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## Interventions and Management

### 1. Selecting assessment tools to characterize upper limb function of children with cerebral palsy: A mega-review of systematic reviews

Leonardo Vinícius Thomé Teixeira da Silva, Milena Vegas, Natalia Aquaroni Ricci, Cristina S Cardoso de Sá, Sandra Regina Alouche

Dev Neurorehabil. 2022 Mar 12;1-14. doi: 10.1080/17518423.2022.2046656. Online ahead of print.

**Aim:** A mega-review of published systematic reviews without restriction on year of publication was implemented to summarize available assessment tools of upper limb (UL) function in children with Cerebral Palsy (CP). **Method:** A multi-prong search strategy was used to identify 12 systematic literature reviews for inclusion in the mega-review. Included reviews were coded by descriptive analyses, which included methodological and reported measurement property description. Methodological quality of the selected systematic reviews was evaluated with the AMSTAR-2. We synthesized the measurement properties of the revised assessment tools and their coverage within the International Classification of Functioning, Disability and Health (ICF) domains. **Results:** The 12 systematic reviews addressed 84 assessment tools. Systematic reviews' methodological quality varied between critically low to moderate. Suggested assessment tools covered ICF domains of body structure and function, and activities and participation. Measurement property data analysis was based mostly on reliability and validity. **Interpretation:** Based on the findings of the mega-review, the ABILHAND-Kids, Assisting Hand Assessment (AHA) and Melbourne Assessment of Unilateral Upper Limb Function (MUUL) are the most suitable tools to evaluate children between 6 and 12 years of age with unilateral CP.

PMID: [35282778](#)

### 2. Assessment of Manual Abilities Using the Box and Block Test in Children with Bilateral Cerebral Palsy

Vanessa Zapata-Figueroa, Fernando Ortiz-Corredor

Occup Ther Int. 2022 Feb 22;2022:9980523. doi: 10.1155/2022/9980523. eCollection 2022.

**Objective:** The aim of this study was to determine the correlation between manual dexterity evaluated with the Box and Block Test (BBT) and the performance of daily activities in children with bilateral cerebral palsy (CP). **Methods:** The BBT was applied to 162 children with cerebral palsy of bilateral distribution aged 6 to 13 years. The level of performance was evaluated according to the Manual Ability Classification System (MACS), Gross Motor Function Classification System (GMFCS), and Pediatric Evaluation of Disability Inventory (PEDI) in the domains of self-care, mobility, and social function. Correlations between the findings of the BBT and the PEDI were determined, and additionally, some specific toileting tasks of the PEDI were evaluated. **Results:** The results of the BBT were lower in the lowest functional levels of the MACS ( $p \leq 0.001$ ). The BBT showed a strong correlation with the domains' self-care ( $r = 0.8$ ), mobility ( $r = 0.7$ ), and social function ( $r = 0.6$ ) of the

PEDI. The BBT was different between children who were able and children who were not able to perform the toileting tasks that were evaluated. A lower capacity in the BBT obtained in children with functional status GMFCS III, IV, and V was associated with poor performance in toileting tasks evaluated in the PEDI. Conclusion: The results of the BBT are correlated with the activities of daily living of children with bilateral CP. The data obtained from this test is used to predict the performance of daily activities of these patients in settings such as school and home and helps to identify contextual factors that influence the level of independence in children with bilateral CP.

PMID: [35281716](#)

### **3. Intra-rater and inter-rater reliability, minimal detectable change, and construct validity of the Edinburgh Visual Gait Score in children with cerebral palsy**

Hirokazu Abe, Shotaro Koyanagi, Yasuaki Kusumoto, Nobuaki Himuro

Gait Posture. 2022 Mar 8;94:119-123. doi: 10.1016/j.gaitpost.2022.03.004. Online ahead of print.

