

CLINICAL PRACTICE CONSIDERATIONS FOR POSTURAL SUPPORT IN LYING FOR CHILDREN AND ADULTS WITH A NEURODISABILITY

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BACKGROUND

This document has been prepared, with support from the Posture and Mobility Group's research fund, to assist professionals prescribing postural support in lying in making their clinical decisions. It is hoped that, in time, it will also contribute to the building of a body of evidence relating to supported lying.

The project was divided into 2 stages. The first stage was a systematic review of the literature for which a group of experts from the University of Exeter Medical School advised on search strategy, design and methodology and were crucial to the robustness and subsequent publishing of the review. This group was comprised of:

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The systematic review was published online by the Journal of British Occupational Therapy on 21st June 2018 and can be obtained here <http://journals.sagepub.com/doi/pdf/10.1177/0308022618778254>. Please refer to Appendix 1 for the characteristics of included papers and their strength of evidence.

The second stage of the project involved gaining expert consensus to add to the findings of the literature review which found only low to moderate evidence to support therapists who prescribe postural supports in lying.

Statements were devised from analysis of the findings of the literature review. These statements and questions about their practice in this field were sent to members of the Posture and Mobility Group who had expressed interest in participating in this expert consensus review (n=43). The agreement results and free comments were accumulated; additional statements prepared and presented for further consideration of agreement in a second round. This second round, as it was sent to participants, is shown in Appendix 2. Participants were given the results of the consensus on statements from round 1 and new statements to consider for agreement. These additional statements arose from comments made in round 1. The results from Round 1 and 2 formed statements which were considered to have achieved consensus and were fixed (these are in bold type below) with extra detail given under ‘factors to consider’, some of which but not all achieved consensus and were included at the discretion of the authors.

A presentation of the results was given at the Posture and Mobility Group’s annual conference in July 2018 for further comments. The subsequent document was returned to the original participants and relevant thoughts were incorporated. The document was also sent to administrators of physiotherapy and occupational therapy specialist groups with a request that they forward it to their members. Any further input was accommodated in the ‘factors to consider’ sections under each statement, again at the discretion of the authors.

INTRODUCTION

Postural management is a therapeutic approach used for children and adults with neurodisabilities. Spasticity and or weakness are common characteristics of these conditions and cause the adoption of postures that are unstable and asymmetrical. These asymmetrical postures may in turn lead to pain, progressive loss of function and fixed changes in body shape including hip dislocation and spinal curvature (Graham, 2004; NICE, 2012; Soo et al, 2006).

Postural management programmes use equipment over 24-hours to support posture in sitting, standing and lying (Gericke, 2006). Postural support in lying is provided primarily at night with whole body systems. There are several manufacturers of these systems which consist of one or more component parts held in position by a base layer or sheet (Polak and Clift 2007). They all have similar therapeutic aims of reducing

asymmetry, increasing comfort and improving sleep. Some provide support only in supine lying or prone while others can also be used for supported side lying (Polak and Clift 2007).

Consideration of the use of postural support at night is recommended by the National Institute for Health and Care Excellence for children and young people with non-progressive brain disorders (National Institute for Health and Care Excellence, 2012), although no evidence of effectiveness was provided. Many therapists are prescribing this equipment routinely in the UK and elsewhere however studies conducted more than a decade ago (DFES, 2007; Polak and Clift, 2007) found that although service users were increasingly demanding postural support in lying equipment, provision by service providers was patchy and funding was often difficult to secure.

The use of postural support in lying at night also has critics. Children with neurodevelopmental disabilities are known to have increased difficulties with sleep (Jan et al., 2008) and some have suggested the equipment may interfere with sleep (Gough, 2009). Perhaps it was for this reason that children and families were found to be less motivated to use sleep positioning systems than day time support in sitting and standing (Pountney et al, 2009).

There is a lack of robust evidence for the effectiveness of postural support in lying. Our recent Cochrane review of sleep positioning systems to reduce hip migration specifically in children with cerebral palsy found only two low quality randomised cross-over trials that met the inclusion criteria in respect of secondary objectives relating to sleep quality and pain (Blake et al., 2015). A recent review searching for evidence of effectiveness of postural management for people with intellectual disabilities and severely impaired motor function reported that the distinct lack of evidence for efficacy of sleep positioning systems should be of urgent concern (Robertson, 2016).

Our systematic literature review (Humphreys et al, 2018) which had a broader remit than the Cochrane review, which could only include randomised controlled trials, found some evidence that there are potential benefits in hip stability, improved sleep quality and an improved quality of life for users that can tolerate using a sleep positioning system but the quality of the evidence is very poor. Many participants had difficulties in adapting to using a sleep positioning system and support from professionals over an extended period of time was often needed. The majority who tried using a sleep positioning system, however, did continue using it. No increased risks were identified in the literature other than those associated with having a severe neurodisability and for some the adverse events increased when taken out of a sleep positioning system they were accustomed to using. There is a question as to whether adverse effects might be under-reported as families may give up using the equipment if sleep disturbance is increased (Hankinson & Morton 2002; Newman, O'Regan & Hensey, 2006) or do not initiate use if they have prior concerns of interfering with sleep (Polak & Clift, 2007).

The studies included in the review are mostly of low quality largely because of the small numbers of participants, the lack of methodological rigour, missing data, lack of information in the reporting or studies that were published only as conference abstracts. In the higher quality

studies participants were already users of sleep positioning systems and this limits the applicability of the evidence to the general population of children and adults with neurodisability.

The guidance given in this document should be considered in terms of 'Considerations for Practice' as the authors are aware that evidence is of low quality and there are limitations in the methodology of the expert consensus review. However, until there is more robust evidence this document is a guide to practice and should be of use to prescribing therapists. It has 5 sections;

1. Who is likely to benefit from a postural support in lying?
2. What are the key aims when prescribing a postural support in lying?
3. What are the key difficulties and how may they be overcome?
4. Core outcomes and how to measure them.
5. Suggestions of outcome measures.

1. WHO IS LIKELY TO BENEFIT FROM POSTURAL SUPPORT IN LYING?

A postural support in lying could be prescribed for a child of any age from soon after birth if clinical presentation, assessment and clear clinical reasoning demonstrate a clinical need.

Factors to consider:

- ❖ Case by case clinical presentation, assessment and clear clinical reasoning should guide prescription of a postural support in lying rather than diagnosis.
- ❖ Early intervention is important.
 - As the risk of sudden infant death syndrome (SIDS) must be taken into consideration, especially in babies under 6 months, multidisciplinary team support will be particularly important when making decisions about very young children using a postural support in lying, especially at night.

