reviewed and assigned to recommendation statements from the consensus process by five members of the guideline development (SA, RM, KH, TC, AP) group. The evidence was evaluated and quantified at this stage according the framework developed for the National Service Framework for Long Term Conditions [36]. The following criteria were used:

Grading of non-research 'opinion':

E1: User and/or carer opinion. E2: Professional or other stakeholder opinion.

Grading of research evidence:

Research A (RA): More than one study of high quality and at least one of these has direct applicability;

Research B (RB): One high quality study or more than one medium quality study and at least one of these has direct applicability or more than one study of high quality of indirect applicability;

Research C (RC): One medium quality study or lower quality studies or Indirect studies only.

Results

Following the nominal sub-group process, 25 initial recommendations were produced. When reviewed by the three Guideline Development Group members, these were reduced to 19 recommendation statements, which are presented in table 1.1.

Insert Table 1.1 near here

Recommendation statements were categorised by the guideline development group, as 'acute care', 'post-acute care' and 'long-term care'. Following voting on endorsement of the recommendations, high agreement between participants was identified, with 15 of the 19 statements supported by >85% of participants. The recommendation statement with the least support was 'it is suggested that, initially once stable, patients sit out of bed in a posturally supportive wheelchair, gradually increasing tolerance to sitting for up to 6-8 hours a day', supported by 61% (N=20) of participants (see table 1.1, number 3). Two recommendation statements were supported by all participants, see table 1.1, numbers 10 and 14, both in the sub-acute section.

The pathway of care flow chart was also divided into the three sections of 'acute care', 'post-acute care' and 'long-term care'. The overall pathway of care was supported by 28 participants (80%) and is presented in Figure 1.1.

Insert Figure 1.1 near here

Where evidence from our scoping review was available to support recommendation statements developed through the consensus process this is indicated. Referencing for statements that have evidence support is provided in table 1.1.

Discussion

Recommendations have been produced under the three sections of ‘acute care’, ‘post-acute care’ and ‘long-term care’. In addition, a pathway for provision of care has been identified for the physical management of people in a prolonged disorder of consciousness. The recommendations provide a basis for standardising current practice and in so doing now allow a standard against which care and effectiveness can be evaluated.

This work undertaken using consensus from a national purposively selected group, has been incorporation into the revised UK national guideline on assessment and management of Prolonged Disorders of Consciousness published by the Royal College of Physicians, London [1], summarising the core recommendations. To aid implementation in practice, further work was undertaken by the physical management guideline development group in conjunction with the Royal College of Physicians guideline development group, to produce a ‘checklist’ of core principles of the guidance on physical management, these are presented in Box 1.1.

Box 1.1

Checklist guidance on physical management for individuals with a disorder of consciousness

To help prevent secondary complications and resultant challenges with care the following monitoring regime is recommended (review in conjunction with the algorithm presented above):