Background: The Edinburgh Visual Gait Score (EVGS) has been used for observational gait assessment in children with cerebral palsy (CP). However, the measurement error of the EVGS and its detailed relationship with gross motor function remain unclear. Research questions: This study aimed to confirm the intra-rater and inter-rater reliability as well as the minimal detectable change (MDC) values for the EVGS with the use of the video analysis software and examine the relationship between the EVGS and the Gross Motor Function Measure 66 (GMFM-66) with regard to construct validity. Methods: This cross-sectional study was conducted for 62 children (mean age  $11.3 \pm 3.9$  years) with spastic CP at Gross Motor Function Classification System (GMFCS) level I (32 children), II (25 children) or III (5 children). Three raters independently scored the EVGS using Kinovea video analysis software. The intra-rater and inter-rater reliability were calculated using intra-class correlation coefficients (ICC<sub>2,1</sub>), and the MDC<sub>90</sub> was calculated using standard error of measurement. The construct validity was examined by correlating the EVGS with the GMFM-66. Results: The EVGS showed good or excellent reliability within each rater (ICC<sub>2,1</sub> = 0.90-0.97) and between raters (ICC<sub>2,1</sub> = 0.91). The MDC<sub>90</sub> of the EVGS ranged from 3.6 to 6.0. There was a significant correlation between the EVGS and the GMFM-66 ( $r = -0.69$  to  $-0.73$ ,  $p < 0.001$ ). Significance: The intra-rater and inter-rater reliability of the EVGS is sufficient for observational gait assessment. The high correlation between the EVGS and the GMFM-66 supports its construct validity. The authors propose an MDC of 6.0 for the EVGS. These results can help in the application of EVGS to children with CP at GMFCS level I-II with mild to moderate gait pathology, as there were few children with CP at GMFCS level III.

PMID: [35279565](#)

### **4. Walking and Fatigue in People with Cerebral Palsy: Brief Report**

Sarrah Husain, James G Wrightson, Erika Johnson, Laura Kristine Brunton, Elizabeth Condliffe

Dev Neurorehabil. 2022 Mar 15;1-4. doi: 10.1080/17518423.2022.2053222. Online ahead of print.

The aim of this study was to examine the relationship between perceived fatigue and perceptions of walking abilities and difficulty in people with cerebral palsy (CP). Twenty individuals with CP (range 10-21y; mean age 14.8y) who usually walk in the community were recruited. Community mobility was assessed using the Functional Mobility Scale. Participants were asked about their walking ability and frequency, perceived effort during walking (using the Children's Effort Rating Table), and perceived fatigue (using the Fatigue Impact and Severity Self-Assessment). Community mobility, frequency, and perceived effort during walking were significantly related to fatigue. No relationship was found between time spent walking (maximum walking time) and fatigue. Here we demonstrate that perceived fatigue is related to walking in people with CP.

PMID: [35289718](#)

### **5. Therapeutic Lower Extremity Power Training Alters the Sensorimotor Cortical Activity of Individuals With Cerebral Palsy**

Morgan Busboom, Brad Corr, Anna Reelfs, Mike Trevarrow, Heidi Reelfs, Sarah Baker, Hannah Bergwell, Tony W Wilson, Noelle G Moreau, Max J Kurz

Arch Rehabil Res Clin Transl. 2022 Jan 25;4(1):100180. doi: 10.1016/j.arrct.2022.100180. eCollection 2022 Mar.

**Objective:** To utilize magnetoencephalographic (MEG) brain imaging to examine potential changes in sensorimotor cortical oscillations after therapeutic power training in individuals with cerebral palsy (CP). **Design:** Cohort. **Setting:** Academic medical center. **Participants:** Individuals with CP (N=11; age=15.9±1.1 years; Gross Motor Function Classification System I- III) and neurotypical controls (NTs; N=16; age=14.6±0.8 years). **Interventions:** Participants with CP underwent 24 (8 weeks; 3 days a week) sessions of high-velocity lower extremity power training on a leg press. The NTs underwent single baseline MEG assessments. **Main outcome measures:** Pre-post bilateral leg press 1-repetition maximum and peak power production were used to assess the muscular performance changes. The 10-m walk and 1-minute walk tests were used to assess mobility changes. **During MEG recordings,** participants used their right leg to complete a goal-directed isometric target-matching task. **Advanced beamforming methods** were subsequently used to image the strength of the sensorimotor beta oscillatory power. **Results:** Before the therapeutic power training, the participants with CP had stronger beta sensorimotor cortical oscillations compared with the NT controls. However, the beta sensorimotor cortical oscillations were weaker and approximated the controls after the participants with CP completed the therapeutic power training protocol. There also was a link between the amount of improvement in leg peak power production and the amount of reduction in sensorimotor cortical oscillations seen after therapy. **Conclusions:** Therapeutic power training appears to optimize the sensorimotor cortical oscillations of individuals with CP, and these neuroplastic changes partly contribute to improvements in the leg peak power production of individuals with CP. Therapeutic power training might provide the key ingredients for beneficial neuroplastic change.

