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

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Background

Current practice in maintaining physical wellbeing of people in a prolonged disorder of consciousness (PDOC) is variable and there is no agreed standard of care. This study addressed this deficit using a consensus process with clinicians recruited nationally in the UK.

Methods

A scoping review of the literature was conducted, followed by an initial meeting (Meeting-1) with purposively selected clinical-experts working in national centres for PDOC. Following agreement of the terms of reference and areas of clinical importance, a consensus meeting (Meeting-2) was conducted using nominal group technique (n=33). Experts were initially asked to consider and amend statements generated from the literature. Following a process of refinement, experts were asked to vote on each statement to indicate their agreement. A majority of experts needed to be in agreement to reach consensus.

Results

Following the nominal group process, 25 initial recommendations were refined to 19 which expressed the principles of physical management for people with a PDOC. Statements are grouped into 'acute-management' (6-recommendations), 'rehabilitation-input' (10-recommendations) and 'long-term care' (3-recommendations), see Figure 1. 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 (see Figure 2), incorporating the recommendation principles was produced (agreement from 28 experts, 83%).

Conclusions

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

Figure 1: Refined recommendations (19)

No	Recommendation statement	% voted Yes	% voted No	% Abstained
0 – 6 weeks: Stabilise Physical management – acute				
1	It is suggested that patient's range of movement at key joints, as a minimum (shoulders, elbows, wrists, hips, knees, hand, head/ neck and ankles), be monitored using the Neutral-0-method	31 (94%)	2 (6%)	0 (0%)
2	It is recommended that a patient's passive functional status be documented using a standardised tool e.g. Arm Activity measure (Arm-A), Leg Activity measure (Leg-A) reference to be added	24 (71%)	9 (26%)	1 (3%)
3	It is suggested initially, when stable, patients sit out of bed for at least 2 hours in a posturally supportive seating in a day which is gradually increased to 6-8 hrs a day.	20 (61%)	13 (39%)	0 (0%)
4	It is suggested that the individual's general state of health including skin integrity, pain and abnormal posturing 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%)
5	All patients in a PDOC are at risk of developing pressure related skin damage. It is recommended that a care plan is therefore put in place for each individual	31 (94%)	1 (3%)	1 (3%)
6	It is suggested that focal interventions (Including physical and pharmacological) 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%)
6 weeks to 3 months Plan physical management – Rehab Unit (In addition to the above, do the following)				
7	It is recommended that all patients receive a specialist assessment of their postural needs by a skilled multidisciplinary team. This must include recommendations of the patients 24 hour postural care plan, including; bed positioning, wheelchair prescription (including wheelchair cushions) and skin care.	33 (97%)	1 (3%)	0 (0%)
8	It is suggested that clinical photography may be used at regular intervals to document postural changes.	33 (97%)	1 (3%)	0 (0%)
9	It is recommended that the Multi-disciplinary team 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%)
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%
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 pressure care needs.	26 (76%)	8 (24%)	0 0%
12	It is recommended that skin health and tissue viability are monitored daily, with referral to tissue viability services as appropriate.	32 (94%)	2 (6%)	0 0%
13	It is recommended that 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%
14	It is suggested that when a patient'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%
15	It is recommended that clinicians 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%)
16	It is recommended that discharge planning from a rehabilitation setting into the community consider the need for ongoing physical management environmental adaptations and equipment	30 (88%)	3 (9%)	1 (3%)
3 months onwards – Consolidate Physical management – Long term care (In addition to the above, do the following)				
17	It is suggested that a monitoring plan using standardised measures be established to review (ROM, Posture, spasticity, tissue viability and continence) the patient every three months which may be extended (up to 12 months) in the presence of stability.	33 (97%)	1 (3%)	0 (0%)
18	It is suggested that prior to transfer to a long term care environment the bed positioning and seating programme be reviewed, and where possible simplified to ensure continuity	29 (85%)	2 (6%)	3 (9%)
19	We would suggest that patients 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%)