- ❖ Use of simple low tech methods of positioning, e.g. pillows, rolls, wedges, could be used for children with cerebral palsy in GMFCS levels III, children with motor delay and for those with neuromuscular conditions if needed and if effective, though use of a commercially available postural support in lying for these groups is not excluded.

However:

- Low tech methods make it more difficult to achieve the desirable position accurately and repeatedly.
- Safety may be more difficult to ensure for the user and prescriber when using equipment that has not been through the rigorous processes of a medical devices quality managements system.
- Safety may be difficult to ensure if children are able to move around in bed.
- Low tech methods may be used in some cases initially to test whether more formal equipment could be tolerated.

A postural support in lying could be prescribed for anyone with a neurodisability who has limited ability to reposition themselves and has habitual pelvic / spinal asymmetry present throughout the day and night. This may be a neurodisability acquired in adulthood with postural or structural skeletal distortion e.g. stroke, MS, Parkinson's, spinal injury, head injury.

Factors to consider:

- ❖ As above, case by case clinical presentation, assessment and clear clinical reasoning should guide prescription of a postural support in lying rather than diagnosis.
- ❖ Functional aims are important as well as postural symmetry. A postural support in lying can help to manage pain, sleep, pressure areas, tone management and feelings of security.
- ❖ Careful consideration of prescription of a postural support in lying at night needs to be given to those who can change their position and move around.
 - Gradual implementation of equipment may improve tolerance.
 - As yet there is no evidence comparing the number of hours of use with effectiveness.
 - Compromise may be possible between allowing some movement and maintaining postural control in key areas.
 - Trial of equipment and risk assessment of safety will be particularly important in these cases.

- ❖ People with dementia and those requiring 'end of life' care could be considered for a postural support in lying.
 - Postural support in lying may provide a reduction of pain, improved sleep, a reduction in the risk of choking and a reduction in the risk of development of pressure ulcers.
 - The use of shaped cushions/pillows may be more tolerable than a whole body system.

2. WHAT ARE THE KEY AIMS WHEN PRESCRIBING A POSTURAL SUPPORT IN LYING?

To prevent or slow down the rate of hip migration and the development of postural asymmetry in very young children with cerebral palsy or other conditions.

Factors to consider:

- ❖ Assessment for appropriateness of prescription for a postural support in lying should begin as soon as a child's motor development is identified as developing differently.
- Assessment tools and outcome measures that address these musculoskeletal changes are essential for measuring change and evidencing effectiveness.
- Hip surveillance pathways (including the Cerebral Palsy Integrated Pathway - CPIP) are evidenced as being effective in managing the risk of hip migration in children with cerebral palsy.

To prevent, maintain or reduce postural or structural asymmetry in older children, adolescents and adults. Provision of a postural support in lying for people with structural asymmetry may have benefits in body function that impact positively on levels of activity and participation.

Factors to consider:

- ❖ Postural asymmetry may or may not be prevented, maintained or reduced but increasing comfort, reducing pain and enabling fewer disturbances during sleep will improve quality of life and may increase function and participation.
- ❖ Where there is existing asymmetry a gradual change of position and regular reassessment of the lying support is likely to be required.
- ❖ Continuing to measure body shape is important in people of all ages. Body structures may continue to distort under the force of gravity if unsupported in lying.

To reduce pain and discomfort from muscle spasms or from the constant adoption of stereotypical positions at night in children and adults with neurodisability.

Factors to consider:

- ❖ The presence of pain should always be considered and assessed for with a repeatable measure however simple.
- ❖ Even very young children with cerebral palsy or other neurodisabilities may experience pain from muscle spasms and or the adoption of stereotypical positions at night if their posture is unsupported.
- ❖ Recognised assessment and outcome measure tools for pain and comfort behaviour are essential where pain is reported by the user or on their behalf by parents/carers or where there are signs of distress in the user.
- ❖ Efforts should be made to capture reporting of pain by the user as there is evidence that parents/carers are likely to under-report their child/client's pain.
- ❖ Use of a postural support in lying may increase pain or discomfort. A gradual change of lying position within a postural support may be required.

To improve the quality of sleep by reducing pain and increasing comfort. A reduction in the number of awakenings during the night will have a positive impact on the quality of life of users, parents and carers.

Factors to consider:

- ❖ The history and assessment of an individual's sleep quality is important prior to prescription of a postural support in lying especially:
 - When the main aim is to improve sleep quality.
 - Because introducing a postural support in lying at night may induce sleep problems where there were none before.
 - Sleep disruption may only occur initially until the user has become accustomed to the new lying support.
 - For awareness of sleep behavioural difficulties that may need help to be resolved prior to or along with the introduction of a postural support in lying.
 - Because sleep quality is a good indicator of the acceptability of the equipment.
- ❖ There are appropriate low tech tools for assessment and measurement of sleep quality which would not burden the parents/carers or the prescriber. These could include sleep diaries and well documented structured verbal reports from users/parents/carers.
- ❖ Those supporting the user and family/carers need to help them to understand the nature of sleep and the associations the user has with the process of going to sleep in order that a postural support in lying at night can be introduced appropriately.

To improve pressure care

Factors to consider:

- ❖ The supportive surface of a postural support in lying and the use of appropriate materials can provide pressure redistribution, shear reduction, and microclimate control which are important aspects of pressure ulcer formation and healing.

To reduce muscle tone

Factors to consider:

- ❖ Provision of increased comfort will help to lower muscle tone. This will help to reduce pain and facilitate assisted activities of daily living.
- ❖ As tone is reduced during sleep, improved sleep will lead to longer periods of reduced muscle tone.

3. WHAT ARE THE KEY DIFFICULTIES THAT MAY BE ENCOUNTERED AND HOW MAY THEY BE OVERCOME?

Some users, families and carers may need support from a competent professional for a considerable length of time while users become familiar with the equipment and carers gain competency.

Factors to consider:

- ❖ Many but not all children, adults and their carers can adapt to using a postural support in lying and for those that cannot other methods of supporting posture will need to be found.
 - If initially refused, the possibility of more robust postural support in lying can always be broached again at a later date.
- ❖ Therapy services should acknowledge and build into their planning the need for ongoing support for users of a postural support in lying.
 - Most support is usually required in the first month after introduction of the lying support.
- ❖ Use of the International Classification of Functioning, Disability and Health (ICF) is invaluable in assessing appropriateness of prescription for an individual.
 - a. Amongst the key personal (user and family/carers) factors would be:
 - Medical factors including epilepsy and percutaneous endoscopic gastrostomy (PEG) feeding.
 - The knowledge and understanding of user, parents/carers of the potential benefits of using a postural support in lying and its role in wider postural care issues.
 - User's ability and willingness to adapt to change in position and routine.