PMID: [35282149](#)

## 6. Power training alters somatosensory cortical activity of youth with cerebral palsy

Hannah Bergwell, Mike Trevarrow, Brad Corr, Sarah Baker, Heidi Reelfs, Tony W Wilson, Noelle G Moreau, Max J Kurz

Ann Clin Transl Neurol. 2022 Mar 17. doi: 10.1002/acn3.51545. Online ahead of print.

**Objective:** Our prior magnetoencephalographic (MEG) investigations demonstrate that persons with cerebral palsy (CP) have weaker somatosensory cortical activity than neurotypical (NT) controls, which is associated with reduced muscular strength and mobility. Power training can improve lower extremity isokinetic strength, muscular power, and walking performance of youth with CP. Potentially, these clinically relevant improvements are partially driven by changes in somatosensory processing. The objective of this investigation was to determine if power training has complementary changes in muscular function and somatosensory cortical activity in youth with CP. **Methods:** A cohort of youth with CP (N = 11; age = 15.90 ± 1.1 years) and NT controls (N = 10; Age = 15.93 ± 2.48 years) participated in this investigation. Youth with CP underwent 24 power training sessions. Pre-post bilateral leg press 1-repetition maximum (1RM), peak power production, 10-m walking speed, and distance walked 1-min were used as outcome measures. MEG neuroimaging assessed the changes in somatosensory cortical activity while at rest. NT controls only underwent a baseline MEG assessment. **Results:** Youth with CP had a 56% increase in 1RM (p < 0.001), a 33% increase in peak power production (p = 0.019), and a 4% improvement in 1-min walk (p = 0.029). Notably, there was a 46% increase in somatosensory cortical activity (p = 0.02). **Interpretation:** These results are the first to show that power training is associated with improvements in muscular function, walking performance, and the resting somatosensory cortical activity in individuals with CP. This treatment approach might be advantageous due to the potential to promote cortical and muscular plasticity, which appear to have carryover effects for improved walking performance.

PMID: [35297546](#)

## 7. Parental Pain Catastrophizing, Communication Ability, and Post-surgical Pain Outcomes Following Intrathecal Baclofen Implant Surgery for Patients With Cerebral Palsy

Breanne J Byiers, Caroline L Roberts, Chantel C Burkitt, Alyssa M Merbler, Kenneth D Craig, Frank J Symons

Front Pain Res (Lausanne). 2022 Feb 22;2:809351. doi: 10.3389/fpain.2021.809351. eCollection 2021.

There is strong evidence that psychosocial variables, including pain catastrophizing, influence parental and child ratings of pain, pain expression, and long-term outcomes among children with chronic pain. The role of these factors among children who have communication deficits due to cerebral palsy (CP) and other intellectual and developmental disabilities is currently

unclear. In this study, parental pain catastrophizing was assessed before intrathecal baclofen (ITB) pump implantation for spasticity management in 40 children and adolescents with CP, aged 4 to 24 years. Pain was assessed before and after surgery with two methods: a parent-reported pain interference scale, and behavioral pain signs during a standardized range of motion exam. Linear mixed models with clinical/demographic factors and scores from the Pain Catastrophizing Scale for Parents (PCS-P), and child spoken language ability as predictors and the pain variables as the outcomes were implemented. On average, both pain outcomes improved after surgery. Only child spoken language ability predicted change in behavioral reactivity scores, with children with phrase speech showing an increase in reactivity at follow-up compared to pre-surgery levels, on average. A significant interaction between PCS-P scores and spoken language ability on change in pain interference scores over time showed that dyads with children with phrase speech whose parents reported high PCS-P scores reported the least improvement in pain interference at follow-up. Due to the preliminary nature of the study, future work is needed to investigate the parental behaviors that mediate the relationships between parental catastrophizing and pain outcomes in this population.

PMID: [35295472](#)

### **8. Clinical Factors Associated With Chronic Pain in Communicative Adults With Cerebral Palsy: A Cross-Sectional Study**

Eric M Chin, Colleen Lenz, Xiaobu Ye, Claudia M Campbell, Elaine Stashinko, Lauren L Jantzie, Gwendolyn Gerner, Alexander H Hoon, Shenandoah Robinson

Front Pain Res (Lausanne). 2020 Nov 24;1:553026. doi: 10.3389/fpain.2020.553026. eCollection 2020.

