

SPECIAL COMMUNICATION

The International Spinal Cord Injury Survey: The Way Forward

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Abstract

As a community survey of individuals living with spinal cord injury in 22 countries, representing all 6 of the World Health Organization regions, the International Spinal Cord Injury (InSCI) community survey is one of the few surveys that highlights not only basic medical issues, but also the impact of spinal cord injury (SCI) on the everyday lives of people. The InSCI survey is part of a much larger project known as the Learning Health System for SCI Initiative (LHS-SCI). The objective of this article is to highlight some of the ongoing and planned next steps at the national and international levels. The implementation phase of the LHS-SCI initiative, beginning with the publication of primary results and extending until 2023, will use the results of the InSCI survey as evidence for implementation of recommendations for improving the societal response to the needs of individuals with SCI at the national level. To illustrate the variety of implementation activities currently underway, we provide country examples from Australia, Morocco, Malaysia, and Germany to demonstrate the diversity of approaches to the implementation of InSCI data. The implementation phase of the LHS-SCI initiative promises to usher in a new era of SCI research that will be seamlessly linked to ongoing and effective implementation actions, at both international and national levels and across settings from clinical practice, health systems management, and national policy.

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The International Spinal Cord Injury (InSCI) community survey is a component of the International Learning Health System for Spinal Cord Injury Study (LHS-SCI), launched in 2017 with the endorsement of the World Health Organization (WHO) and supported by the International Society for Physical and Rehabilitation

Medicine (ISPRM) and the International Spinal Cord Society (ISCoS).¹ As the initial phase of the LHS-SCI, the role of InSCI was to generate evidence regarding the lived experience of individuals with spinal cord injury (SCI) internationally by means of the InSCI community survey.² Recognizing that it is not enough

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to create merely and disseminate evidence about the lived experience of people with SCI, the second phase was to use these data as the basis for implementing nationally-relevant recommendations designed to improve the existing societal response to the needs of individuals with SCI. From the outset, the intention was to align InSCI data with the recommendations of a joint WHO and ISCoS report, “International Perspectives on Spinal Cord Injury” (IPSCI)³ and the WHO’s “Rehabilitation 2030: A Call for Action.”⁴ Now that the InSCI community survey has been completed, the first preliminary publications of the results are being made available in this issue of *Archives of Physical Medicine and Rehabilitation*. The way forward, described here, is to begin the implementation phase of InSCI results.

Other articles in this issue describe the methodology of the InSCI community survey conducted in 22 countries between 2017 and 2019, the application of graphical modeling in the representation of InSCI functioning data to understand the lived experience of individuals with SCI across countries, and a closer look at the results of InSCI in 3 important domains: participation (represented by work and employment), environmental factors, and the societal response to SCI needs as captured by InSCI and supplementary data. In this final article, our objective is to position the InSCI survey within the overall LHS-SCI initiative and introduce the implementation phase. Implementation is the way forward for LHS-SCI, and it is important to briefly highlight some of the ongoing and planned next steps at the national and international levels.

The survey: the lived experience of individuals with SCI and the societal response

Although InSCI provides the first comprehensive description of the situation of individuals living with SCI across nations from all 6 WHO regions, it is far more than a health condition-specific survey. InSCI goes beyond the standard indicators of mortality and morbidity to collect information about an individual’s lived experience in terms of functioning, as conceptualized in WHO’s International Classification of Functioning, Disability and Health.⁵ InSCI seeks to capture the impact on a person’s basic life activities and social participation, in light of the individual’s full environmental context—physical, interpersonal, and social. Following the language of the International Classification of Functioning, Disability and Health, this is what is meant by “the lived experience of persons with SCI.”

There are other examples of general national health surveys that attempt to capture the lived experience in this sense. This is usually accomplished by a module on disability or limitations in activities of daily living. The WHO itself has moved in this direction by developing and implementing a population Model

Disability Survey in several countries designed specifically to capture the overall phenomena of decrements of functioning, that is, disability, across the population.⁶ However, InSCI is the first international survey designed to comprehensively capture the lived experience of a specific health condition. Moreover, InSCI embodies 3 significant innovations.