- Competency of parents and carers: ability and willingness to learn.
- Readiness of parents and carers to persevere in encouragement of use of a postural support in lying.
- Cultural differences and attitudes towards disability.
- b. Amongst the key environmental factors would be:
 - The knowledge and experience, i.e. competence, of the prescriber.
 - Ability of the prescriber to build rapport with the user, parents/carers
 - Co-sleeping
 - Co-sleeping can be accommodated with use of a postural support in lying with careful planning, ingenuity and imagination.
 - Sharing a bedroom with siblings
 - Support from the multi-disciplinary team.
 - Therapy services provision for ongoing follow up and support.
 - Number of primary carers.
- ❖ Thermal discomfort needs to be considered.
 - Monitoring of core temperature before and after implementation of the lying support may be required and measures taken if necessary.

People with severe motor disorders may have a great variability in their respiratory function and demonstrate significant 'silent' respiratory compromise during sleep. The respiratory risks of an individual should be assessed prior to prescription of a postural support in lying.

Factors to consider:

- ❖ Risk assessment of medical and respiratory problems is essential prior to prescription of a postural support in lying especially when being used at night.
- ❖ Low tech methods may be used to inform the risk assessment but any highlighted concerns should be referred on for further medical assessment prior to prescription of a postural support in lying.

- ❖ Although many community practitioners may find this difficult to implement, research on children and young people with severe motor disorders recommends respiratory assessment once using a postural support in lying at night unless respiratory risks are already known. If there are known respiratory risks assessment should take place before intervention for 3 consecutive nights in their own sleeping environment. Following intervention further testing should take place.
- ❖ The needs of individuals who use supplementary respiratory support (e.g. BiPAP) must be taken into consideration.

Aspiration, reflux, vomiting and choking are as likely to occur in or out of a postural support in lying. For the population of people with severe neurodisability the risks of using a postural support in lying are similar to those of not using a postural support in lying but individually the risks will be different.

Factors to consider:

- ❖ Risk assessment tools, standardised or non-standardised should be used by all prescribers of postural supports in lying. A risk assessment plan for each individual should be agreed and documented.
- ❖ The design of the equipment for postural support in lying will need to be considered for those that may require quick removal of supports.

It is essential that prescribers are fully competent to ensure the prescription is correct and risks have been analysed and reduced.

Factors to consider:

- ❖ It is essential that anyone prescribing a postural support in lying has the appropriate knowledge, skills and experience. This will ensure that users, families and carers receive an effective service and prescribers comply with the requirements of their professional bodies.
- ❖ The prescriber should have a good knowledge of a wide variety of supported lying products on the market to best meet the needs of individual clients.

- ❖ Good liaison between the prescriber and the equipment provider is important in ensuring an effective, timely and responsive service to the client.

Knowledge and understanding of the potential benefits of lying support at night in the wider context of postural care are important for the user, parents, carers and staff in the multi-disciplinary team.

Factors to consider:

- ❖ Delivering training in postural care for parents and carers is likely to lead to higher levels of understanding of the need for postural supports in lying and increased perseverance in their use.
- ❖ Users, parents and carers need to feel confident and competent in use of the equipment.
 - Guidance may include photographs, written advice and any other methods appropriate in achieving consistency of positioning and use of the lying support.
- ❖ The potential user, parents / carers should have the choice at all times to use or not to use a postural support in lying and to change their mind without risk to the therapy services they receive.
- ❖ The prescriber needs to have the competency to provide training to users, parents and carers, understanding that different people may need different materials and a different delivery style.

4. CORE OUTCOMES AND HOW TO MEASURE THEM: Future data collection in clinical practice.

Prior to prescription of a postural support in lying the aims and outcomes of the prescription must be identified through careful assessment and then documented.

Factors to consider:

- ❖ The following core outcomes have been identified by review of the literature and through expert consensus.

- Pain and comfort
- Integrity of the hip joint
- Body symmetry
- Quality of sleep
- Respiratory function
- Quality of life for users and carers
- Activity and Participation
- Pressure area and ulcer status
- Reasons for potential candidates deciding against using a postural support in lying

Standardised, validated outcome measures are necessary when conducting research but informal measures are acceptable in practice if they are repeatable and enable comparisons to be made.

Factors to consider:

- ❖ Although there is consensus about what to measure there is no consensus about which tools to use.
 - Standardised, validated measures may be more readily available in hospital or clinic settings while low tech tools may be the preferable choice in the community.
 - All prescribers should be able to use appropriate measures which do not place a burden on the time they have available or that of the parents or carers.
 - A list of useful outcome measure tools follows.

5. SUGGESTIONS OF OUTCOME MEASURES

Pain and comfort

- Visual Analogue Scale (VAS)
- Faces Pain Rating Scale (FPS-R)
- Paediatric Pain Profile (PPP)(adapted version)
- CPChild Questionnaire
- CP QOL Questionnaire
 - Child self report
 - Primary caregiver
- Disability Distress Assessment Tool (Dis-DAT)
- Non-Communicating Adults Pain Checklist-Revised (NCAPC)
- Clinical observations of heart rate

Integrity of the hip joint

- Hip Migration Percentage
- Hip abduction

Body symmetry

- Photographs, in standardised positions to enable reproducibility.
- Goldsmith Indices of Body Symmetry
- Chailey Levels of Ability - Supine lying
- Oxford Management of Physical Disability assessment sheet (MPD-24/7)
- Cobb angle

Quality of sleep

- Chailey Sleep Questionnaire
- Sleep diaries
- Sleep Disturbance Scale for Children (SDSC)
- Actigraphy
- Paediatric Sleep Questionnaire
- Sleep Disturbance Index
- Simple videosomnography
- Daytime wakefulness measures
- Thermochron ibuttons to measure skin temperature

Respiratory function

- Oxyhaemoglobin saturation
- Carbon dioxide measures
- Frequency of use of medications
- Number of admissions to hospital for respiratory problems
- Heart rate measures

Quality of life for users and carers

- Low tech family narratives

- Individualised measures
 - Canadian Occupational Performance Measure (COPM)
 - Goal Attainment Scaling (GAS)
 - Therapy Outcome Measures (TOMS)
- CPChild Questionnaire
- CP QOL Questionnaire
 - Child self report
 - Primary caregiver
- Parental Stress Index
- Family Impact of Assistive Technology Scale

Activity and Participation

- Individualised measures
 - Canadian Occupational Performance Measure (COPM)
 - Goal Attainment Scaling (GAS)
 - Therapy Outcome Measures (TOMS)
- CPChild Questionnaire
- CP QOL Questionnaire
 - Child self report
 - Primary caregiver

Pressure monitoring

- Body mapping of historical pressure areas and current ones.