Chronic pain is prevalent in adults with cerebral palsy. We aimed to explore associations between chronic pain and somatosensory, motor, cognitive, etiologic, and environmental factors in adults with cerebral palsy. This cross-sectional study enrolled 17 adult participants with cerebral palsy (mean age 31 years; 8 female; Gross Motor Functional Classification Status levels I-V) able to self-report and 10 neurotypical adult volunteers (mean age 34 years; 9 female). Participants reported pain characteristics, demographics, and affective factors. Physical examination included somatosensory and motor evaluation. Between-group comparisons used a ranksum test, and correlation analyses estimated effect size in terms of shared variance ( $\rho^2$ ). Individuals with cerebral palsy reported greater pain intensity, neuropathic qualities, and nociceptive qualities than control participants. Higher pain intensity was associated with female gender ( $\rho^2 = 16\%$ ), anxiety/depression symptoms ( $\rho^2 = 10\%$ ), and lower household income ( $\rho^2 = 19\%$ ). It was also associated with better communicative ability ( $\rho^2 = 21\%$ ), spinothalamic (sharp/temperature) sensory abnormalities ( $\rho^2 = 33\%$ ), and a greater degree of prematurity ( $\rho^2 = 17\%$ ). This study highlights similarity of chronic pain associations in people with cerebral palsy with patterns seen in other populations with chronic pain. Spinothalamic sensory abnormalities suggest central pain mechanisms.

PMID: [35295692](#)

### **9. Crossing the line? Ethics of parenteral nutrition in paediatric neurodisability complicated by intestinal failure**

Zoe McCallum, Clare Delany, Lynn Gillam

Review Arch Dis Child. 2022 Mar 14;archdischild-2021-323500. doi: 10.1136/archdischild-2021-323500. Online ahead of print.

Children with severe neurological impairment (such as cerebral palsy or congenital anomalies) are living longer, although medically complex, lives. Feeding intolerance is an increasing problem that is emerging as a new end-of-life issue. Long-term parenteral nutrition (LTPN) is technically feasible in these children. However, clinicians are concerned about whether it is appropriate in these circumstances or whether it constitutes a treatment 'too far'. This narrative review of the literature identifies, categorises and explores the ethical foundations and reasons for clinician hesitancy about the use of LTPN in this population. The categories of reasons are: lack of clear diagnostic criteria for feeding failure; risks of LTPN to the child; burden of LTPN to the family/caregivers; burden of LTPN to the child; difficulty in cessation of LTPN; and the concept that feeding failure may be a preterminal sign. These reasons are all ultimately about risks and burden outweighing the benefits. We argue that the risks of LTPN have decreased over time, the burden for individual children and their parents may be less than imagined, and the benefit is a realistic prospect. Case-by-case consideration, giving due weight to child and parental perspectives, can show that LTPN is ethically justified for some children with severe neurological impairment.

PMID: [35288420](#)

## 10. The Impact of Cognition on Motor Learning and Skill Acquisition Using a Robot Intervention in Infants With Cerebral Palsy

Raghuveer Chandrashekhar, Hongwu Wang, Josiah Rippetoe, Shirley A James, Andrew H Fagg, Thubi H A Kolobe

Front Robot AI. 2022 Feb 25;9:805258. doi: 10.3389/frobt.2022.805258. eCollection 2022.

**Background:** Cerebral Palsy (CP) is a neurodevelopmental disorder that encompasses multiple neurological disorders that appear in infancy or early childhood and persist through the lifespan of the individual. Early interventions for infants with CP utilizing assisted-motion robotic devices have shown promising effects in rehabilitation of the motor function skills. The impact of cognitive function during motor learning and skill acquisition in infants using robotic technologies is unclear. **Purpose:** To assess the impact of cognitive function of infants with and without CP on their motor learning using the Self-Initiated Prone Progression Crawler (SIPPC) robot. **Methods:** Statistical analysis was conducted on the data obtained from a randomized control trial in which the movement learning strategies in infants with or at risk for CP was assessed during a 16-week SIPPC robot intervention. Cognitive function was measured by the Bayley scales of Infant and Toddler Development-Third edition (Bayley-III) and motor function was measured by the Movement Observation Coding Scheme (MOCS). The infants were categorized into three distinct groups based on their cognitive scores at baseline: "above average" (n1 = 11), "below average" (n2 = 10), and "average" (n3 = 26). Tri-weekly averages of the MOCS scores (observations at five time points) were used for the analyses. This study involved computing descriptive statistics, data visualization, repeated measures analysis of variances (rmANOVA), and survival analyses. **Results:** The descriptive statistics were calculated for the MOCS and Bayley III scores. The repeated measures ANOVAs revealed that there was a statistically significant effect of time ( $p < 0.0001$ ) on scores of all subscales of the MOCS. A statistically significant effect of interaction between group and time ( $p < 0.05$ ) was found in MOCS scores of subscales 1 and 2. The survival analyses indicated that infants in different cognition groups significantly differed ( $p < 0.0001$ ) in their ability to achieve the crawling milestone within the 16-week intervention period. **Conclusion:** The findings in this study reveal the key movement strategies required to move the SIPPC robot, assessed by the MOCS, vary depending on the infants' cognition. The SIPPC robot is well-matched to cognitive ability of infants with CP. However, lower cognitive ability was related to delayed improvement in their motor skills.

