

List of Peer-Reviewed Publications Resulting from the Projects of the National Population Health Study of Neurological Conditions

Note: At the time this list was posted (March 2015), several researchers had publications in the review stage and/or were in the process of preparing manuscripts for submission.

National Surveys	
1	Findings from the Canadian Community Health Survey (2010-2011)
2	Survey on Living with Neurological Conditions in Canada
3	Survey of Neurological Conditions in Institutions in Canada
Pan Canadian Research Projects	
4	Neurological Conditions in British Columbia
5	<p>Expansion of a Canadian Multi-Regional Population-Based Cerebral Palsy Registry</p> <ul style="list-style-type: none"> • Benini, Ruba, Lynn Dagenais, and Michael I. Shevell. "Normal imaging in patients with cerebral palsy: What does it tell us?" <i>The Journal of Pediatrics</i>. Feb;162(2):369-74. • Dufresne D, Dagenais L, Shevell MI. Prevalence and characteristics of severe sensory impairment in a population-based cohort of children with cerebral palsy. <i>Ann Neurol</i> 72 (Suppl): S186, 2012. • Goia E, Oskoui M, Williams E, Shevell MI, Kirton A. Placental pathology and arterial perinatal stroke. <i>Can J Neurosci</i> Volume 41 Number 3 (Supplement 1) May 2014. • Hall N, Dagenais L, Birnbaum R, Dumas F, Gosselin J, Koclas L, Majnemer A, Shevell MI. Communicating a diagnosis of cerebral palsy: An analysis of caregiver satisfaction and stress. <i>Ann Neurol</i> 58 (Suppl 9): S112, 2005. • Kirton A. Modeling developmental plasticity after perinatal stroke: Defining central therapeutic targets in cerebral palsy. <i>Ped Neurol</i> 2013, 48(2):81-94. • Kyriakopoulos P, Oskoui M, Dagenais L, Shevell MI. Term neonatal encephalopathy antecedent cerebral palsy: a retrospective population-based study. <i>Eur J Paediatr Neurol</i>. 2013 May;17(3):269-73. • Kryiakopoulos P, Oskoui M, Dagenais L, Shevell MI. Term neonatal encephalopathy antecedent cerebral palsy: A population-based analysis. <i>Dev Med Child Neurol</i> 54 (Suppl 4): 153-154, 2012. • Kyriakopoulos, Paulina, Maryam Oskoui, Lynn Dagenais, and Michael I. Shevell. "Does antenatal tobacco or alcohol exposure influence a child's cerebral palsy? A population-based study." <i>Pediatric Neurology</i>. 47.5. Nov. 2012: 349-54. • Oskoui M, Coutinho F, Dykeman J, Jetté N, Pringsheim T. An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. <i>Dev. Med. Child Neurol</i>. 2013 Jun;55(6):509-19. • Oskoui M, Joseph L, Dagenais L, Shevell M. Prevalence of cerebral palsy in Quebec: alternative approaches. <i>Neuroepidemiology</i>. 2013;40(4):264-8. • Oskoui M, Majnemer A, Dagenais L, Shevell MI. The relationship between gross

	<p>motor function and manual ability in cerebral palsy. <i>J Child Neurol</i>. 2013 Dec;28(12):1646-52.</p> <ul style="list-style-type: none"> • Self, Lauren, Lynn Dagenais, and Michael Shevell. " Congenital non-central nervous system malformations in cerebral palsy: a distinct subset?" <i>Developmental Medicine & Child Neurology</i>. 54. May 2012: 748-52. • Shevell MI, Dagenais L, Hall N, REPACQ. The relationship of cerebral palsy subtype & functional motor impairment: A population based study. <i>Ann Neurol</i> 64(Suppl 12): S103, 2008. • Shevell M, Dagenais L, Oskoui M. The epidemiology of cerebral palsy: new perspectives from a Canadian registry. <i>Semin. Pediatr. Neurol</i>. 2013 Jun;20(2):60-4. • Shevell A, Wintermark P, Benini R, Shevell M, Oskoui M. Chorioamnionitis and cerebral palsy: Lessons from a patient registry. <i>Eur J Paediatr Neurol</i>. 2014 Jan 2. pii: S1090-3798(13)00210-9. • Solaski M, Majnmer A, Oskoui, M. Contribution of socioeconomic status on the prevalence of cerebral palsy: a systematic search and review. <i>Dev Med Child Neurol</i>. 2014 Apr 19; 1-9 • Towsley K, Shevell MI, Dagenais L & REPACQ. A population based study of neuroimaging findings in children with cerebral palsy. <i>Ann Neurol</i> 68(Suppl 14): S106, 2010. • Zhang J, Oskoui M, Shevell MI. A population based study of communication impairment in cerebral palsy. <i>Ann Neurol</i> 74 (Suppl 17): S138, 2013. • Zhang J, Oskoui M, Shevell MI. A population-based study of communication impairment in cerebral palsy. <i>J Child Neurol</i> 2014 July 22; 1-8.