Though not an outcome as such it will be important to have a record of the reasons for potential candidates deciding against using a postural support in lying or starting but not persisting with its use.

Factors to consider:

- ❖ It is currently unknown what percentage of candidates who are offered postural supports in lying decide not to use them.
- ❖ The reasons for their decision would be useful information that could help to guide practice within individual services.
- ❖ Publication of this data would enhance the evidence base within the field.

CONCLUSION

The findings from the literature review and from expert consensus support the recommendations above. This document provides guidance for practitioners prescribing postural support in lying and should assist them in making the necessary clinical decisions.

REFERENCES

Aburto N and Brown S. (2015) Pilot research study into the effects of sleep systems on quality of sleep, pain and joint range. Posture and Mobility Group.

Blake S, Logan S, Humphreys, G, Matthews J, et al. (2015) Sleep positioning systems for children with cerebral palsy. Cochrane Database of Systematic Reviews. JohnWiley & Sons, Ltd.

Dawson NC, Padoa KA, Bucks RS, et al. (2013) Ventilatory function in children with severe motor disorders using night-time postural equipment. *Developmental Medicine & Child Neurology* 55: 751-757.

DFES (2007) Aiming high for disabled children: better support for families. HM Treasury.

Gericke T. (2006) Postural management for children with cerebral palsy: Consensus statement. *Developmental Medicine and Child Neurology* 48: 244.

Goldsmith S. (2000) Postural care at night within a community setting: A feedback study. *Physiotherapy* 86: 528-534.

Gough, M. (2009) Continuous postural management and the prevention of deformity in children with cerebral palsy: an appraisal. *Developmental Medicine and Child Neurology*, 51, 105-110

Graham HK. (2004) Mechanisms of deformity. . In: Scrutton D, Damiano, D. & Mayston, M. (ed) *Management of the motor disorders of children with cerebral palsy*. . 2nd ed.: Mac Keith Press.

Hankinson J and Morton RE. (2002) Use of a lying hip abduction system in children with bilateral cerebral palsy: a pilot study. *Developmental Medicine & Child Neurology* 44: 177-180.

Hill CM, Parker RC, Allen P, et al. (2009) Sleep quality and respiratory function in children with severe cerebral palsy using night-time postural equipment: a pilot study. *Acta Paediatrica* 98: 1809-1814.

Humphreys G, Mandy A and Pountney T. (2012) Posture and sleep in children with cerebral palsy: a case study. *Association of Paediatric Chartered Physiotherapists* 3: 48-56.

Humphreys G, King T, Jex J, Rogers M, Blake S, Thompson-Coon J, Morris C (2018) Sleep positioning systems for children and adults with a neurodisability: a systematic review. Published online on 21st June. Available at <https://journals.sagepub.com/doi/10.1177/0308022618778254>

Innocente R. (2014) Night-time positioning equipment: A review of practices. *New Zealand Journal of Occupational Therapy* 61: 13-19.

Jan, J. E., Owens, J. A., Weiss, K. M. D., Johnson, P., Wasdell, M. B., Freeman, R. D. & Ipsiroglu, O. S. (2008) Sleep hygiene for children with neurodevelopmental disabilities. *Pediatrics*, 122, 1343-1350.

Lawrence S, Hill L and Page C. (2007) 24 hour postural care - the quest for objective data. . Canadian seating and mobility conference.

Moens S, McCaughey E, Quint C, et al. (2014) Routine respiratory screening for children with severe motor disorders using night-time postural equipment (sleep systems): A qualitative study. *Journal of Sleep Research* 23: 321.

Mol EM, Monbaliu E, Ven M, et al. (2012) The use of night orthoses in cerebral palsy treatment: sleep disturbance in children and parental burden or not? *Research in Developmental Disabilities* 33: 341-349.

Newman CJ, O'Regan, M., Hensey, O. (2006) Sleep disorders in children with cerebral palsy. *Developmental Medicine & Child Neurology* 48: 564-568.

NICE. (2012) *Spasticity in Children and Young People with Non-Progressive Brain Disorders: Management of Spasticity and Co-Existing Motor Disorders and Their Early Musculoskeletal Complications* (NICE Clinical Guidelines, No. 145.). London: RCOG press.

Polak F and Clift M. (2007) *The Use of Night Time Postural Management Equipment: A Survey of UK Paediatric Chartered Physiotherapists*.

Pountney, T. E., Mandy, A., Green, E. & Gard, P. R. (2009) Hip subluxation and dislocation in cerebral palsy - a prospective study on the effectiveness of postural management programmes. *Physiotherapy Research International*, 14, 116-127.

Robertson J, Baines, S., Emerson, E., Hatton, C. . (2016) Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review. *Journal of applied research in intellectual disabilities*: 1-18.

Royden H, Mithyantha R, Clarke S, et al. (2013) Impact of sleep systems (SS) on posture and quality of life (QOL) in children with neurological disabilities. *Archives of Disease in Childhood: Education and Practice Edition* 98: A51-A52.

Soo B, Howard JJ, Boyd RN, et al. (2006) Hip displacement in cerebral palsy. *The journal of bone and joint surgery*, 88-A: 121-129.

Underhill J, Bryan E and Pountney T. (2012) The effect of sleep systems on sleep-wake patterns and pain levels in non-ambulant children and young people with cerebral palsy. *Association of Paediatric Chartered Physiotherapists* 3: 57-64.