PMID: [35280958](#)

## 11. Effects of Augmented Reality Intervention on the Range of Motion and Muscle Strength of Upper Extremity in Children with Spastic Hemiplegic Cerebral Palsy: A Randomized Clinical Trial

Wardah Hussain Malick, Rizwana Butt, Waqar Ahmed Awan, Muhammad Ashfaq, Qamar Mahmood

Games Health J. 2022 Mar 14. doi: 10.1089/g4h.2021.0128. Online ahead of print.

**Objective:** To determine the effects of augmented reality (AR) interventions on the upper extremity's (UE's) range of motion (ROM) and muscle strength in children with spastic hemiplegic cerebral palsy (SHCP). **Materials and Methods:** Thirty children with SHCP, aged 6 to 12 years, were randomly divided into three interventional groups. Each group received an AR game that is, Balance It, Bubble Pop, or Scoop'd (WonderTree, Pakistan). The UE's ROM and muscle strength were assessed at the baseline and after 8 weeks of intervention through goniometer and manual muscle testing, respectively. Paired-sample t-test and Wilcoxon signed-rank test were used for analyzing the changes in ROM and muscle strength within the groups respectively. One-way analysis of variance (ANOVA) and Tukey's test were used for the differences in ROM, whereas the Kruskal-Wallis test was used for the differences in muscle strength, between the groups. **Results:** Within-group analysis revealed that all the groups significantly improved in ROM of the majority of joints and in the strength of various muscles of UE ( $P < 0.05$ ). The elbow extension ROM was significantly different when a comparison was made between the interventional groups ( $P < 0.05$ ). Balance It group showed more significant improvement in the elbow extension ROM as compared with the Scoop'd group. However, the comparison between the groups showed no significant difference in the muscle strength of UE ( $P > 0.05$ ). **Conclusion:** The AR games intervention was beneficial and effective for improving the ROM of majority of the joints and strength of various muscles of UE in children with SHCP. Clinical Trial Registration number: NCT04171232.

PMID: [35285674](#)

## 12. Motor-related health care for 5-year-old children born extremely preterm with movement impairments

Raquel Costa, Adrien M Aubert, Anna-Veera Seppänen, Ulrika Ådén, Lemke Sarrechia, Michael Zemlin, Marina Cuttini, Mairi Männamaa, Véronique Pierrat, Arno van Heijst, Henrique Barros, Samantha Johnson, Jennifer Zeitlin, SHIPS research group



Dev Med Child Neurol. 2022 Mar 17. doi: 10.1111/dmcn.15202. Online ahead of print.

**Aim:** To (1) determine the proportion of 5-year-old children born extremely preterm (EPT) with movement difficulties including cerebral palsy (CP) and the proportion of these children receiving motor-related health care (MRHC), and (2) describe factors associated with receiving MRHC. **Method:** Children born before 28 weeks' gestation in 2011 to 2012 in 11 European countries were assessed with the Movement Assessment Battery for Children, Second Edition (MABC-2) at 5 years of age. Information on family characteristics, child health including CP diagnosis, and health care use were collected using parent-report questionnaires. MRHC was defined as visits in the previous year with health care providers (physical and occupational therapists) specialized in assessing/treating motor problems. We analysed receipt of MRHC and associated factors among children at risk of movement difficulties (MABC-2 score 6th-15th centiles), with significant movement difficulties (SMD;  $\leq$ 5th centile) or with CP. **Results:** Of 807 children assessed at 5 years 7 months (SD 4 months; 4 years 7 months-7 years 1 month), 412 were males (51.1%), 170 (21.1%) were at risk of movement difficulties, 201 (24.9%) had SMD, and 92 (11.4%) had CP. Those who received MRHC comprised 89.1% of children with CP, 42.8% with SMD, and 25.9% at risk of movement difficulties. MRHC for children with SMD varied from 23.3% to 66.7% between countries. Children were more likely to receive MRHC if they had other developmental problems or socioemotional, conduct, or attention difficulties. **Interpretation:** Efforts are needed to increase MRHC for 5-year-old children born EPT with movement difficulties.