First, InSCI represents a new generation of health surveys that respond to the information needs of a global future characterized by well-known epidemiological and demographic trends. In part because of better preventive and curative health care, population aging, and a shift from communicable to chronic non-communicable diseases, the world’s population will be living longer but with more limitations in functioning.⁷⁻¹⁰ Although health scientists need to understand the disease, its causes, and the biomedical details of the health problems we experience, the performance of our health (and social) systems will be increasingly measured in terms of the extent to which these services and supports allow individuals in the population to lead fulfilling, socially active lives. In short, we will assess the success of our health and social response to health problems not only in terms of how long, but also in terms of how well we live.¹¹

Second, the information regarding functioning collected by InSCI represents 2 perspectives: the person and society. From the person’s perspective, information about the impact of a health condition, such as SCI, on activities of daily living; interpersonal relationships; and participation in education, employment, or other major life activities reveals not only what it means to live with SCI, but also what is needed to live a better life with SCI. Information about the societal response provides the extent and patterns of decline in functioning across different domains beyond mobility, cognition, communication, seeing, and hearing. Although this information describes population health and functioning decline, it also, and more importantly, helps to define specific population resource and service needs that respond to these declines in functioning. Because functioning information captures these 2 perspectives, the LHS-SCI initiative was designed from its inception to enhance the societal response to SCI, namely all state actions and inactions that have a direct impact on the lives of individuals, particularly the lived experience of persons with SCI.¹²

Finally, because InSCI is an international survey describing the lived experience of persons with SCI in different health and social systems, it provides a starting point for comparing how different systems and societies respond to the needs of individuals with SCI. This comparative information provides the evidentiary basis that can guide the specific, concrete changes required by policy recommendations to improve these systems. The WHO has long recommended that any general assessment of the performance of a health system should take into account functioning outcomes, and specifically the degree to which it responds to functioning needs.¹³ More generally, the overall performance of systems in terms of societal response to the needs of people with SCI can be evaluated in terms of the impact on functioning and, more broadly, well-being. Although SCI is a condition with a very low prevalence, it provides an ideal index case and “canary in the mine” for health systems research because SCI creates needs that call upon health and social services across the continuum of care and service delivery settings.

The implementation challenge

InSCI is a unique and potentially powerful health survey, providing information that can improve the societal response

List of abbreviations:

InSCI	International Spinal Cord Injury
IPSCI	International Perspectives on Spinal Cord Injury
ISCoS	International Spinal Cord Society
ISPRM	International Society of Physical Rehabilitation and Medicine
LHS-SCI	Learning Health System for Spinal Cord Injury Study
SCI	spinal cord injury
WHO	World Health Organization

to SCI. InSCI provides internationally comparable data on functioning and the actual lived experience of persons with SCI. This provides the evidential basis for social change, but what remains is a particularly daunting challenge. As merely reporting and disseminating research results are inert activities, to obtain optimal advantage, InSCI findings must be implemented to shape and deliver information that informs agenda-setting and policy formation to respond to the needs of individuals with SCI. Implementation is the next step: using evidence and analytical conclusion to bring about social change. There is no algorithm that can transform a rich dataset into concrete improvements in clinical practice, management, or policy. It is a challenge to align new information with the global recommendations of IPSCI, which are not only multisectorial, affecting both policy and practice, but often require coordination between administrative levels, demanding engagement of a wide range of stakeholders and often necessitating changes in behavior. This is the challenge of implementation.¹⁴

The WHO has developed implementation research as the study of the processes used to implement health research into practice and policy. Implementation must identify the contextual factors that facilitate, or act as barriers to, effective implementation and develop indicators for monitoring and evaluation.^{15,16} By contrast implementation science is the study of theories of change and implementation constructs that guide the process of implementing health-related research at the micro (individual or clinical), meso (community or organizational), and macro (system and policy) levels.¹⁷ Implementation strategies are the concrete methodologies for doing so.¹⁸ In the LHS-SCI initiative, the implementation strategy focuses on the highest macro level, namely national health systems and policies.

The LHS and implementation strategies

As its name suggests, the LHS-SCI initiative is committed to a theory of change at the health systems and policy levels derived from the American Institute of Medicine's 2007 platform for the rethinking of American health research and health system reform known as the learning health system approach.^{19,20}

Stripped to its basics, the learning health system is a cyclical program of continuous reform based on evidence in which issues are identified, an evidence-based response is developed and put into practice, and the consequences or outcomes are monitored and evaluated. From observed successes or failures, new issues are identified, calling for new evidence and the cycle repeats.²¹ A health system that learns is one that develops the sustainable capacity to identify and understand—at the level of clinical practice, administration of services, and national health policy—weaknesses and constraints. It uses research evidence to develop and put into effect changes that avoid or mitigate the effects of what does not work and encourages what does work. A learning health system is agile in its response to new circumstances, flexible in its ability to preserve what works and discard what does not, and inventive in using research evidence in the most impactful manner to solve problems and remove obstacles in practice, administration, and policy.