6	<p>Canadian Longitudinal Study on Aging: Neurological Conditions Initiative</p> <ul style="list-style-type: none"> • Keezer MR, Bouma HK, Wolfson C. The diagnostic accuracy of screening questionnaires for the identification of adults with epilepsy: a systematic review. <i>Epilepsia</i>. 2014 Nov;55(11):1772-80. • Keezer MR, Pelletier A, Stechysin B, Veilleux M, Jetté N, Wolfson C. The diagnostic test accuracy of a screening questionnaire and algorithm in the identification of adults with epilepsy. <i>Epilepsia</i>. 2014 Nov;55(11):1763-71.
7	<p>Canadian Primary Care Sentinel Surveillance Network – Neurodegenerative Conditions</p>
8	<p>Use and Gaps in Health and Community Based Services for Neurological Populations: A Systems Analysis</p> <ul style="list-style-type: none"> • Jaglal et al. Development of a Chronic Care Model for Neurological Conditions (CCM-NC). <i>BMC Health Services Research</i> 2014 14:409.
9	<p>Innovations in Data, Evidence and Applications for Persons with Neurological Conditions</p> <ul style="list-style-type: none"> • Costa A, Poss JW, Peirce T, Hirdes JP. Acute care inpatients with long-term delayed-discharge: evidence from a Canadian health region. <i>BMC Health Services Research</i>, 2012;12:172. • Danila O, Hirdes JP, Maxwell CJ, Marrie RA , Patten SB, Pringsheim T, Jetté N. Prevalence of Neurological Conditions across the Continuum of Care Based on interRAI Assessments. <i>BMC Health Services Research</i>, 2014;42(1):16-24. • Foebel AD, Hirdes JP, Heckman GA, Kergoat MD, Patten SB, Marrie, RA. Diagnostic Data for Neurological Conditions in Standardized Assessments in Home Care, Nursing Home and Mental Health Care Settings: A Validity Study. <i>BMC Health Services Research</i>, 2013 (13) 457.