- **Establish the physical and postural management needs** of individuals through a plan for positioning in lying (bed) and sitting (wheelchair), with regular changes of position (repositioning). The development of the plan should involve (as a minimum) Physiotherapist, Occupational Therapist and Nurse.
- **Assessment and provision of the appropriate bed positioning system** including skin pressure relief management as needed. Simple bed positioning aids should be considered first, followed by more complex positioning aids dictated by patient need. Appropriate training should be provided on use to family, carers and professionals, and should be incorporated into the care-plan (e.g. photographic guidelines).
- **Provision of seating system** following assessment including provision of a pressure relieving cushion to achieve optimum seated position. Appropriate training should be provided on use to family, carers and professionals, and should be incorporated into the care-plan (e.g. photographic guidelines).
- **Sitting tolerance should be gradually increased** and carefully monitored to maintain the individual's skin integrity and optimal posture. Sitting tolerance of 6-8 hours is feasible if no issues occur.
- **Community-based assessment:** Individuals transferred into community care should be reassessed by a therapist (Physiotherapist or Occupational Therapist) and other relevant professionals within 3 months of their discharge from the hospital setting. This initial assessment should check that the patient remains stable and that the care plan established in the hospital remains appropriate.
- **Initial quarterly review:** During the first year living in the community, the individual should be reviewed by a therapist at 3 monthly intervals to help adapt their care plan as they settle into their new home. The frequency of reviews over subsequent years may be reduced provided the person is stable.
- **Annual review and assessment:** Individuals who are established in a long term care environment, who are stable and remain well managed, should receive an annual review of their physical and postural management plan. This should encompass a review of their posture in the wheelchair and bed, re-examination of joint range of movement, repeat assessment through validated outcome measures (i.e. Range of Movement at key joints, Arm Activity measure (ArmA) and Leg Activity measure (LegA) for passive function/care and a review of their skin care and continence regimes (14-16).
- **Re-referral:** Any change in physical or postural status must initiate a referral to the appropriate therapy or nursing team (12). External referrals to appropriate specialists should be made by the treating/ reviewing therapists once a problem is identified, examples could include:
    - Referral to a specialist spasticity management service. Systemic, regional (e.g. intrathecal) and focal (e.g. botulinum toxin) should be available options.
    - A posture management service (specialist in Posture and Mobility).
    - Splinting/orthotic service.

The Nominal Group Process (n=34) was used, initially to identify a pathway of care, and second to agree recommendations for standards of care. The overall pathway was supported by 80% of group participants, the remaining participants felt some elements of the pathway could be refined and therefore abstained from endorsement. The pathway represents an overview of the pathway of care needed to manage and monitor people in a prolonged disorder of consciousness. While there are certainly areas that will need refinement as further evidence emerges, it will allow initial standardisation of physical care processes to improve current provision and allow future comparison against the standard pathway now developed.

The pathway incorporates management in bed and in a wheelchair or specialist seating system. It incorporates focal interventions as needed throughout the pathway and emphasises the potential management required in 'acute', 'post-acute' and 'long-term' care. The pathway incorporates progression and refinement of the physical management programme. Importantly the ongoing monitoring of the persons physical state is emphasised (range of movement and care needs) with revision of the management plan and recommended intervention if needed.

Recommendations under the three sections of 'acute', 'post-acute' and 'long-term' care were also generated by the group as described in the methods and results. For recommendations that related to acute care, 6 were produced. The lowest consensus vote was for the item 'Initially, when stable, people should sit out of bed for at least 2 hours a day, in posturally supportive seating, which is gradually increased to 6-8 hrs a day' by 61% of group members. In the group process meeting, there had been discussion about the need to specify the actual time for which people should be seated (i.e. 2 hours), with disagreement about the actual time (both more and less time). However, 2 hours represented a clear consensus in the meetings (reflected in the recommendation), though as discussed initial seating time may be much shorter than this (e.g. 30 minutes).

High levels of consensus were again reached in the 'post-acute care' recommendations. The lowest percentage agreement (74%), was for the item about monitoring changes in symptoms such as spasticity related to bladder or bowel management. This item was well endorsed, but was felt not to be

as important by those participants who did not endorse it. Management of the risks of incontinence to skin integrity or constipation potentially impacting spasticity in individuals was also emphasised as an item of importance, endorsed by 94% of participants. While independent continence is not possible for people in a prolonged disorder of consciousness, management of incontinence is critical to prevent secondary complications and both bladder and bowel interventions can be put in place to achieve this.

In the longer-term care of individuals, there is an emphasis on monitoring and review at both the point of transfer into community settings (both nursing home care and individuals own homes) and in the longer term. Individuals in a prolonged disorder of consciousness will have complex physical management challenges requiring management on an ongoing basis. The recommendations and pathway emphasise the need for ongoing management and review to best care for people in this situation and avoid costly health interventions through lack of management long-term.

