Rick Hansen Institute
Institut Rick Hansen

A world without paralysis after spinal cord injury

Health Economics

Agenda for SCI Research in Canada

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The Rick Hansen Institute (RHI) in collaboration with the Ontario Neurotrauma Foundation (ONF) is supporting the development and implementation of a health economics agenda for spinal cord injury (SCI) research in Canada. In recognition of RHI's core programs, concurrent Canadian SCI Network member-led initiatives, and the paucity of empirical health economic evidence in the field of SCI, the intent is to lead collaboration between individuals and organizations with relevant experience, expertise, and influence (e.g., healthcare professionals, health system managers and administrators, consumers and consumer advocacy organizations, payers, health policy- and other decision-makers, health technology and service innovators, funding agencies, researchers, implementation scientists, health economists) to establish evidence of the burden of SCI and the costs and consequences of initiatives aimed at mitigating the burden. To extend a notion introduced to researchers in the field of SCI [1–3], a collective health economic research agenda can lead to the establishment of empirical evidence to inform clinical and system level decisions in SCI as well as help to ensure due consideration in the allocation of healthcare and research funding. Implementation of a collective SCI research agenda will also support the translation of ideas and SCI research (basic science, pre-clinical, and clinical research) into practice and policy to benefit people with SCI and the healthcare system.

In support of RHI's vison and mission, the health economics agenda for SCI research in Canada will direct economic research in SCI to:

- Increase the breadth, quality, and applicability of health economic analyses in the field of SCI
- Inform and encourage decisions concerning the care of individuals with SCI in Canada
- Support Canadian SCI Network initiatives, including initiatives to expand the implementation of evidence-informed practices and support health technology and service innovation to prevent excess healthcare costs and protect and promote the well-being of individuals with SCI, their families, and supporters

Leveraging Existing Resources

The agenda emphasizes the importance of leveraging the expertise and experience in RHI and ONF's national network in SCI research and care as well as stakeholder engagement to develop relevant agenda actions. Short-term actions are largely directed by the demand for information to support the SCI expert-informed RHI CARE, CURE, and Commercialization programs [4–6].
To ensure continued success, universal application of established standards for health economic analysis as well as engagement of consumers (individuals with SCI, their families, and supporters) and other decision-makers at the individual, organizational, regional, provincial, and national levels is necessary. Endorsement of standards with consideration of the challenges and nuances specific to research in the field of SCI is expected to result in greater accessibility and application of appropriate health economic methodologies. This, in turn, will enable greater comparability of evidence for decision-making.

The Value of Economic Analysis

A dominant concern within Canada's publicly funded healthcare system is the allocation of limited resources. Although there are several important pieces to the Canadian healthcare puzzle, economic analysis is an accepted and effective method for generating information to inform decisions. Economic research methodologies and techniques can serve to illustrate the burden of SCI, including the direct and indirect cost of secondary health conditions, and establish evidence of the costs and consequences of initiatives aimed at mitigating the burden of SCI and secondary conditions. The former has the potential to encourage action and direct future research, while the latter can inform decisions concerning the care of individuals with SCI. In the absence of robust evidence of the economic burden of secondary health conditions – a leading determinant of the lifetime cost of SCI [7] – and the value of initiatives aimed at mitigating the burden, there is greater potential for under investment and/or misplaced investment in evidence-informed best practice implementation and health technology and service innovation in SCI. It is important to acknowledge that decisions in healthcare are not necessarily influenced by evidence of clinical or cost-effectiveness alone. They may involve a balance between empirical evidence, preferences, experiences, emotions, politics, and other factors [8].