Over the next decade, the Institute of Medicine perfected the path to a continuously learning health care system, by stressing 2 infrastructural improvements. The first is the generation and implementation of good evidence. Although the learning health care system is a natural development from evidence-based medicine,²² it moves beyond this to addresses the persistent problem of obtaining evidence to actually change practice. The

learning health care system also adds sustainable feedback loops between research and practice so research questions can be refined for timeliness and relevance to clinical decision making and policy development. These data can be successfully managed in terms of performance indicators to monitor success or failure, and thus to learn continuously.

The LHS-SCI Initiative began with the development and fielding of the InSCI community survey in 2017. However, even at the beginning, the intention was to incorporate an implementation phase once findings from the survey were available. Building on ongoing work at the University of Lucerne in Switzerland, the LHS-SCI incorporated implementation strategies developed by Lavis et al,²³ initially in collaboration with the WHO, and specifically applied to the European regional office of the WHO,²⁴ now located at the McMaster Health Forum in Canada. The LHS-SCI Initiative turned to these sources as they focused on the same level of implementation that the Initiative does, namely at the health systems and policy level. The Initiative therefore proposed to use 2 main implementation tools to assist participating countries in bringing about evidence-informed policy change. These tools, slightly modified from their original formulations, are policy briefs and stakeholder dialogues.^{25,26} In addition, and more fully described below, the Initiative also found it necessary to interject a preliminary tool, the summary country report, to facilitate preparation of the policy brief.

The policy brief is a concise, accessible, and fully evidence-based discussion paper that identifies and gives evidentiary background for a specific issue concerning some aspect of the overall societal response to SCI needs. It is country-specific and informed by all available data, including the complete informational base provided by the InSCI survey data, supplemented as necessary by other country-level information. The policy brief would typically focus on 1 or 2 specific SCI service issues and present identifiable and feasible options for addressing them. The policy brief forms the evidentiary basis for a stakeholder dialogue, the primary mechanism of engagement, consensus-building, and implementation strategy planning and development. This is a structured communication process involving representative stakeholders in a position to effect change in practice or policy. These stakeholders work collaboratively toward a common understanding of the issue, the best option to address it, and to reach an agreement about a practical, step-by-step implementation strategy to resolve the issue set out in the policy brief.²⁷

Main outcomes

The way forward to implementation: current state of play

The results of the InSCI survey, assisted by the informal networking activities of the 2 supporting professional societies, ISCoS and ISPRM, in line with their workplans with the WHO as professional organizations in an official relationship with the WHO, have supported countries that wish to raise awareness about and advocate for the adequacy of the country's societal response to the needs of persons with SCI, particularly with regard to the adequacy of rehabilitation services. This is especially important for countries with poorly developed or fragmented rehabilitation systems. As individuals with SCI are frequent users of rehabilitation and other health services,^{28,29} they will be more directly impacted by difference in the performance of health systems. As more fully discussed in an article in this issue, "Comparison of the Social Response to Functioning Needs of People With SCI Across

Over 20 Countries," InSCI data can provide evidence for standard socioeconomic indicators that can serve as performance indicators of health systems, as applied to persons with SCI. Given the availability of InSCI data from 22 socially and economically diverse countries, these indicators can be linked to quality of life or functioning outcomes to highlight how differences in health system configurations affect the lived experience of people with SCI. But this is just the beginning.

InSCI data analyses focusing on the societal response constitute the essential, but nonetheless preliminary, evidential foundation for implementation. The key lesson from implementation research is that real-world social, economic, political, and cultural contextual factors determine the success or failure of any implementation action.¹⁶ Researchers are often tempted to rely on standard socioeconomic indicators, often for no better reason than that these data are available, to provide this context. Early on in the LHS-SCI initiative, efforts were made to describe and comparatively analyze societal responses to SCI based on standard socioeconomic indicators and key informant responses to a country report template (see the *American Journal of Physical Medicine and Rehabilitation* 2017 Supplement³⁰). Now that the InSCI community survey has been completed, it is becoming apparent that a more extensive attempt to capture the real world contextual factors is necessary.