WHO (2001) *International Classification of Functioning, Disability and Health*. Accessed on 17.12.18 at <https://www.who.int/classifications/icf/en/>

Appendix 1: Characteristics of included studies and strength of evidence

First author and date in order of relevance to this review	Study design	No. of Participants (full data)	Age Range	Diagnoses	Type of Postural Support in Lying used in study	Duration	Quality Rating of Study	Comments
Underhill 2012	RCT	11 (10)	5 – 15yrs	Cerebral palsy GMFCS III - V	5 X Chailey Lying Support 1 x Jenx Dreama 5 x Symmetrisleep	8 nights	Medium	Sample, context, outcomes closely match focus of review but small number of participants who were well established users of postural supports in lying and for fewer than recommended nights of actigraphy. Used a variety of types of SPSs. Actigraphy important method of data collection on sleep quality.
Dawson 2013	Within subject cross-over study	15 (13)	1 – 19yrs	Severe Motor Disorders (9/13 with CP)	Not stated	14 nights	Medium	Sample, context and outcomes closely match focus of review. Sample are potentially less complex medically and socially because only 59% of those eligible were approached. Context is child's own home sleeping environment
Humphreys 2012	Interviews and observational	7 families	2 – 6yrs	Cerebral palsy GMFCS levels III - V	3 x Chailey Lying Support 2 x Dreama 1 x Symmetrisleep 2 x Sleepform	4 – 6 mths	Low	Collecting views of users of postural supports in lying, family and therapists. Sample, context, outcomes, closely match focus of review. Small number of participants and limited quotes to support themes. More quantitative methods would have contributed to strength of evidence.
Hill 2009	RCT	11 (9)	5 – 16yrs	Severe cerebral palsy	Not stated	2 nights	Medium	Sample are established users of postural supports in lying. Outcome measures used were appropriate. Setting in a sleep lab does not replicate the usual sleeping environment for the child. Risk of selection bias present as potential participants excluded by therapists.
Goldsmith 2000	Interviews based on questionnaire	31 families	9mths – 19yrs	Not known	Symmetrisleep	12 mths	Low	Sample, context, outcomes relate closely to focus of study. Limited data. Questionnaire not included. Lickert scale not best for finding views. Potential for selective outcome reporting from funding.
Hankinson 2002	Pilot prospective cohort study	14 (7)	4 – 14yrs	Bilateral cerebral palsy	Jenx Dreama	18 mths	Low	Sample, context and outcomes closely match focus of review but missing data, small numbers and potential bias from funding.
Moll 2012	Cross-sectional survey	82 of which 19 using NTPME	6 – 15yrs	Cerebral palsy GMFCS I -V	Not stated	N/A	Medium	Children in Flemish schools, looking at sleep, useful in an international context. Useful in the comparison of postural support in lying compared with other orthoses used at night and none. But difficulty in

								separating postural supports in lying and other orthoses. Parental personality and competence related to the experience of burden is potentially new.
Aburto 2015	Pilot prospective cohort study	4	3 – 21yrs	Not known	Symmetrisleep	6 mths	Low	Insufficient information from abstract only but sample, context and outcomes closely matching focus of review.
Moens 2014	Focus groups, interviews.	20 x PT / OTs 5 x carers	N/A	N/A	N/A	N/A	Low	Design and analysis are appropriate but limited by poster presentation only. Appropriate involvement of parents of children using sleep systems
Royden 2013	Retrospective cohort study	58	0.5 – 19.25 yrs	Cerebral palsy and non-cerebral palsy	Not stated	12 mths	Low	Insufficient information from conference abstract only. Sample, context and outcomes relate closely to this review but with much missing data. Other factors (eg intervention such as botox, surgery) that could have contributed to changes in the outcome measures were not considered.
Polak 2007	Postal survey	448 PTs	N/A	N/A	N/A	N/A	Low	Postal survey not most effective for gaining views of therapists (24% response rate). Unable to substantiate parents views as they are expressed via the therapists' opinions.
Newman 2006	Postal survey	Parents of 173 ch	6- 12yrs	Cerebral palsy GMFCS I - V	N/A		Low	No data on postural supports in lying. Subjective comment on why they make no appearance in difference to sleep quality (families stop using).
Innocente 2014	Postal survey to users of night time postural support	16	Not given	Neurodisabilities	Not stated	N/A	Low	Setting in New Zealand. Very small numbers. No separate data specifically on postural supports in lying though users are included.
Lawrence 2007	Descriptive report	5	Mid 20s	Moderate & severe musculoskeletal conditions	Symmetrisleep	5 yrs	Low	Descriptive report with no data.

Appendix 2: Round 2 of the expert consensus survey (including results of Round 1)

Sleep Positioning Systems for Children and Adults with a Neurodisability Round 2

Strong Consensus to Agree: 90% of participants agree or strongly agree with the statement.

Consensus to Agree: 80% of participants agree or strongly agree with the statement.

Near Consensus to Agree: 75% of participants agree or strongly agree with the statement.

Strong Consensus to Disagree: 90% of participants disagree or strongly disagree with the statement.

Consensus to Disagree: 80% of participants disagree or strongly disagree with the statement.

Near Consensus to Disagree: 75% of participants disagree or strongly disagree with the statement.

SECTION 1: To determine who is most likely to benefit from using a Sleep Positioning System (SPS) Who do you think should/could be prescribed a sleep positioning system?

1. For Infants and young children with a neurodisability before the onset of changes in body shape:

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	<ul style="list-style-type: none"> • Those with a diagnosis of CP, GMFCS level III could be prescribed a SPS • A child with a neuromuscular condition e.g. Duchenne’s or SMA could be prescribed a SPS • A child with any condition affecting posture could be prescribed a SPS
Near Consensus to Agree	<ul style="list-style-type: none"> • A child with CP with any level of GMFCS could have access to a SPS • A child with motor delay who may have low muscle tone affecting posture could be prescribed a SPS • Children of any age from soon after birth
Strong Consensus to Disagree	
Consensus to Disagree	<ul style="list-style-type: none"> • Only those with a diagnosis of CP, GMFCS levels IV and V should be prescribed a SPS
Near Consensus to Disagree	<ul style="list-style-type: none"> • Only children over a certain age

Inferences drawn from comments:

- Case by case clinical presentation, assessment and clear clinical reasoning should guide prescription of an SPS rather than diagnosis.
- Early intervention is important. Comments include ‘the earlier the better,’ ‘over 12 months,’ ‘over 2 generally but clinical reasoning if younger’
- Use of simple low tech methods of positioning could be used for children in GMFCS levels III, II & I and for those with neuromuscular conditions if needed and if effective. This does not exclude the use of an SPS with these groups.
- Do not over treat.

