

Publikationslista MMCUP

Vetenskapliga publikationer:

1. Alriksson-Schmidt A, Lundkvist Josenby A, Lindquist B, Westbom L. Pain and health status in adults with myelomeningocele living in Sweden. (Accepterad för publikation i Journal of Pediatric Rehabilitation Medicine 2018).
2. Bodin CR, Rasmussen MM, Tabor A, Westbom L, Tiblad E, Ekelund CK, Wulff CB, Vogel I, Petersen OB. Ultrasound in Prenatal Diagnostics and Its Impact on the Epidemiology of Spina Bifida in a National Cohort from Denmark with a Comparison to Sweden. *Biomed Res Int.* 2018 Feb 1;2018:9203985.
3. Alriksson-Schmidt A, Arner M, Westbom L, Krumlinde-Sundholm L, Nordmark E, Rodby-Bousquet E, Hägglund G. A combined surveillance program and quality register improves management of childhood disability. *Disabil Rehabil.* 2017; 39:830-6.
4. Persson M, Janeslätt G, Peny-Dahlstrand M. Daily time management in children with spina bifida. *J Pediatr Rehabil Med.* 2017; 10: 295–302.
5. Thibadeau J, Reeder MR, Andrews J, Ong K, Feldkamp ML, Rice S, Alriksson-Schmidt A. Understanding the Natural Progression of Spina Bifida: Prospective Study. *JMIR Res Protoc.* 2017 Sep 14;6(9):e180. doi: 10.2196/resprot.7739.
6. Vu Minh Arnell M, Abrahamsson K. Urinary continence appears to enhance social participation and intimate relations in adolescents with myelomeningocele. Submitted.
7. Alriksson-Schmidt AI, Thibadeau JK, Swanson ME, Marcus D, Carris KL, Siffel C, Ward E. The natural history of spina bifida in children pilot project: research protocol. *JMIR Res Protoc.* 2013 Jan 25;2(1):e2. doi: 10.2196/resprot.2209.
8. Alriksson-Schmidt A. Transition in young people with myelomeningocele. *Dev Med Child Neurol.* 2011 Jul;53(7):581-2. doi: 10.1111/j.1469-8749.2011.03945.x. Epub 2011 Mar 21. PubMed PMID: 21418203.
9. Burström K, Bartonek Å, Broström EW, Sun S, Egmar AC. EQ-5D-Y as a health-related quality of life measure in children and adolescents with functional disability in Sweden: testing feasibility and validity. *Acta Paediatr.* 2014; 103:426-35.
10. Vu Minh Arnell M, Seljee Svedberg K, Lindehall B, Möller A, Abrahamsson K. Health-related quality of life compared to life situation and incontinence in adults with myelomeningocele: Is SF-36 a reliable tool? *J Pediatr Urol.* 2013; 9:559-66.
11. Vu Minh Arnell M(1), Seljee Svedberg K, Lindehall B, Möller A, Abrahamsson K, Peny-Dahlstrand M, Krumlinde Sundholm, L, Gosman-Hedström G. Patterns of participation in school-related activities and settings in children with spina bifida. *Disabil Rehabil.* 2013; 35:1821-7.

12. Donlau M, Mattsson S, Glad-Mattsson G. Children with myelomeningocele and independence in the toilet activity: a pilot study. *Scand J Occup Ther.* 2013 Jan;20(1):64-70.
13. Nilsson D, Svensson J, Korkmaz BA, Nelvig H, Tisell M. Decreased head circumference in shunt-treated compared with healthy children. *J Neurosurg Pediatr.* 2013; 12:483-90.
14. Mattsson S, Dahl M, Olsson I, Wendelius M, Westbom L, Åström E. A Swedish national follow-up programme for children and adolescents with myelomeningocele. *Cerebrospinal Fluid Res* 2009;6:S43.
15. Olsson I, Dahl M, Mattsson S, Wendelius M, Åström E, Westbom L. Medical problems in adolescents with myelomeningocele (MMC): an inventory of the Swedish MMC population born during 1986-1989. *Acta Paediatr.* 2007 96:446-9.

Artiklarna 1-3 och 15 grundas på MMCUP registerdata. Artiklarna 5 och 7 handlar om Spina Bifida-registret vid CDC i USA, som vi samrätt med under uppbyggnaden av MMCUP och där Ann Alriksson-Schmidt har deltagit i båda registren. Övriga artiklar redogör för utveckling och prövning av instrument och variabler under utformning av uppföljning vid MMC och för inmatningsformulär i MMCUP .