Mitigating the Burden of SCI

The initial agenda actions are intended to establish baseline evidence of the burden of secondary health conditions experienced by individuals with SCI. Notable conditions include pressure ulcers, urinary tract infections, respiratory conditions, and neuropathic pain. Evidence of the burden of secondary health conditions will enable comparative economic analyses to inform decisions. It is expected that the application of cost-utility and benefit-cost analysis will lead to more informed healthcare decisions, however the burden represents the benefits potentially realized through the translation of evidence-informed practices and innovations in the prevention and management of secondary conditions. Therefore, evidence of the burden of secondary conditions is considered a prerequisite for decision-informing health economic analysis. Furthermore, it is expected that an understanding and appreciation of decision influences and constraints will assist in the establishment of actionable evidence in SCI.

Evidence of the burden of secondary health conditions or the benefits of averting secondary conditions in Canadian SCI populations is limited. It should therefore come as no surprise that empirical evidence of the relative costs and consequences of initiatives aimed at mitigating the burden is limited [9]. The breadth and quality of cost-effectiveness evidence in SCI is also largely dependent on that of clinical-effectiveness evidence. The small size of the SCI population compared to other disease and disability groups significantly limits the number of potential research participants. This inherent limitation is a barrier to assessing the clinical and cost-effectiveness of health technologies and services (preventative, diagnostic, therapeutic, and other) with application to SCI.

The Challenges

There are additional factors that are expected to contribute to the paucity of cost-effectiveness evidence in SCI, including limited knowledge of and access to economic data in the field - both of which are required to assess the costs and consequences of initiatives aimed at mitigating the burden of SCI and secondary conditions. Prospective clinical research efforts in SCI have largely focused on the efficacy and safety of emerging interventions and innovations to inform clinical practice but have failed to effectively assess incremental costs and consequences. Neglecting economic parameters during the research design can result in disappointment and/or unanticipated costs if it is later determined that economic assessment is required. Although there are advantages to retrospective analysis, there are also significant challenges in extracting detailed patient level information from administrative records. Administrative databases also typically fail to capture important parameters necessary for comparative health economic analysis (e.g., longitudinal healthcare resource utilization and expenditure data,

patient reported outcome measures, intervention and therapeutic details). Furthermore, although healthcare professionals generally agree on the clinical significance of an integrated continuum of SCI care, there is an apparent failure to adequately integrate data collected across the care continuum. It is believed that this is partially responsible for the insufficiency of cost-effectiveness evidence in SCI.

Implementing Standards

There is also a limited understanding and application in SCI of economic principals and standards for health economic analysis. There are existing guidelines describing standard methodologies and criteria for health economic analysis and reporting[10–14]; however, they are not consistently applied in the field of SCI. Increased confidence in the conclusions of comparative economic analyses is an expected benefit of more widely integrated standards in SCI research. As Mittmann *et al* [15] demonstrate, there is also value in providing domain specific methodological guidance within existing standards for economic analysis. Without universal adoption of standards for economic analysis, the quality of evidence is expected to suffer. An opportunity to enable more informed discussions of the costs and consequences of initiatives believed to be of benefit to individuals with SCI and the healthcare system may also be missed.

Collaboration is Key

Collaboration between dedicated experts with knowledge in SCI and health economics is required to operationalize the agenda. Canadian SCI Network initiatives at the regional and provincial levels will continue to provide opportunities to address gaps in knowledge. RHI and ONF will continue to support the development of partnerships and applied health economic research to establish evidence and inform decisions at the individual, organizational, regional, and provincial levels. RHI and ONF will also continue to develop a national plan of action and capacity for clinical and health economic research.

Supporting Actionable Evidence

A health economics agenda for SCI will allow RHI and ONF to directly support the establishment of actionable evidence. Endorsement of standards for health economic analysis with consideration of the challenges and nuances specific to SCI research will increase the accessibility of economics in the field of SCI and empower the larger SCI research community to undertake high-quality economic analyses. Consequently, the breadth, reliability, defensibility, and comparability of cost-effectiveness evidence in SCI will increase and decision-makers will be better informed.