Strengths and constraints in development:

The consensus process has been conducted with a purposely selected group of clinicians who all work with those in a prolonged disorder of consciousness at specialist centres across the UK. However, the very nature of purposive selection introduces possible bias into participant involvement. However, this was mitigated by focusing on representation nationally and ensuring engagement with the most relevant participants rather than any other factors.

The approach to Nominal Group Technique broadly followed the approaches used by others in healthcare settings [30, 31, 33, 34, 37]. However, some differences are evident. In the consensus process we used three groups, with three rounds of consensus. The guidance for facilitation within the groups was uniform, but variation in addressing the recommendations and pathway of care will have occurred and overall is a strength. As a result of having three sub-groups a process was required to refine the outputs into a single set of consensus recommendations and a pathway of care. A process of assimilation and then voting was used to address this, which was effective, though not typical in the nominal group approach. However, addressing the development in this way was designed to achieve greater numbers of participants in the process to achieve national representation and yet still gain

consensus. In this sense the modified Nominal Group Technique applied was very successful and has resulted in outputs of sufficient quality to be included in national guidelines [1].

The resulting recommendations and pathway of care provide a national standard and basis for service evaluation. They provide a standard against which care and effectiveness can be evaluated. A further clinically accessible guideline document is planned for publication to enable implementation into practice, supported by online resources.

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Table 1.1 Recommendations for care

No.	Recommendation statement	Consensus process (% vote)			Evidence grade
		Yes	No	Abstain	
0 – 6 weeks: Stabilise Physical management – acute					
1	Range of movement at key joints, as a minimum (shoulders, elbows, wrists, hips, knees, hand, head/ neck and ankles), should be monitored using the Neutral-0-method	31 (94%)	2 (6%)	0 (0%)	E2
2	Passive functional status should be documented using a standardised tool e.g. Arm Activity measure (Arm-A), Leg Activity measure (Leg-A).	24 (71%)	9 (26%)	1 (3%)	E2
3	Initially, when stable, people should sit out of bed for at least 2 hours a day, in posturally supportive seating, which is gradually increased to 6-8 hrs a day.	20 (61%)	13 (39%)	0 (0%)	RC E1 E2 [38, 39]
4	The persons general state of health including skin integrity, pain and abnormal posturing should be monitored and if necessary seating time be adjusted to account for this (e.g. reduced wheelchair sitting times).	32 (97%)	1 (3%)	0 (0%)	RB E1 E2 [40-42]
5	All people in a Prolonged Disorder of Consciousness are at risk of developing pressure related skin damage. A care plan should therefore be put in place for each individual	31 (94%)	1 (3%)	1 (3%)	RB E1 E2 [40-42]