2. For Children and adolescents with postural or structural skeletal distortion:

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	
Near Consensus to Agree	
Strong Consensus to Disagree	
Consensus to Disagree	<ul style="list-style-type: none">• Only those with a diagnosis of CP should be prescribed a SPS
Near Consensus to Disagree	
No Consensus	<ul style="list-style-type: none">• Neuromuscular conditions e.g. Duchenne's or SMA

Inferences drawn from comments:

- Case by case clinical presentation, assessment and clear clinical reasoning should guide prescription of an SPS rather than diagnosis.
- Individuals who have conditions that affect posture / movement should be considered for a sps regardless of their diagnosis

3. For Adults with postural or structural skeletal distortion:

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	
Near Consensus to Agree	<ul style="list-style-type: none">• Anyone with postural or structural skeletal distortion• Anyone with a neurodisability acquired in adulthood e.g. stroke, MS, Parkinson's
Strong Consensus to Disagree	
Consensus to Disagree	<ul style="list-style-type: none">• Only those coming into adult services from children's services who had a SPS already or were considered for a SPS but didn't get one supplied• Only those with a diagnosis of CP• Only those with learning disability
Near Consensus to Disagree	
No Consensus	

Inferences drawn from comments:

- Case by case clinical presentation, assessment and clear clinical reasoning should guide prescription of an SPS rather than diagnosis.
- SPSs may also be beneficial for people with spinal injury, head injury, dementia whose posture is affected and those needing end of life care.
- SPSs may also be beneficial for those whose needs are transient during episodes of reduced mobility such as post-surgery or trauma.

- SPS doesn't just affect posture but has an influence on pressure care, comfort, respiration , for pain management, to assist tone management, to improve quality and quantity of sleep, safety and temperature regulation.

ADDITIONAL KEY STATEMENTS	Rating	Comments
Use of simple low tech methods of positioning could be used for children in GMFCS levels III, II & I if needed and if effective.		
Use of simple low tech methods of positioning could be used for children with neuromuscular conditions if needed and if effective.		
Use of simple low tech methods of positioning could be used for children with motor delay who may have low muscle tone affecting posture if needed and if effective.		
An SPS could be prescribed for a child of any age from soon after birth if clinical presentation, assessment and clear clinical reasoning demonstrate a clinical need.		
Particular attention should be given to those under 12 months re SIDS concerns.		
An SPS could be prescribed for anyone with a neurodisability who has limited ability to reposition themselves and has habitual pelvic / spinal asymmetry present throughout the day and night		
An SPS may not be tolerated or appropriate for those who can change their position or who move around a lot at night.		

<p>An SPS could be prescribed for anyone with a neurodisability acquired in adulthood with postural or structural skeletal distortion e.g. stroke, MS, Parkinson's, spinal injury, head injury</p>		
<p>People with dementia and those requiring 'end of life' care could be considered for an SPS</p>		
<p>People with transient needs e.g. post surgery or recovery from trauma could be considered for an SPS</p>		
<p>Preferred terminology, please rate the following terms:</p> <p>Sleep Positioning System</p>		
<p>Postural Support in Lying</p>		
<p>Sleep System</p>		
<p>Night Time Postural Support System</p>		
<p>Night Time Positioning Equipment</p>		
<p>Night Time Postural Support Equipment</p>		
<p>Supported Lying</p>		
<p>Supported Lying System</p>		
<p>Others Terms? Please specify</p>		

SECTION 2: To determine the key reasons for prescribing a SPS

1. To prevent or reduce hip migration and postural asymmetry in young children

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	<ul style="list-style-type: none">• Supporting young children with CP in a SPS can slow down or prevent the rate of hip migration and the development of postural asymmetry• Supporting young children with other conditions than CP in a SPS can slow down or prevent the rate of hip migration and the development of postural asymmetry• Assessment for appropriateness of prescription for a SPS should begin as soon as a child's motor development is identified as developing differently• Assessment tools and outcome measures that address musculoskeletal changes are essential for measuring change and evidencing effectiveness• Hip surveillance pathways should be accessed to manage hip integrity for children with CP
Near Consensus to Agree	
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	

Inferences drawn from comments:

- The early identification of those at risk of asymmetry is important as it enables close observation and monitoring.
- Hip surveillance pathways (including the Cerebral Palsy Integrated Pathway - CPIP) are clearly evidenced as being effective in managing the risk of hip migration in children with CP if suggested actions are carried out.
- There is recognition from practitioners' that there is a lack of empirical evidence that hip migration can be affected by the use of an SPS. Practitioners also comment that they have a number of individual cases that suggest a positive correlation.
- Recognition that assessment tools and outcomes measures need to be multi-faceted e.g. not just musculoskeletal but also domains of participation, function, activity as well as qualitative measures of pain/comfort etc.

2. To improve or maintain body shape in those with postural or structural skeletal distortion

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	<ul style="list-style-type: none">• Children, adolescents and adults with postural or structural asymmetry should be considered for a SPS to maintain or reduce their asymmetry• Provision of a SPS for people with structural asymmetry may have benefits in body function that impact positively on levels of activity and participation i.e less pain, less disturbance during sleep, improved respiration
Near Consensus to Agree	
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	

Inferences drawn from comments:

- Function and participation can be improved as a result of using an SPS e.g. activities of daily living being easier to accomplish and improvements in sleep having a positive impact on carers' quality of life.

3. To reduce pain and increase comfort

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	<ul style="list-style-type: none">Pain and comfort can be positively influenced by the use of SPS
Consensus to Agree	<ul style="list-style-type: none">Even very young children with CP may experience pain from muscle spasms and /or the adoption of stereotypical positions at night if posture is unsupported
Near Consensus to Agree	<ul style="list-style-type: none">Recognised assessment and outcome measure tools for pain and comfort behaviour are essential for measuring change and evidencing effectiveness of positioning in a SPS
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	<ul style="list-style-type: none">

Inferences drawn from comments:

- There is strong consensus that pain and comfort can be positively influenced by use of an SPS however there is no consensus as to which appropriate outcome measure to use to record pain or discomfort.
- Assessment and outcome measures of pain are not necessary for everyone but are essential where there pain is reported by the user or on their behalf by parents/carers or where there are signs of distress in the user.

- Efforts should be made to capture reporting of pain and comfort by the user by any appropriate means.