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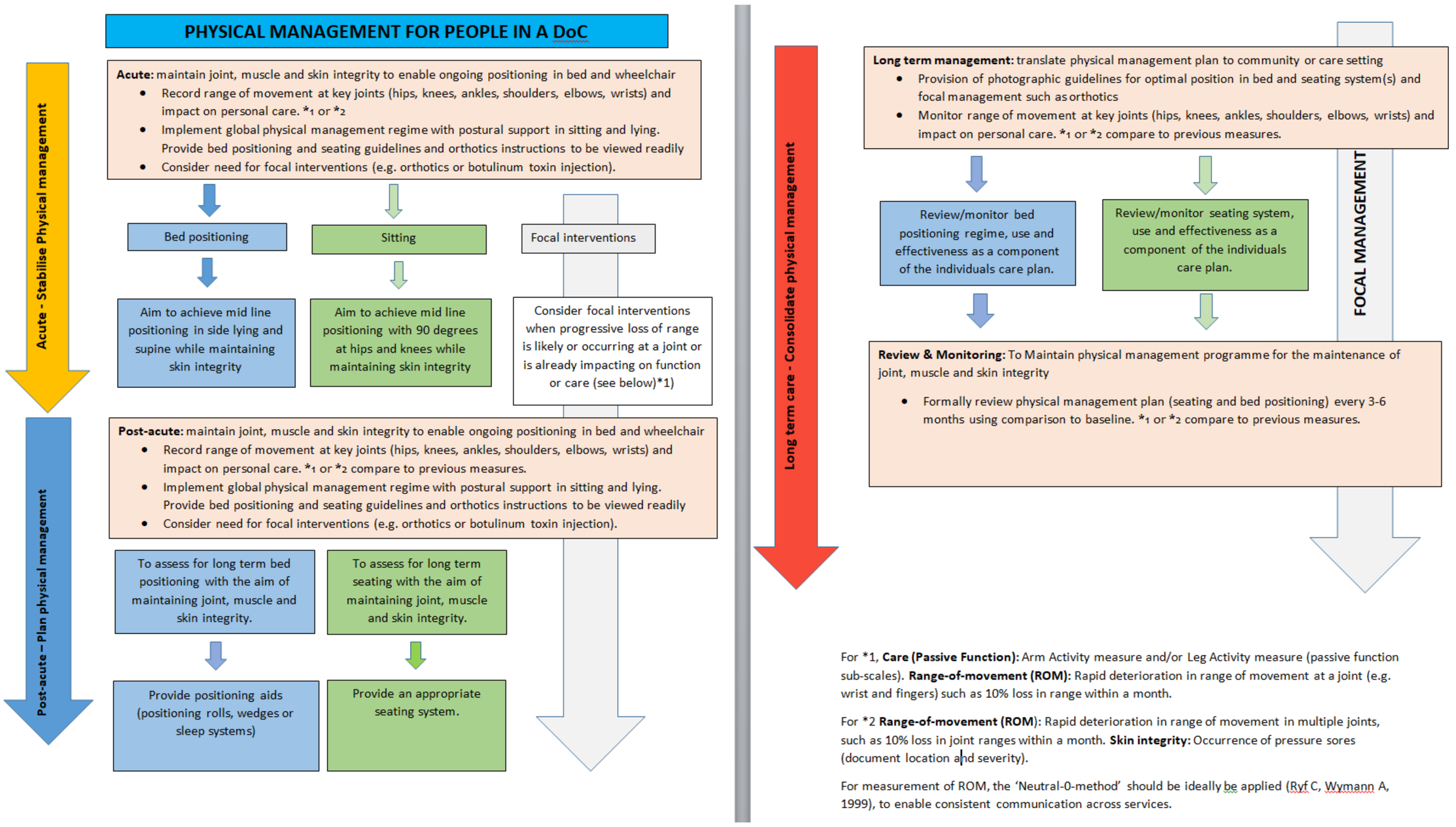
Figure 2: Clinical Pathway of care



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.

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 (Ryf C, Wymann A, 1999), to enable consistent communication across services.

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2 Putting patients at the HEART of everything we do; NHS London North West University Healthcare NHS Trust; Centre for Nurse, Midwife & AHP Led Research; KING'S College LONDON
3 Royal Hospital for Neuro-disability
4 NHS Barts Health NHS Trust
5 PMG Posture & Mobility Group
6 WARWICK THE UNIVERSITY OF WARWICK
7 Keele UNIVERSITY