	<ul style="list-style-type: none"> • Hirdes JP, Poss JW, Mitchell L, Korngut L, Heckman GA. Use of the interRAI CHES Scale to Predict Mortality among Persons with Neurological Conditions in Three Care Settings. <i>PLoS One</i>. 2014 Jun 10;9(6). • Kehyayan V, Korngut L, Jetté N and Hirdes JP. Profile of patients with amyotrophic lateral sclerosis across the continuum of care in Canada: a population-based study. <i>Can J Neurol Sci</i> 2014 March;41(2):246-252. • Maher A, Ioannidis G, Jantzi M, Hirdes JP, Giangregorio L, Papaioannou A. Individuals with neurological diseases are at increased risk of fracture within 180 days of admission to long-term care in Canada. <i>Age & Ageing</i>, 2015 Mar;44(2):252-7. • Martin L. Re-examining the relationship between intellectual disability and receipt of inpatient psychiatry and complex continuing care services in Ontario (Canada). <i>International Journal of Developmental Disabilities</i> Volume 60, Issue 2 (April 2014), pp. 65-79. • Maxwell CJ, Vu M, Hogan DB, Patten SB, Jantzi M, Kergoat MD, Jetté N, Bronskill SE, Heckman GA, Hirdes JP. Patterns and Determinants of Dementia Pharmacotherapy in a Population-Based Cohort of Home Care Clients. <i>Drugs & Aging</i> 2013 Jul;30(7):569-585. • Vu M, Hogan DB, Patten S, Jetté N, Bronskill SE, Heckman GA, Kergoat MD, Hirdes JP, Chen J, Zehr M, Maxwell CJ. A comprehensive profile of the sociodemographic, psychosocial and health characteristics of Ontario home care clients with dementia. <i>Chronic Dis Inj Can</i>. 2014 Jul;34(2-3):132-44.
10	<p>The Everyday Experience of Living with and Managing a Neurological Condition</p> <ul style="list-style-type: none"> • Audulv A, Packer T, Versnel J. Identifying gaps in knowledge: A map of the qualitative literature concerning life with a neurological condition. <i>Chronic Illn.</i> 2014 Aug 1;10(3):192-243. • Packer T, Kephart G, Ghahari S, Audulv A, Versnel J, Warner G. (2015). The Patient Activation Measure: a validation study in a neurological population. <i>Quality of Life Research</i>. Online DOI 10.1007/s11136-014-0908-0 • Roger K, Wetzel M, Hutchinson S, Packer T, Versnel J. (2014). "How can I still be me?": Strategies to maintain a sense of self in the context of a neurological condition. <i>International Journal of Qualitative Studies on Health and Well-Being</i>. 9(23): 534. • Versnel J, Packer T, Weeks LE, Brown J, Godwin M, Hutchinson S, Kephart G, MacKenzie D, Roger K, Stadnyk R, Villeneuve M and Warner G: Study protocol: The everyday experience of living with and managing a neurological condition (the LINC study): study design. <i>BMC Neurology</i> 2013,13:30. • Warner G, Packer T, Villeneuve M, Audulv A, Versnel J. (2015). A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors. <i>Disability and Rehabilitation, Early</i>. online: 1-23. • Weeks L, Villeneuve M, Hutchinson S, Roger K, Versnel J, Packer T. (in press). What we learned about mentoring research assistants employed with a complex mixed methods health study. <i>Canadian Journal of Higher Education</i>.
11	<p>Understanding from Within: Developing Community-Driven and Culturally Relevant Models for Understanding and Responding to Neurological Conditions among Aboriginal People</p>

12	<p>Validation of Administrative Data Algorithms to Determine Population Prevalence and Incidence of Alzheimer's Disease and Other Dementias, MS, Epilepsy and Parkinson's Disease (Parkinsonism)</p> <ul style="list-style-type: none"> • Butt D, Tu K, Young J, Green D, Wang M, Ivers N, Jaakkimainen L, lam R, Guttman M. A Validation Study of Administrative Data Algorithms to Identify Patients with Parkinsonism with Prevalence and Incidence Trends. <i>Neuroepidemiology</i>, 2014;43(1):28-37. • Krysko, KM, Ivers NM, Young J, O'Connor P, Tu K, Identifying individuals with multiple sclerosis in an electronic medical record. <i>Mult Scler</i>. 2015 Feb;21(2):217-24. • Tu K, Wang M, Jaakkimainen L, Butt D, Ivers NM, Young J, Green D and Jetté N. Assessing the validity of using administrative data to identify patients with epilepsy. <i>Epilepsia</i> 2014 Feb;55(2)335-342. • Widdifield J, Bombardier C, Bernatsky S, Paterson JM, Green D, Young J, Wang M, Ivers N, Butt D, Jaakkimainen L, Thorne JC, Tomlinson G, Ahluwalia V, Tu K. An administrative data validation study of the accuracy of algorithms for identifying Rheumatoid Arthritis: The influence of the reference standard on algorithm performance. <i>BMC Musculoskeletal Disorders</i> 2014 Jul; 23(15)216.