Two new steps in the implementation phase of the LHS-SCI initiative, the use of InSCI summary country reports and issue identification and prioritization stakeholder dialogues, will respond to this essential requirement for effective implementation to optimize the impact of data from the InSCI community survey and for each country participant to meet its own societal response challenges through implementation that bridges policy, research, and practice.

InSCI summary country reports

The LHS-SCI Initiative is launching a mechanism for systematically capturing national contextual information to expand the evidentiary basis for implementation. A template has been prepared to guide individual countries in data collection on the health and social system background of the societal response to SCI in that country. It is hoped that country reports will make it easier to integrate InSCI-derived health systems information with a broadly based health and social service information, based on indicators from the European Observatory and other sources. Each participating country in the LHS-SCI will gather information about all features of their country's societal response to the needs of individuals with SCI. In some instances, this information is readily available, but the experience of the InSCI consortium is that much of the data has never been collected or was not collected in a manner that is comparable to other countries. The country report is designed to fill this gap.

Issue identification and prioritization

A decade of implementation research and practice has shown that the gap between research and policy or practice is rarely bridged by the direct application of the implementation strategies of policy briefs and stakeholder dialogues. The problem is not that these tools are inappropriate or ineffective, but rather that because of real-world contextual factors, health and social systems are complex adaptive systems and it is not always obvious where changes should, or can, be made to effect desired results. More often than not, the major obstacle to implementation is that of identifying practical or policy issues that are both significant and

remediable. Issue identification is an essential first step in implementation: where does a country's societal response to the needs of individuals with SCI break down; why does this occur; and is it practical, or even possible, to ameliorate the situation? This is information that only experts fully aware of the local circumstance and the socioeconomic and political context of the proposed changes can provide. Given that it is unlikely that there is a single systematic issue or problem that needs to be addressed, identification of issues will invariably lead to issue prioritization, identifying what issue needs to be addressed first, either because it has the most direct impact on people's lives or because other issues cannot be addressed at all until it is.

Issue identification and prioritization depend on evidence, which country reports can provide. The appropriate mechanism for issue identification and prioritization is a variant of the stakeholder dialogue tool. A true stakeholder dialogue typically involves individuals who are positioned to bring about change. For these less structured dialogues, the range of participants will be selected, not so much on their status as champions of implementation, but rather as experts fully knowledgeable of the socioeconomic and political context of the societal response to the needs of individuals in that country. InSCI country representatives are best placed to identify who these stakeholders are. Specifics of the structure and practicalities of these stakeholder dialogues is left to them.

Some examples of current activities in the way forward

In the current timetable of the LHS-SCI initiative, planning for the next wave of the InSCI community survey will begin in 2021 for initiation in early 2022. The dissemination of InSCI results is under way with the initial publication of the articles in this series and will continue with a series of publications using information regarding comparisons between countries, including data from common national modules added to the InSCI survey, and papers based wholly on national data. Concurrently, the implementation phase of LHS-SCI is in progress and implementation activities will subsequently be based on the information collected in the country reports with issue identification and prioritization stakeholder dialogues. There have already been noteworthy actions taken at the national level, which we include here as case examples.

Australia: regional variations

The Australian InSCI study combines data from SCI services in 4 Australian states, a government insurance agency and 3 consumer organizations (using privacy-preserving data management and linkage processes) to create a representative, population-based, anonymized dataset. This model with engagement with stakeholders provides a powerful vehicle for advocacy, dissemination, and translation of the study's findings. A key next step is community engagement to empower individuals with SCI and their families in the process. Focus group discussions with people with SCI and consumer organization partners to discuss survey results and to flesh out and prioritize the most important issues and actions relating to the lived SCI experience, informing a policy brief for stakeholder dialogues.

The Australian InSCI demonstrates that further research is needed to better understand different trajectories, transitions, and drivers in return to work. Implementation activities will focus on addressing modifiable environmental barriers and enablers such as

return to driving programs and transportation. Subgroup analyses between states will inform discussions with key policy makers and health care planners, at both a state and national level, in relation to resource allocation, planning, and delivery of future health care services for Australians with SCI.