Leveraging Opportunities

There is currently a demand for applied health economic research in the field of SCI and an anticipated increase in demand. Because of this, effort will be directed to engage health economists as well health policy analysts, healthcare professionals, health technology and service innovators, researchers, and health policy- and other decision-makers worldwide. National collaboration is expected to increase the consistency of data and a Canada-wide health economics agenda for SCI will leverage the strengths, resources and opportunities within the Canadian SCI Network.

Finally, continued development of the Rick Hansen Spinal Cord Injury Registry (RHSCIR) [16], the RHI Access to Care and Timing (ACT) patient simulation and health economic model [17,18], and SCI informatics activities present unique opportunities to:

- Conduct applied health economic research in SCI
- Lead the establishment of evidence to inform decisions
- Help guide future initiatives in SCI research and care

In Summary

The health economics agenda for SCI involves applied research to fill described gaps in knowledge as well as promotion of standards or functional guidelines for health economic analysis within the context of SCI. It integrates economic methods and techniques in the assessment of evidence-informed best practices and innovative health technologies and services with application to SCI.
Steps to address the lack of empirical evidence and inform decisions concerning the care of individuals with SCI in Canada include:

1) Establish robust evidence of the burden of secondary health conditions and initiatives aimed at mitigating the burden

- Alignment of health economic research actions or activities to described gaps in knowledge to support existing RHI and ONF programs, strategies, and initiatives
- Synthesis (environmental scan, systematic review, rapid review, etc.) of literature and ongoing research in the Canadian SCI Network related to the burden of secondary conditions and the cost-effectiveness of initiatives with application to SCI
- Review of existing evidence-informed practices in the prevention and management of notable secondary conditions as well as emerging health technologies and services with application to SCI
- Identification and assessment of opportunities to increase the utility of the RHI Access to Care and Timing (ACT) model to predict the costs and consequences of initiatives with application to SCI
- Application of standards for measuring the burden of secondary conditions and the direct and indirect costs and consequences of initiatives aimed at mitigating the burden
- Continued support of ongoing health economic research in British Columbia and Ontario to establish evidence of the burden of pressure ulcers experienced by individuals with SCI during initial inpatient stay and following return to community-living
- Continued pursuit and assessment of opportunities (partnerships, resource utilization and cost data sources, and data linkages) to establish evidence of the burden of pressure ulcers and other notable secondary conditions

2) Promote the integration of established Canadian standards for health technology assessment

- Endorsement of the CADTH guidelines for economic evaluation of health technologies
- Documentation and assessment of applicable demographic, diagnosis, intervention, resource utilization, cost, and patient outcome data maintained in clinical, regional, provincial, and national administrative databases
- Recommendation of standards or flexible guidelines for measuring the costs of initiatives aimed at mitigating the burden of secondary conditions and the direct and indirect benefits to individuals (including patient reported outcome measures), care providers, and the healthcare system from preventing, mitigating the severity, and/or improving the healing rate of notable secondary conditions
- Engagement of stakeholders and decision-makers at different levels to determine the forms of evidence or information metrics expected to influence or assist decisions concerning the care of individuals with SCI
- Assessment of perceived barriers to encouraging action through health economic analysis

3) Support the application of appropriate methodologies for comparative health economic analysis of evidence-informed best practices and innovative health technologies and services with application to SCI

- Development of a model for providing health economic research support to members of the Canadian SCI Network
- Development of health economic research capacity through continued student and trainee support, mentorship, stakeholders engagement, pursuit of administrative data and data linkages, and further consideration of services offered by organizations and institutions specializing in environmental scans and rapid reviews of preventative and therapeutic technologies and services

References

1. Angevine, P.D., and Berven, S. (2014). Health economic studies: An introduction to cost-benefit, cost-effectiveness, and cost-utility analyses. Spine 39, S9–15.

2. Whitehurst, D.G.T., and Mittmann, N. (2013). The value of health economics research in spinal cord injury. Spinal Cord 51, 586–7.