13	<p>Systematic Review of Factors Influencing the Onset of Neurological Conditions</p>
14	<p>Systematic Review of Factors Influencing the Progression of Neurological Conditions</p>
15	<p>Neurological Registry Best Practice Guidelines and Implementation Toolkit</p> <ul style="list-style-type: none"> • Hamilton M, Genge A, Johnston M, Lam D, Mobach T, Marriott J, et al. Patient Recruitment by Neurological Registries. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S23-6. • Hogan D, Warner J, Patten S, Godlovitch G, Mehina E, Dagenais L, et al. Ethical and Legal Considerations for Canadian Registries. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S5-22. • Jette N, Atwood K, Hamilton M, Hayward R, Day L, Mobach T, et al. Linkage Between Neurological Registry and Administrative Data. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S32-34. • Jette N, Johnston M, Pringsheim T, Korngut L. The Case for Neurological Registry Best Practice Guidelines in Canada. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S1-3. • Johnston M, Campbell C, Godlovitch G, Day L, Wysocki J, Dagenais L, et al. Online Neurological Registries. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S41-45. • Johnston M, Campbell C, Hayward R, Lowerison M, Noonan VK, Pfister T, et al. Registry Data Storage and Curation. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S35-40. • Korngut L, Johnston M, Pringsheim T and Jetté N. The future of neurological patient registries. <i>Clin Pract</i> Vol. 11, No. 5, Pages 509-516. • Korngut L, MacKean G, Casselman L, Johnston M, Day L, Lam D et al. Perspectives on Neurological Patient Registries: A literature review and focus group study. <i>BMC Medical Research Methodology</i> 2013 Nov 9;13(1):135. • Mah JK, Warner J, Hall R, Smith E, Steeves T, Donner E, et al. Evaluation of Neurological Patient Registries. Canadian Journal of Neurological Sciences. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S60-61. • Marriott J, Noonan VK, Donner E, Lowerison M, Lam D, Day L, et al. Neurological

	<p>Registry Quality Control and Quality Assurance. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S47-50.</p> <ul style="list-style-type: none"> • Pringsheim T, Lam D, Day L, Genge A, Hogan DB, Shevell M, et al. Validation and Interpretation of Neurological Registry Data. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S51-53. • Pringsheim T, Marrie RA, Donner E, Shevell M, Lam D, Day L, et al. Neurological Registry Feasibility and Sustainability. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S55-59. • Smith E, Warner J, Johnston M, Atwood K, Hall R, Mah JK, et al. Neurological Registry Data Collection Methods and Configuration. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S27-31. • Warner J, Johnston M, Korngut L, Jette N, Pringsheim T. Common Data Elements for Neurological Registries. <i>Can J Neurol Sci</i> 2013 Jul;40(4 Suppl 2):S62-63.