Morocco: raising awareness

Morocco has poorly developed rehabilitation settings as rehabilitation has not been a priority. The Moroccan LHS-SCI has therefore focused on raising awareness on the tremendous challenges faced by SCI patients in Morocco. From the start of the survey, we involved the Ministry of Health and the Ministry of Solidarity of the Woman of the Family and Social Development so the survey experience will create national leadership in research and advocacy for SCI patients. The results of this study will highlight the gap between the needs of people with SCI and the current situation of Moroccan rehabilitation services, currently organized exclusively in unspecialized outpatient settings. They have also brought an opportunity to trigger a debate on the urgent need to develop specialized inpatient rehabilitation centers for many health conditions. After the final country report is published, we plan to host an official high-level meeting with the country's political decision-makers and the participation of stakeholders and lead experts around the world.

Malaysia: a 2-pronged approach

The Malaysian team uses a 2-pronged approach to drive policy change in the care of individuals with SCI in Malaysia, utilizing the strength of both health care professionals and individuals with SCI. The initial implementation plan is based on 3 recommendations from the IPSCI report: promote appropriate research and data collection; improve health sector response to SCI; and empower people with SCI and their families. After completion of the InSCI survey, rehabilitation physicians in Malaysia agreed to use a systematic and standardized format to document demographics, SCI characteristics and secondary complications, and functional outcomes for all patients with SCI referred for rehabilitation. As inpatient rehabilitation is not readily available or adequate in Malaysia, this initiative could provide evidence of the need for such service. At the same time, there is a move to empower individuals with SCI to be more active and vocal in advocacy work by providing them with training, knowledge, and support. In 2019, SCI rehabilitation activities such as the Asian Spinal Cord Network Conference, the World SCI Day, and a "Stop Pressure Injury" workshop attracted participation from individuals with SCI. The association created a website and Facebook page to reach more individuals with SCI and to disseminate pertinent information. A community project with SCI consumers is being planned for 2020 to address prevalent health problems reported by the Malaysian InSCI study.

Germany: direct approach to the Ministry of Health

The German team in LHS-SCI is based at the Department of Rehabilitation Medicine at the Hannover Medical School and is an activity of the German-Speaking Medical Society for Paraplegia under the leadership of Dr Christoph Gutenbrunner. The implementation phase, led by Andrea Bökel, was begun before InSCI data was fully collected from the German centers. A catalog of 10 demands for care and services, based on earlier research and discussions and supported by preliminary results from the InSCI data, was circulated among relevant professional and consumer associations and a consensus was reached both on the content of the list

and priorities. These activities helped to create a network of experts—people with SCI, clinicians, professional associations, and researchers—that provided support throughout the process. A brochure was created and sent to the Ministry of Health in anticipation of an SCI Day that had been organized by the German-Speaking Medical Society for Paraplegia and the Association for Persons with SCI. On the basis of this original document and further discussions with stakeholders, a short 4-page policy brief was prepared based on the top 3 issues that had already been raised: the need to enhance labor market participation, to address unmet medical needs of people with SCI, and to respond to specific environmental barriers. The policy brief formed the background document for a successful public relations event, the SCI Day on September 5, 2019. The next steps are to build on and strengthen the network of stakeholders, improving both leadership and ownership of the issues, and to refine the policy brief and organize a stakeholder dialogue in early 2021.

Conclusion

The implementation phase of the LHS-SCI initiative promises to usher in a new era of SCI research that will be linked to effective implementation actions at both international and national levels and across settings from clinical practice, health systems management, and national policy. The LHS-SCI initiative is, at this stage, a proof of concept of a holistic approach to evidence-based implementation in practice and policy to strengthen the societal response to SCI. As such, the initiative should be viewed as still being at a developmental stage. Its true value will eventually be demonstrated by concrete implementation and other follow-up activities conducted in each participating country. The hope, finally, is that the initiative will serve as a model for other health conditions and, more broadly, as the basis for general health system reform.