6	Focal interventions (Including physical and pharmacological) should be considered when either progressive/ predicted loss of range is occurring at a joint or is already impacting on care, if there is a possibility of improving or maintaining management.	33 (97%)	1 (3%)	0 (0%)	RC E1 E2 [43-46]
6 weeks to 3 months Plan physical management – Rehab Unit (In addition to the above, do the following)					
7	A specialist assessment of postural needs by a skilled multidisciplinary team should be undertaken. This must include recommendations on 24 hour postural care plan, including; bed positioning, wheelchair prescription (including wheelchair cushions) and skin care.	33 (97%)	1 (3%)	0 (0%)	RC E1 E2 [40-42]
8	Clinical photography may be used at regular intervals to document postural changes.	33 (97%)	1 (3%)	0 (0%)	E2
9	The Multi-disciplinary team should establish a 24-hour cycle of postural care, based on specialist recommendations. This should include the provision of all equipment needed to fulfil the 24-hour postural care plan (i.e. splints, wheelchairs and bed positioning aids).	32 (97%)	1 (3%)	0 (0%)	RC E1 E2 [40, 42]
10	During admission, the 24-hour care plan will require continual review and adaptation before arriving at a personalised postural management plan for discharge	33 100%	0 0%	0 0%	E1 E2
11	Where possible, the postural management plan should be simplified prior to discharge to assist with continuity in a community setting. Discharge plans should include clear turning /repositioning regimes and address pressure care needs.	26 (76%)	8 (24%)	0 0%	E1 E2
12	Skin health and tissue viability should be monitored daily, with referral to tissue viability services as appropriate.	32 (94%)	2 (6%)	0 0%	E1 E2
13	A personalised continence plan must be established to manage the risks of incontinence and poor continence health to skin and muscle tone.	32 (94%)	2 (6%)	0 0%	E1 E2
14	When an individual's condition has stabilised they should be provided with their own seating system (including an appropriate cushion) which is specific to their needs	34 (100%)	0 0%	0 0%	E1 E2
15	Clinicians should monitor and appropriately treat any unexplained changes in neurological symptoms (for example worsening spasticity) that could be caused or exacerbated by constipation or urinary tract infections	25 (74%)	6 (18%)	3 (8%)	E1 E2
16	Discharge planning from a rehabilitation setting into the community, should consider the need for ongoing physical management, environmental adaptations and equipment	30 (88%)	3 (9%)	1 (3%)	E1 E2
3 months onwards – Consolidate Physical management – Long term care (In addition to the above, do the following)					
17	A monitoring plan using standardised measures should be established to review (range of movement, posture, spasticity, tissue viability and continence) the individual every three months which may be extended (up to 12 months) in the presence of stability.	33 (97%)	1 (3%)	0 (0%)	E2
18	Prior to transfer to a long-term care environment the bed positioning and seating programme should be reviewed and where possible simplified to ensure continuity.	29 (85%)	2 (6%)	3 (9%)	E2
19	We would suggest that people discharged into the community (care or Nursing home or patients own home) are reviewed by a specialist therapist within 3 months of the transfer	29 (85%)	2 (6%)	3 (9%)	E2