3. Dejong, G., and Batavia, A.I. (1991). Toward a health services research capacity in spinal cord injury. Paraplegia 29, 373–389.

4. Rick Hansen Institute. (2013). Rick Hansen Institute CARE program: Providing equitable care for Canadians with SCI. Vancouver, BC.

5. Rick Hansen Institute. (2014). Rick Hansen Institute CURE program: Supporting promising research. Vancouver, BC.

6. Rick Hansen Institute. (2014). Rick Hansen Institute commercialization program: Supporting the commercialization of innovations for spinal cord injury. Vancouver, BC.

7. Krueger, H., Noonan, V.K., Trenaman, L.M., Joshi, P., and Rivers, C.S. (2013). The economic burden of traumatic spinal cord injury in Canada. Chronic Dis. Inj. Can. 33, 113–22.

8. Mills, A.E., and Spencer, E.M. (2005). Values based decision making: A tool for achieving the goals of healthcare. HEC Forum 17, 18–32.

9. Chan, B., McIntyre, A., Mittmann, N., Teasell, R., and Wolfe, D. (2014). Economic Evaluation of Spinal Cord Injury., in: Teasell, R.W., Miller, W.C., Wolfe, D.L., Townson, A.F., Hsieh, J.T.C., Connolly, S.J., Noonan, V.K., Loh, E., and McIntyre, A. (eds). *Spinal Cord Injury Rehabilitation Evidence. Version 5.0*. pps. 1–21.

10. Canadian Agency for Drugs and Technologies in Health. (2006). Guidelines for the Economic Evaluation of Health Technologies, 3rd Edition. Ottawa, ON.

11. National Institute for Health and Care Excellence. (2013). Guide to methods of technology appraisal. London.

12. National Institute for Health and Care Excellence. (2014). Guide to the processes of technology appraisal. London.

13. Husereau, D., Drummond, M., Petrou, S., Carswell, C., Moher, D., Greenberg, D., Augustovski, F., Briggs, A.H., Mauskopf, J., and Loder, E. (2013). Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement. Value Heal. 16, e1–5.

14. Husereau, D., Drummond, M., Petrou, S., Carswell, C., Moher, D., Greenberg, D., Augustovski, F., and Briggs, A.H. (2013). Consolidated Health Economic Evaluation Reporting Standards (CHEERS) — Explanation and Elaboration: A Report of the ISPOR Health Economic Evaluation Publication Guidelines Good Reporting Practices Task Force. Value Heal. 16, 231–250.

15. Mittmann, N., Evans, W.K., Rocchi, A., Longo, C.J., Au, H.-J., Husereau, D., Leighl, N.B., Isogai, P.K., Krahn, M.D., Peacock, S., Marshall, D., Coyle, D., Taylor, S.C.M., Jacobs, P., and Oh, P.I. (2012). Guidelines for health technologies: specific guidance for oncology products in Canada. Value Heal. 15, 580–5.

16. Noonan, V.K., Kwon, B.K., Soril, L., Fehlings, M.G., Hurlbert, R.J., Townson, A., Johnson, M., and Dvorak, M.F. (2012). The Rick Hansen Spinal Cord Injury Registry (RHSCIR): A national patient-registry. Spinal Cord 50, 22–7.

17. Atkins, D., Noonan, V.K., Santos, A., Lewis, R., Fehlings, M., Burns, A., and Dvorak, M. (2012). Secondary complications in SCI across the continuum: Using operations research to predict the impact and optimize management strategies. Top. Spinal Cord Inj. Rehabil. 18, 57–66.

18. Santos, A., Gurling, J., Dvorak, M.F., Noonan, V.K., Fehlings, M.G., Burns, A.S., Lewis, R., Soril, L., Fallah, N., Street, J.T., Bélanger, L., Townson, A., Liang, L., and Atkins, D. (2013). Modeling the patient journey from injury to community reintegration for persons with acute traumatic spinal cord injury in a Canadian centre. PLoS One 8, e72552.

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