PMID: [35298035](#)

### **13. The Use and Outcomes of Motor Rehabilitation Services Among People With Cerebral Palsy Change Across the Lifespan**

Gwenaël Cornec, Sylvain Brochard, Gaele Drewnowsk, Isabelle Desguerre, Philippe Toullet, Audrey Fontaine, Yann Le Lay, Julia Boivin, Eric Bérard, Maria Bodoria, Vincent Gautheron, Javier De la Cruz

Front Neurol. 2022 Feb 10;12:771348. doi: 10.3389/fneur.2021.771348. eCollection 2021.

**Background and aims:** The provision of coordinated and multidisciplinary rehabilitation programs that adapt to the individual with cerebral palsy (CP) evolving rehabilitation needs throughout the different phases of life is highly challenging for healthcare systems. The aim of this study was to report the changes in motor rehabilitation (MR) environmental factors, service use and patient outcomes between children and adults with cerebral palsy and to identify if changes took place earlier or later than the standard division between pediatric and adult healthcare systems at 18 years. **Methods:** We used data from the French ESPaCe survey to select a set of indicators for MR environmental factors, service use and patient outcomes, highlighted by patients and families in previous studies. We then compared the distribution of the indicator data between children and adults, as well as between four transition age groups: children under 12, adolescents up to 17 years, young adults, and adults over 25 years of age. We estimated odds ratios adjusted for motor involvement, associated impairments and informant type. **Results:** A total of 997 respondents over 2 years of age were included in this study (484 children and 513 adults). Finding an available physiotherapist was very difficult for almost half of the children, and a greater proportion of adolescents and adults. Physiotherapy was provided in a private outpatient practice for twice as many adults over 25 years as children and adolescents. The weekly amount of physical therapy decreased as outpatient practice increased. Multidisciplinary rehabilitation decreased sharply from adolescence and was halved at adulthood. Satisfaction with the MR program decreased from childhood into adolescence and adulthood. Perceived impact of physiotherapy on people with CP and their main carers were less positive in adolescents. **Conclusions:** Healthcare policies should focus on accessibility issues at all ages, consider adolescents as a specific population, consider a wide transition phase (12-25 yo) and maintain a multidisciplinary approach at adulthood. There is a strong need for national rehabilitation strategies for individuals with CP.

PMID: [35281990](#)

### **14. Indigenous health equity in health register ascertainment and data quality: a narrative review**

Karen Wright, Rachel M Tapera, N Susan Stott, Alexandra Sorhage, Anna Mackey, Sian A Williams

Int J Equity Health. 2022 Mar 12;21(1):34. doi: 10.1186/s12939-022-01635-2.

**Background:** Health registers play an important role in monitoring distribution of disease and quality of care; however, benefit is limited if ascertainment (i.e., the process of finding and recruiting people on to a register) and data quality (i.e., the accuracy, completeness, reliability, relevance, and timeliness of data) are poor. Indigenous peoples experience significant health