Keywords

Implementation science; Learning health system; Rehabilitation; Spinal cord injuries

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References

- Gross-Hemmi MH, Post MW, Ehrmann C, et al. Study protocol of the International Spinal Cord Injury (InSCI) community survey. *Am J Phys Med Rehabil* 2017;96(2 Suppl 1):S23-34.
- Fekete C, Post MW, Bickenbach J, et al. A structured approach to capture the lived experience of spinal cord injury: data model and questionnaire of the International Spinal Cord Injury community survey. *Am J Phys Med Rehabil* 2017;96(2 Suppl 1):S5-16.
- World Health Organization, International Spinal Cord Society. International perspectives on spinal cord injury. Available at: <https://apps.who.int/iris/handle/10665/94190>. Accessed August 27, 2020.
- World Health Organization. Rehabilitation 2030: a call for action. Available at: <https://www.who.int/rehabilitation/rehab-2030/en/>. Accessed August 27, 2020.
- World Health Organization. International classification of functioning, disability and health. Geneva: World Health Organization; 2001.
- World Health Organization. Model disability survey. Available at: <https://www.who.int/disabilities/data/mds/en/>. Accessed August 27, 2020.
- United Nations. World population ageing 2015. Available at: http://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf. Accessed August 27, 2020.
- World Health Organization. World report on ageing and health. Geneva: World Health Organization; 2015.
- World Health Organization. Preventing chronic diseases: a vital investment. WHO global report. Geneva: World Health Organization; 2005.
- Chatterji S, Byles J, Cutler D, Seeman T, Verdes E. Health, functioning and disability in older adults – present status and future implications. *Lancet* 2015;385:563-75.
- Stucki G, Bickenbach J. Health, functioning, and well-being: individual and societal. *Arch Phys Med Rehabil* 2019;100:1788-92.
- Barzallo D, Gross-Hemmi MH. The cross-cultural societal response to sci health and related systems. *Am J Phys Med Rehabil* 2017; 96(Suppl):S41-54.
- World Health Organization. The world health report 2000—health systems: improving performance. Available at: <https://www.who.int/whr/2000/en/>. Accessed August 27, 2020.
- Stucki G, Bickenbach J. The implementation challenge and the Learning Health System for SCI initiative. *Am J Phys Med Rehabil* 2017;96(Suppl):S55-60.
- de Savigny D, Adam T. Systems thinking for health systems strengthening. Alliance for Health Policy and Systems Research. Geneva: World Health Organization; 2009.
- Peters DH, Tran NT, Adam T. Implementation research in health: a practical guide. Geneva: World Health Organization; 2013.
- Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci* 2009;4:50.
- Curran GM, Bauer M, Mittman B, Pyne JM, Stetler C. Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. *Med Care* 2012;50:217-26.
- Institute of Medicine. Learning what works: infrastructure required for comparative effectiveness research: workshop summary. Washington, DC: The National Academies Press; 2011.
- Institute of Medicine. The healthcare imperative: lowering costs and improving outcomes: workshop series summary. Washington, DC: The National Academies Press; 2010.
- National Academies Press (US): The Learning Healthcare Series. Available at: <https://www.nap.edu/download/11903>. Accessed August 27, 2020.
- Delaney BC, Curcin V, Andreasson A, et al. Translational medicine and patient safety in Europe: TRANSFoRm—architecture for the Learning Health System in Europe. *Biomed Res Int* 2015;2015: 961526.
- Lavis JN, Oxman AD, Lewin S, et al. SUPPORT tools for evidence-informed health policymaking (STP). *Health Res Policy Syst* 2009; 7(Suppl):1-7.
- Lavis JN, Catallo C, editors. Bridging the worlds of research and policy in European health systems. Copenhagen: WHO Regional Office for Europe; 2013.
- Boes S, Mantwill S, Kaufmann C, et al. Swiss Learning Health System: a national initiative to establish learning cycles for continuous health system improvement. *Learn Health Sys* 2018;2:e10059.
- Rubinelli S, von Groote P. Stakeholder dialogue as deliberation for decision making in health policy and systems: the approach from argumentation theory. *Am J Phys Med Rehabil* 2017;96(Suppl): S17-22.
- Fafard P. Evidence and healthy public policy: insights from health and political sciences. Available at: <http://www.ncchpp.ca/docs/FafardEvidence08June.PDF>. Accessed August 27, 2020.
- Gemperli A, Ronca E, Scheel-Sailer A, Koch HG, Brach M, Trezzini B. Health care utilization in persons with spinal cord injury: part 1—outpatient services. *Spinal Cord* 2017;55:823-7.
- Ronca E, Scheel-Sailer A, Koch HG, Gemperli A. Health care utilization in persons with spinal cord injury: part 2—determinants, geographic variation and comparison with the general population. *Spinal Cord* 2017;55:828-33.
- The International Spinal Cord Injury Survey and the Learning Health System for SCI. In: Bickenbach J, editor. *Am J Phys Med Rehabil* 2018;96(Suppl 2).