4. To improve quality of sleep

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	<ul style="list-style-type: none"> • The history and assessment of an individual’s sleep quality is essential prior to prescription of a SPS for risk assessment of medical and respiratory problems that may be influenced by use of a SPS • Those supporting the user and family/carers need to help them understand the nature of sleep and the associations the user has with the process of going to sleep
Near Consensus to Agree	<ul style="list-style-type: none"> • The history and assessment of an individual’s sleep quality is essential prior to prescription of a SPS for awareness of sleep behavioural difficulties that may need to be resolved prior to introduction of a SPS
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	<ul style="list-style-type: none"> • Outcome measure tools for quality of sleep are essential for prescription, measuring change and evidencing effectiveness

Inferences drawn from comments:

- The use of low tech tools is common in the assessment of sleep quality including sleep diaries, verbal reports from users/parents/carers

5. Other considerations for prescribing a SPS

- Reduction in tone and reduced energy expenditure
- Pressure care
- To improve comfort in day time positioning systems
- Support for respiration
- Reflux management
- Temperature regulation
- Independent mobility in bed
- Manual handling
- Safety
- To promote Relaxation

ADDITIONAL KEY STATEMENTS

Rating Comments

Different outcomes are important for people at different ages and those outcomes need to be measured

Including outcomes that address musculoskeletal changes e.g. hip migration percentage, hip abduction and body symmetry are essential in children aged 0-7years

Including outcomes that address musculoskeletal changes e.g. hip migration percentage, hip abduction and body symmetry are important in children and adolescents aged 7-14years

Including outcomes that address musculoskeletal changes e.g. hip migration percentage, hip abduction and body

<p>symmetry are only important if the clinical presentation suggests change in adolescents aged 14-21years</p>		
<p>Including outcomes that address body symmetry are important if the clinical presentation suggests change in adults aged 21 onwards but other outcomes will also be important</p>		
<p>Outcomes for older people will be very individual</p>		
<p>Assessment and outcome measures of pain are not necessary for everyone being prescribed a SPS</p>		
<p>Assessment and outcome measures of pain are not necessary for everyone being prescribed a SPS</p>		
<p>Assessment and outcome measures of pain are essential where pain is reported by the user or on their behalf by parents/carers or where there are signs of distress in the user.</p>		
<p>Efforts should be made to capture reporting of pain by the user as there is evidence that parents/carers are likely to under-report their child/client's pain</p>		
<p>Efforts to record sleep quality, in terms of sleep latency (how long to get to sleep), length of time asleep and number of awakenings, prior to prescription of an SPS, using any repeatable measures, should be made in all cases in order that any change can be recognised</p>		
<p>Others reasons for prescribing a SPS are:</p> <p style="padding-left: 40px;">Reduction of muscle tone and hence energy expenditure</p>		

To assist in pressure care		
To improve comfort in day time positioning systems		
As a support for respiration		
To improve temperature regulation		
Reflux management		
To aid independent mobility in bed		
For ease of manual handling		
For safety		
For relaxation		
Others Comments? Please specify		

SECTION 3: To determine the key difficulties that may be encountered and methods of overcoming them

1. Difficulties adapting to using a SPS

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	<ul style="list-style-type: none"> • Some may need support from a competent professional for a considerable length of time while users become familiar with the equipment and carers gain competency
Consensus to Agree	<ul style="list-style-type: none"> • Many but not all children, adults and their carers can adapt to using a sleep positioning system • Therapy services should acknowledge and build into their planning the need for ongoing support for users of SPS equipment • Use of the ICF: <ul style="list-style-type: none"> a. What would you consider to be the key personal factors? <ul style="list-style-type: none"> ○ Users, parents' and carers' readiness to persevere in encouragement of use of SPS? ○ User's ability to adapt to change? b. What would you consider to be the key environmental factors? <ul style="list-style-type: none"> ○ Knowledge and experience of prescriber? i.e. competence ○ How the user and carers were introduced to the subject of using a SPS eg. was adequate information given and training on wider postural care issues? ○ Is there therapy services provision for ongoing follow up and support?

Near Consensus to Agree	
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	<ul style="list-style-type: none"> • Use of the ICF: <ul style="list-style-type: none"> a. What would you consider to be the key personal factors? <ul style="list-style-type: none"> ○ Resolution or adaptation of sleep behaviour difficulties e.g a child unable to sleep in own bed? b. What would you consider to be the key environmental factors? <ul style="list-style-type: none"> ○ Housing and conditions for sleeping e.g. co-sleeping, sharing a bedroom with a sibling? •

Inferences drawn from comments:

- Parents/carers need to commit to trying to have a consistent approach to bedtimes and sleep to allow a fair trial of an SPS to determine whether it will be suitable for the child/adult
- The potential user/ parents/ carers should have choice and control at all times to use/not use an SPS and to change their mind without risk to the service they receive.
- Co-sleeping can be accommodated with careful planning, ingenuity and imagination
- Night time positioning may take a long time to get used to and may need to be introduced gradually, important to 'go at their pace'
- Other personal factors
 - Competency of parents/carers e.g. parental learning disability, neglect

- Cultural differences and attitudes towards disability
- Multiple carers
- Personal preference of sleep position and difficulty in changing that if preference is not for supine
- It is essential that prescribers are fully competent to ensure the prescription is correct and risks have been analysed and reduced.
- Experience of working with a variety of different SPSs enables problem solving of individual positioning and sleep difficulties
- Knowledge and understanding of the potential benefits of night time positioning are important for the user, parents/carers and other staff in the multi-disciplinary team
- Support from the medical team is essential when risks have been identified prior to prescription of an SPS

2. RISKS AND ADVERSE EVENTS

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	<ul style="list-style-type: none"> ● Reflux, vomiting and choking are as likely to occur in or out of a SPS. The risks of using a SPS are similar to those of not using a SPS for people with severe neurodisability, so a risk assessment plan should be agreed and documented ● Supported lying at night should improve comfort and more even load distribution hence reducing the risk of development of pressure areas providing the supporting surface is appropriate
Near Consensus to Agree	<ul style="list-style-type: none"> ● Risks need to be identified prior to prescription using standardised assessment tools
Strong Consensus to Disagree	

Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	•

Inferences drawn from comments:

- Risks do need to be measured to enable services to show due diligence in provision to families and stakeholders eg. commissioners
- Risks do not necessarily have to be measured with standardised measures tools

Other risks

- Thermal discomfort and the impact on sleep and skin care
- Incorrect use of the equipment by parents/carers
- Epilepsy and discomfort from having seizures within the SPS
- Circulation problems e.g. oedema
- Safety if PEG feeding

3. RESPIRATORY FUNCTION

Consensus Gained in Round 1

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DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	<ul style="list-style-type: none"> • The respiratory risks of an individual should be assessed prior to prescription of a SPS • In any individual, positioning in a SPS may improve or worsen respiratory function
Near Consensus to Agree	
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	<ul style="list-style-type: none"> • Respiratory assessment is essential prior to prescription of a SPS. For those with a known risk, respiratory function tests should take place preferably in their usual sleep environment for 3 consecutive nights prior to use of an SPS

Inferences drawn from comments:

- Respiratory assessment is not commonly available in the community or if referred on does not happen in a timely manner
- It would be challenging for prescribers to implement assessment of respiratory risk
- Based on their own academic research on children and young people with ‘severe motor disorders’ Southampton recommend respiratory assessments once using an SPS unless respiratory risks are already known in which case before, for 3 consecutive nights in their own sleeping environment, and after intervention testing should take place
- Supine supported lying is the best position to preserve body shape but respiratory requirements may take precedence and require alternative positions
- The needs of individuals who use supplementary respiratory support (eg BiPAP) must be considered