Key: E1: User and/or carer opinion. E2: Professional or other stakeholder opinion.

Grading of research evidence: Research A (RA): More than one study of high quality and at least one of these has direct applicability;
Research B (RB): One high quality study or more than one medium quality study and at least one of these has direct applicability or more

than one study of high quality of indirect applicability; Research C (RC): One medium quality study or lower quality studies or Indirect studies only.

Figure 1.1

Caption:

Figure 1.1 An overview pathway to consider physical and postural management provision for people in Prolonged Disorder of Consciousness.

Notes:

Authors' contribution:

Stephen Ashford (SA) developed the project plan, methodology and in conjunction with Rasheed Ahamed Mohammed Meeran (RM) designed the process followed for consultation and nominal group technique. He was involved in data collection, analysis, categorisation and review. SA produced the initial draft of the manuscript.

Rasheed Ahamed Mohammed Meeran (RM) conceived of the initial project concept and with SA developed the methodology. He was involved in data collection, analysis, categorisation and review.

Teresa Clark (TC) was involved in project planning, data collection, analysis, categorisation and review.

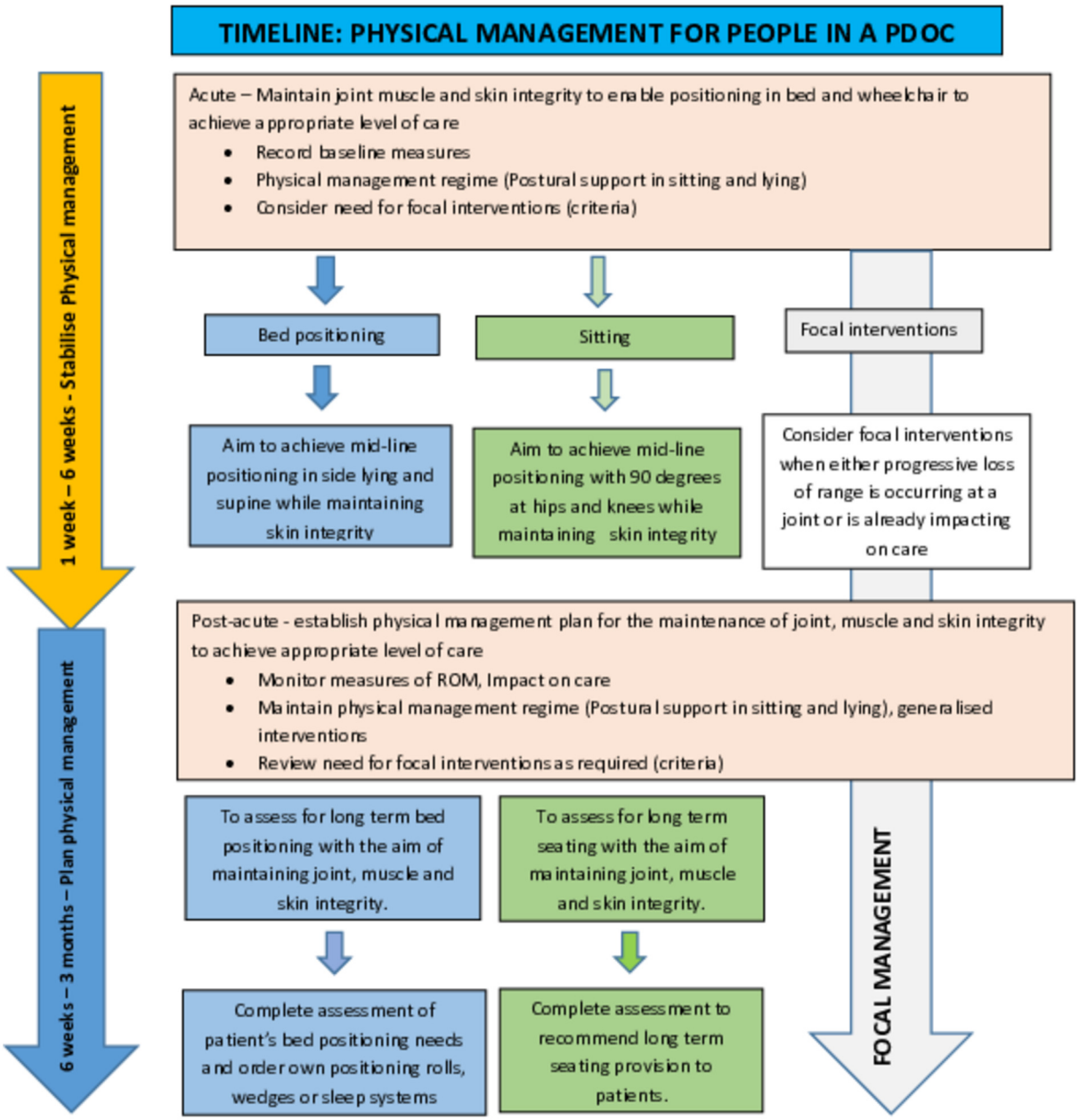
Macarena Montesinos Ruiz (MM) was involved in project planning.