inequities globally, yet health data for, and about, Indigenous peoples is often of poor quality. This narrative review aimed to (i) identify perceived barriers for the ascertainment of Indigenous peoples on health registers, and (ii) collate strategies identified and used by health registers to support comprehensive ascertainment and high-quality data for Indigenous peoples. Methods: A Kaupapa Māori theoretical framework was utilized to guide this work. Four electronic databases were systematically searched for original articles and screened for eligibility. Studies involving health registers with Indigenous population(s) identified were included if either ascertainment or data quality strategies were described. Data extraction focused on the reporting of research involving Indigenous peoples using the CONSIDER checklist domains, ascertainment, and data quality. Results: Seventeen articles were included spanning publication between 1992 and 2020. Aspects of four of eight CONSIDER domains were identified to be included in the reporting of studies. Barriers to ascertainment were themed as relating to 'ethnicity data collection and quality', 'systems and structures', 'health services/health professionals', and 'perceptions of individual and community-level barriers'. Strategies to support ascertainment were categorized as 'collaboration', 'finding people', and 'recruitment processes'. Categorized strategies to support data quality were 'collaboration', 'ethnicity data collection and quality', 'systems-level strategies', and 'health service/health professional-level strategies'. Conclusions: Poor-quality data for Indigenous peoples in health registers prevents the achievement of health equity and exemplifies inaction in the face of need. When viewed through a critical structural determinants lens, there are visible gaps in the breadth of strategies, particularly relating to the inclusion of Indigenous peoples in health register and research governance, and actions to identify and address institutional racism. Indigenous led research, meaningful collaboration, and a sharing of knowledge and experiences between health registers is recommended to enable research and health registers that support Indigenous self-determination and health equity.

PMID: [35279132](#)

### 15. First-trimester biomarkers and the risk of cerebral palsy

Mads Langager Larsen, Gija Rackauskaite, Kasper Pihl, Peter Uldall, Gorm Greisen, Lone Krebs, Christina Engel Hoei-Hansen

Early Hum Dev. 2022 Mar 14;167:105564. doi: 10.1016/j.earlhumdev.2022.105564. Online ahead of print.

Background: Cerebral palsy (CP) is the most common severe motor disability and a manifestation of early brain damage. Aims: To analyze if abnormal levels of first-trimester biomarkers were associated with CP. Furthermore, to investigate their clinical applicability in early predicting of CP. Study design: Nationwide cohort study. Subjects: We included 258,057 singleton live births, born during 2008-2013 with completed first-trimester assessments. Outcome measures: Data on beta subunit of human chorionic gonadotropin (beta-hCG), pregnancy-associated plasma protein-A (PAPP-A), nuchal translucency thickness, and biparietal diameter (BPD) were converted to multiple of the medians (MoM). Associations were analyzed by comparing mean and extreme levels between pregnancies with and without CP. All CP diagnoses were validated by trained neuropsychiatrists. Logistic regression was used to create an early prediction model. Results: The mean beta-hCG value was significantly lower in pregnancies with CP (0.96MoM [95% CI 0.91-1.02] vs 1.04MoM [1.04-1.04],  $p = 0.01$ ) and the mean PAPP-A value tended to be lower (0.96MoM [0.91-1.01] vs 1.01MoM [1.00-1.01],  $p = 0.07$ ). Moreover, fetuses that developed CP more likely had a BPD measurement below the fifth percentile (7.5% vs 5%,  $p = 0.045$ ). The final prediction model had poor discrimination. Conclusions: Pregnancies with CP tend to have lower values of beta-hCG and PAPP-A in the first trimester, however, the associations are mediated differently. Nonetheless, abnormal levels of the most common first-trimester biomarkers only have weak associations with CP; resulting in inadequate predictive abilities when included in an early prediction model.

PMID: [35303658](#)

### 16. Unusual presentation of acute encephalopathy with biphasic seizures and late reduced diffusion in Miller-Dieker syndrome

Satoru Kobayashi, Mai Kamishima, Kyoko Yokoi, Satoshi Suzuki

Case Reports BMJ Case Rep 2022 Mar 16;15(3):e248190. doi: 10.1136/bcr-2021-248190.

Acute encephalopathy with biphasic seizures and late reduced diffusion (AESD) is a unique subtype of acute encephalopathy that occurs in children. A girl aged 2 years and 8 months with Miller-Dieker syndrome (MDS) was admitted for status epilepticus and high fever. Brain MRI performed on the third day postadmission showed abnormally high intensities in the subcortical white matter on diffusion-weighted images. Acute encephalitis/encephalopathy was diagnosed based on the electroencephalography (EEG) findings of diffuse high-voltage delta waves. Six days postadmission, frequent apnoeic episodes

were observed, with oxygen desaturation due to cluster seizures. Subclinical seizures were found on amplitude-integrated EEG (aEEG). The disturbance of consciousness was difficult to recognise because of severe developmental disabilities due to MDS. EEG aids in the evaluation of consciousness, and aEEG can be helpful in monitoring and controlling subclinical seizures in the biphasic phase of AESD, especially in patients with underlying neurological disorders.