4. TRAINING

Consensus Gained in Round 1

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	<ul style="list-style-type: none">• Users, parents and carers need to feel competent in use of the equipment• Delivering training to users, parents and carers is likely to lead to higher levels of adherence in use of a SPS
Consensus to Agree	<ul style="list-style-type: none">• Users, parents and carers need to understand the rationale for prescription of a SPS in the wider context of postural care
Near Consensus to Agree	
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	<ul style="list-style-type: none">• Training should be approved and monitored by recognised associations to ensure content validity and trainer competency

Inferences drawn from comments:

- The focus and bias of recognised associations of trainers may not agree with a prescriber's views
- Formal training will not suit all carers, either because of personal factors or time frames

- Prescribers of an SPS must be competent practitioners in the field of night time postural management, complying with their professional bodies' codes of practice e.g. CSP, BAOT, HCPC
- The prescriber needs to have the competency to provide training to users and parents/carers, understanding that different parents/carers may need different materials and a different delivery style.

Additional Key Statements	Rating	Comments
<p>If agreeing to try an SPS parents/carers need to commit to a consistent approach to bedtimes and sleep to allow a fair trial of an SPS to determine whether it will be suitable for the child/adult</p>		
<p>Planning of how and where the potential user will sleep and how the equipment may fit with the rest of the family is essential prior to prescription but multi-occupancy of the bedroom and/or co-sleeping</p>		
<p>Prescriber knowledge and experience of a variety of different SPSs enables potential users' individual personal and environmental factors to be met more easily than by adherence to one product supplier only</p>		
<p>Risk assessment tools, standardised or non-standardised should be agreed upon locally and used consistently by all prescribers of SPSs within that service</p>		
<p>Support from the multidisciplinary team (including medical consultant) is essential when providing a postural care service and decisions about risk jointly taken with the user and parents/carers</p>		
<p>Respiratory assessment is essential prior to prescription of a SPS.</p>		

For those with a known risk, respiratory function tests should take place preferably in their usual sleep environment for 3 consecutive nights prior to use of a SPS.		
It is essential that anyone prescribing an SPS keeps within their scope of practice by only practising in the areas that they have the appropriate knowledge, skills and experience for, to ensure that they comply with the requirement by their professional body.		
The prescriber needs to have the competency to provide training to users and parents/carers, understanding that different parents/carers need different materials and a different delivery style		
Others Comments? Please specify		

SECTION 4: To develop a list of core outcomes and how best to measure them

FUTURE DATA COLLECTION IN CLINICAL PRACTICE

Consensus Gained in Round 1

1. OUTCOMES should include:

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	<ul style="list-style-type: none"> Pain and comfort

Consensus to Agree	<ul style="list-style-type: none"> • Integrity of the hip joint • Body symmetry • Quality of sleep • Respiratory function • QOL for users and carers • Causes of potential users not taking up or not continuing to use a SP
Near Consensus to Agree	
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	

Inferences drawn from comments:

- Other outcomes suggested
 - Management of tone
 - Use of medication
 - Daytime wakefulness
 - Activity and participation including ease of seating
 - Ulcer status

2. MEASURES should include:

a. Pain and Comfort, Integrity of the hip joint, Body Symmetry, Quality of Sleep, Respiratory function, Quality of life for users and carers.

DEGREE OF CONSENSUS	STATEMENT
Strong Consensus to Agree	
Consensus to Agree	
Near Consensus to Agree	
Strong Consensus to Disagree	
Consensus to Disagree	
Near Consensus to Disagree	
No Consensus	<ul style="list-style-type: none"> • Paediatric Pain Profile • Faces Pain Rating Scale (FPS-R) • CP Child Questionnaire • Visual analogue scale • Hip Migration Percentage • Hip abduction • Cobb angle • Goldsmith's Index • Chailey Sleep Questionnaire • Paediatric Sleep Questionnaire • Sleep Disturbance Scale • Sleep diaries • Actigraphy • Oxyhaemoglobin saturation • Carbon dioxide measures • CP child Questionnaire

	<ul style="list-style-type: none">• Parental stress index• Family impact of assistive technology scale
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Inferences drawn from comments:

- Other measures for pain and comfort suggested
 - Dis-DAT (Disability Distress Assessment Tool)
 - Parent/Carer CP QOL Questionnaire
 - Caregiver Questionnaire
 - Heart rate, salivary cortisol, pulse oximetry
 - Videosomnography
 - Sleep disturbance index score (adapted Quine 1991)
 - PPP (adapted version)
 - Thermal comfort measures
 - Pressure mapping
- Other measures suggested for body symmetry
 - Chailey Level of Ability - Supine lying
 - Oxford MPD-24/7
 - Photographs
- Other measures suggested for quality of sleep
 - Simple videosomnography
 - ThermoChron iButtons to measure skin temperature
 - Daytime wakefulness
 - Some monitoring is expensive which may prohibit wide scale use e.g. actigraphy
- Other measures suggested for respiratory function
 - Use of medications
 - Number of admissions to hospital
 - Heart rate variability measured with Camntech Actihear (can be administered at home)
- Other measures suggested for Quality of life
 - Parent/carer QOL questionnaire

- Low tech 'Family stories'
- Caregiver questionnaire
- Individualised measures
 - COPM
 - GAS

Inferences drawn from comments in section 4:

- Although there is consensus about what to measure there is no consensus about how to measure i.e. which tools to use
- Access to sleep laboratories is extremely limited in many places
- Availability of measurement tools is a problem in the community
- Availability in the community is sometimes prohibited by the costs of the tools
- Time to administer the tools is a problem
- The administration of measurement tools can be an extra burden on parents/carers

ADDITIONAL KEY STATEMENTS	Rating	Comments
Please rate these other outcomes for using an SPS		
Management of tone		
Use of Medication		
Daytime wakefulness		
Activity and participation including eg ease of seating		
Pressure areas/Ulcer status		
Measuring outcomes is an important requirement to		

document due diligence to families and commissioners		
Assessment prior to prescription of an SPS must identify and document the aims of the prescription.		
Identification of the aims will inform which domains the outcome measures can be chosen from.		
Standardised, validated outcomes are necessary when conducting research but informal outcomes are acceptable in practice if they enable comparisons to be made.		
Others Comments? Please specify		

Many thanks for your valuable time in completing the survey.