16	<p>Understanding the Epidemiology of Neurological Conditions and Building the Methodological Foundation for Surveillance</p> <ul style="list-style-type: none"> • de Robles P, Fiest KM, Frolkis AD, Pringsheim TM, Atta C, St.Germaine-Smith C, Day L, Lam D and Jetté N. The worldwide incidence and prevalence of primary brain tumours: A systematic review and meta-analysis. <i>Neuro Oncol</i>. 2014 Oct 13. • Evans C, Beland SG, Kulaga S, Wolfson C, Kingwell E, Marriott J, Koch M, Makhani N, Morrow S, Fisk J, Dykeman J, Jetté N, Pringsheim T and Marrie RA. Incidence and prevalence of multiple sclerosis in the Americas: a systematic review. <i>Neuroepidemiology</i> 2013 Jan 24;40(3):195-210. • Fiest KM, Pringsheim T, Patten SB, Svenson LW and Jetté N. The role of systematic reviews and meta-analyses of incidence and prevalence studies in neuro-epidemiology. <i>Neuroepidemiology</i> 2014;42(1):16-24. • Kingwell E, Marriott JJ, Jetté N, Pringsheim T, Makhani N, Morrow S, Fisk J, Evans C, Beland SG, Kulaga S, Dykeman J, Wolfson C, Koch MW, Marrie RA. Incidence and prevalence of multiple sclerosis in Europe: a systematic review. <i>BMC Neurology</i> 2013 Sept 26;13(1):128. • Knight T, Steeves T, Day L, Lowerison M, Jetté N and Pringsheim T. The prevalence of tic disorders: A systematic review. <i>Pediatr Neurol</i> 2012 Aug;47(2):77-90. • Mah JK, Korngut L, Dykeman J, Day L, Pringsheim T and Jetté N. A systematic review and meta-analysis on the epidemiology of Duchenne and Becker muscular dystrophy. <i>Neuromuscular Disord</i> 2014 Jun;24(6):482-491. • Makhani N, Morrow S, Fisk J, Evans C, Beland SG, Kulaga S, Kingwell E, Marriott J, Dykeman J, Jetté N, Pringsheim T, Wolfson C, Marrie RA and Koch M. MS incidence and prevalence in Africa, Asia, Australia and New Zealand: A systematic review. <i>Multiple Sclerosis and Related Disorders</i>, Volume 3, Issue 1, 48 – 60. • Oskoui M, Coutinho F, Dykeman J, Jetté N and Pringsheim T. An update on the prevalence of cerebral palsy: A systematic review and meta-analysis. <i>Dev Med Child Neurol</i> 2013 Jun;55(6):509-519. • Pringsheim T, Fiest K and Jetté N. The international incidence and prevalence of neurological conditions – How common are they? <i>Neurology</i> 2014 Oct;83(18):1661-1664. • Pringsheim T and Jetté N. Prevalence estimates of Huntington's disease in Caucasian populations are gross underestimates. Reply to letter. <i>Mov Disord</i> 2012 Nov;27(13):1708-1709. • Pringsheim T, Jetté N, Frolkis A, Lam D and Steeves T. The prevalence of Parkinson's disease: A systematic review and meta-analysis. <i>Mov Disord</i> 2014 Nov;29(13):1583-1590. • Pringsheim T, Wiltshire K, Day L, Dykeman J, Steeves T and Jetté N. The

	<p>incidence and prevalence of Huntington Disease: A systematic review and meta-analysis. <i>Mov Disord</i> 2012 Aug;27(9):1083-91.</p> <ul style="list-style-type: none"> • Steeves T, Day L, Dykeman J, Jetté N and Pringsheim T. The prevalence of primary dystonia: A systematic review and meta-analysis. <i>Mov Disord</i> 2012 Dec;27(14):1789-1796. • St.Germaine-Smith C, Metcalfe A, Pringsheim T, Roberts J, Beck C, Hemmelgarn B, McChesney J, Quan H and Jetté N. Recommendations for optimal ICD codes to study neurological conditions: A systematic review. <i>Neurology</i> 2012 Sept 3;79(10):1049-55. • St.Germaine-Smith C, Metcalfe A, Pringsheim T, Roberts J, Beck C, Hemmelgarn B, McChesney J, Quan H and Jetté N. What are the best diagnostic codes to identify neurological conditions in population-based administrative health data? An international systematic review of validation studies. <i>Neurology</i> 2012 Sept 3;79(10):1049-55.
National Surveillance Expansion	
17	Expansion of the Canadian Chronic Disease Surveillance System for National Surveillance of Neurological Conditions
Microsimulation Project	
18	National Population Health Study of Neurological Conditions Microsimulation Component: Health and Economic Modelling of Neurological Conditions