PMID: [35296495](#)

### **17. Relationship among four functional classification systems and parent interpredicted intelligence level in children with different clinical types of cerebral palsy**

Sefa Unes, Merve Tuncdemir, Cemil Ozal, Ozge Cankaya, Kübra Seyhan Biyik, Kıvanc Delioglu, Ceren Gunbey, Mintaze Kerem Gunel, Banu Anlar

Dev Neurorehabil. 2022 Mar 18;1-7. doi: 10.1080/17518423.2022.2051629. Online ahead of print.

Objective: To investigate the relationships between four functional classification systems in children with cerebral palsy (CP) and parent-interpredicted intelligence level, and the functional status in clinical types of CP. Methods: Two hundred and twenty-five children with CP ages between 2 and 18 (mean age  $6.5 \pm 4.4$ ) years included using the Surveillance of CP in Europe (SCPE) database in Turkey. Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), Communication Function Classification System (CFCS) and Eating and Drinking Classification System (EDACS) levels were classified by clinical observation, and intelligence quotient (IQ) was determined by parent reports. Results: Correlations were found between all functional levels; the strongest were between GMFCS-MACS ( $r = 0.784, p < .001$ ), CFCS-EDACS ( $r = 0.772, p < .001$ ). Strong correlations were found for the IQ-CFCS ( $r = 0.762, p < .001$ ) and IQ-EDACS ( $r = 0.634, p < .001$ ). Correlations were stronger in children with bilateral CP and IQ level  $<70$ . Conclusions: Taken together, these four classification systems and reported IQ levels can adequately describe overall functioning for children with CP. Our results can guide clinicians in the rehabilitation of children with CP.

PMID: [35301928](#)

### **18. Rehabilitation status of children with cerebral palsy and anxiety of their caregivers during the COVID-19 pandemic**

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Objective: The purpose of the study is to explore the rehabilitation status of children with cerebral palsy (CP) and anxiety level of their caregivers during the Coronavirus disease-2019 (COVID-19) pandemic. Methods: Caregivers of children with CP who were being followed up in our outpatient CP clinic were contacted between May 28 and June 26, 2020. Two hundred and six caregivers who voluntarily agreed to participate were administered the State-Trait Anxiety Inventory and were questioned about the rehabilitation status of their children. Demographic data, other health problems, Gross Motor Function Classification System, and Manual Ability Classification System levels of children were recorded from their files. Results: All children were at home with their families during the pandemic. Their mean age was  $9.58 \pm 3.84$  years. One hundred and ninety-nine children were going to the rehabilitation center before the pandemic, only three children went to the rehabilitation center twice a week during the pandemic period. The anxiety level of all the caregivers was found to be high. Trait anxiety of the caregivers who did not perform home exercise to their children were found to be statistically significantly higher than those who performed exercise ( $p < 0.05$ ). Conclusion: Rehabilitation strategies should focus on reducing anxiety level in caregivers of children with CP and effective homecare therapy techniques should be acquired by the caregivers.

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### **19. Preparing for snow-sport events at the Paralympic Games in Beijing in 2022: recommendations and remaining questions**

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During the 2022 Winter Paralympic Games in Beijing, the Para snow-sport events will be held at high altitudes and in possibly cold conditions while also requiring adjustment to several time zones. Furthermore, the ongoing COVID-19 pandemic may lead to suboptimal preparations. Another concern is the high rate of injuries that have been reported in the Para alpine and snowboard events. In addition to these challenges, Para athletes various impairments may affect both sports-specific demands and athlete health. However, the group of Para snow-sport athletes is an understudied population. Accordingly, this perspective paper summarises current knowledge to consider when preparing for the Paralympic Games in Beijing and point out important unanswered questions. We here focus specifically on how sport-specific demands and impairment-related considerations are influenced by altitude acclimatisation, cold conditions, travel fatigue and jetlag, complications due to the COVID-19 pandemic, and injury prevention and sports safety considerations. As Para athletes with spinal cord injury, limb deficiency, cerebral palsy and visual impairment account for the majority of the Para snow-sport athletes, the focus is mainly on these impairment groups. In brief, we highlight the extra caution required to ensure athlete health, performance and sports safety among Para athletes participating in the snow-sport events in the 2022 Beijing Paralympic Games. Although there is an urgent need for more high-quality research focusing on Para winter athletes, we hope these non-consensus recommendations will help prepare for the 2022 Beijing Paralympic Winter Games.

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