Abstracts presenterade/accepterade 2017 till internationella kongresser:

1. Forsgren M, Alriksson-Schmidt A, Lundkvist Josenby A, Ståhl N, Westbom L. Myelomeningocele in Sweden: Survival and causes of death in two cohorts over ten-years. Free paper oral presentation vid AACPD (American Academy for Cerebral Palsy and Developmental Disabilities), Cincinnati, USA, oktober 2018.
2. Lundkvist-Josenby A, Alriksson-Schmidt A, Westbom L. The Swedish Myelomeningocele Follow-Up Program (MMCUP). 3rd World Congress on Spina Bifida San Diego USA 16-20 mars 2017. *J Pediatr Rehabil Med: An Interdisciplinary Approach* 2017; 10 (S1): S 41.
3. Alriksson-Schmidt A, Lundkvist-Josenby A, Lindquist B, Westbom L. Adults with myelomeningocele living in southern Sweden – How are we doing? 3rd World Congress on Spina Bifida San Diego USA 16-20 mars 2017. *J Pediatr Rehabil Med: An Interdisciplinary Approach* 2017; 10 (S1): S 99.
4. Alriksson-Schmidt A, Lundkvist-Josenby A, Lindquist B, Westbom L. Pain and health status in adults with myelomeningocele living in southern Sweden. 3rd World Congress on Spina Bifida San Diego USA 16-20 mars 2017. *J Pediatr Rehabil Med: An Interdisciplinary Approach* 2017; 10 (S1): S 64-65.
5. Bondjers L, Abrahamsson K, Vu Minh Arnell M, Olsson I. Four Cohorts of Adolescents with Myelomeningocele from Western Sweden. 3rd World Congress on Spina Bifida San Diego USA 16-20 mars 2017. *J Pediatr Rehabil Med: An Interdisciplinary Approach* 2017; 10 (S1): S 100.
6. Lindquist B, Jacobson H, Strinnholm M, Peny-Dahlstrand M. Cognition in Spina Bifida and its Consequences in Daily Life – A Life-span Perspective. A Systematic Review. 3rd World

Congress on Spina Bifida San Diego USA 16-20 mars 2017. J Pediatr Rehabil Med: An Interdisciplinary Approach 2017; 10 (S1): S 78.

7. Peny-Dahlstrand M, Bergqvist L, Hofgren C, Öhrvall A-M. Can the Cognitive Orientation to Daily Occupational Performance (CO-OP) Approach Enhance Executive Functions and Participation in Young Adults with Spina Bifida – A Multiple Case Study. 3rd World Congress on Spina Bifida San Diego USA 16-20 mars 2017. J Pediatr Rehabil Med: An Interdisciplinary Approach 2017; 10 (S1): S 79.
8. Peny-Dahlstrand M. A Model for the Process of Task Performance to Explain Difficulties in Daily Life in Persons with Spina Bifida. 3rd World Congress on Spina Bifida San Diego USA 16-20 mars 2017. J Pediatr Rehabil Med: An Interdisciplinary Approach 2017; 10 (S1): S 25.
9. Persson M, Janeslätt G, Peny-Dahlstrand M. Daily time management in children with spina bifida. 3rd World Congress on Spina Bifida San Diego USA 16-20 mars 2017. (Ej publicerad med övriga abstracts, eftersom studien var inskickad för bedömning i annan tidskrift)
10. Gimeno, H, Novak I, Polatajko H, Öhrvall A-M, Peny-Dahlstrand M. Can the CO-OP Approach™ be beneficial for young adults with spina bifida or cerebral palsy. Using Cognitive training (CO-OP Approach) as a rehabilitative tool for children with neurodevelopmental disorder including cerebral palsy, instructional course. 71 Annual Meeting the AACPD, Montreal Canada, 13–16 september 2017.
11. Vu Minh Arnell M, Abrahamsson K. Urinary continence appears to enhance social participation and intimate relations in adolescents with myelomeningocele. Poster och muntlig presentation vid ESPU (European Society for Paediatric Urology), Barcelona, Spanien 19-22 April 2017

Abstracts 1-5 grundas på data från registret, nummer 6 är en översiktsartikel som ligger till grund för kognitionsuppföljningen i MMCUP uppföljningsprogram och de variabler som valts till kvalitetsregistret. I studierna rapporterade i abstracts 7-11 har olika variabler och instrument prövats och utgör underlag för inmatningsformulär i MMCUP. Population och andra uppgifter i MMCUP-registret har också används för planering av studierna.