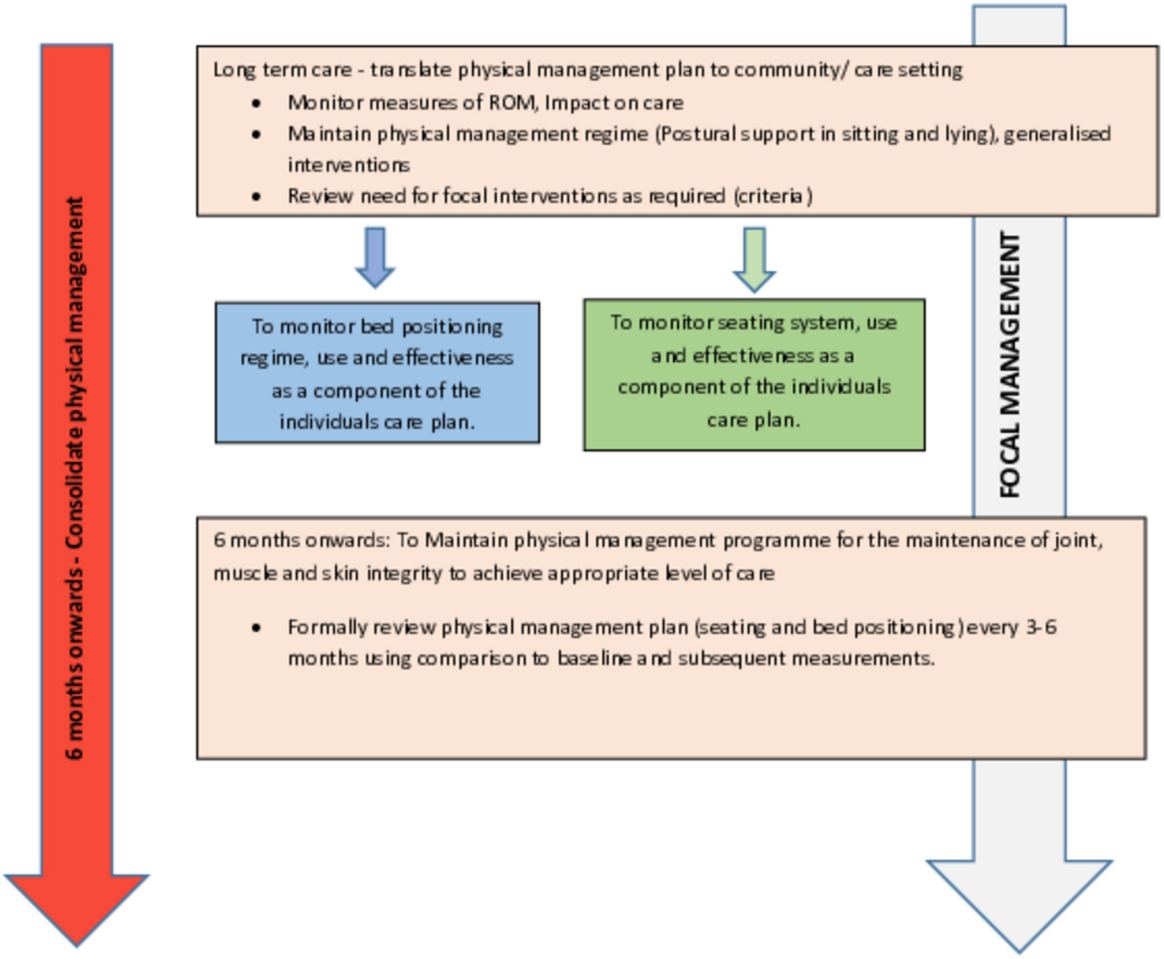
Karen Hoffman (KH) was involved in project planning, data collection, analysis, categorisation and review.

Diane Playford (DP) was involved in project planning.

Anand Pandyan (AP) was involved in project planning, data collection, analysis, categorisation and review.

All authors contributed to the development of the manuscript through version review and read and approved the final version.





For *1, **Care (Passive Function):** Arm Activity measure and/or Leg Activity measure (passive function sub-scales). **Range-of-movement (ROM):** Rapid deterioration in range of movement at a joint (e.g. wrist and fingers) such as 10% loss in range within a month [1-3].

For *2 **Range-of-movement (ROM**): Rapid deterioration in range of movement in multiple joints, such as 10% loss in joint ranges within a month. **Skin integrity:** Occurrence of pressure sores (document location and severity).

For measurement of ROM, the 'Neutral-0-method' should be ideally be applied [4], to enable consistent communication across service.