

# The International Spinal Cord Injury Survey and the Learning Health System for Spinal Cord Injury

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The experience of living with spinal cord injury (SCI) has fundamentally changed in recent years, across the world. In part because of improvements in emergency response to injury, clinical care, and acute rehabilitation, people with SCI, especially in high-resource countries, are living longer and in part because of the growing recognition that what matters to people living with SCI is the extent to which they can live independently and fully participate in all aspects of their community life.<sup>1</sup> This need to focus on optimal functioning is part of the fundamental paradigm shift incorporated within the World Health Organization's (WHO's) *International Classification of Functioning, Disability, and Health in Rehabilitation (ICF)*.<sup>2</sup> The *ICF* conceptualizes the lived experience of a health condition such as SCI both in terms of *biological health*—the impairments that are experienced—and in terms of *lived health* understood as the outcome of a complex interaction between the health condition and environmental and personal factors.<sup>3</sup> This focus, moreover, is reflected in the political domain by the explicit recognition that persons with disabilities enjoy human rights to full inclusion and participation in all areas of social life, on an equal basis with others.<sup>4</sup>

This shift in focus also calls for a new kind of information that can capture, not only the individual's lived experience, in all of its range and complexity, but also information about how societies respond to the needs of persons with a lifetime, chronic, and multifaceted health condition such as SCI. The challenge is, in light of the conceptual model of the lived experience of SCI offered by the *ICF*, to collect robust and relevant information both about the biological capacity of individuals with SCI and the actual performance of activities and domains of participation, given environmental and personal determinants that may facilitate or hinder that performance. Compounding this challenge is the need to not only faithfully record the societal response to the perceived needs of persons with SCI, but also evaluate the extent to which this response effectively enhances the individual's performance in domains of personal and social life. The societal response will include not only essential health services, and especially the full range of rehabilitation services and psychological and psychosocial supports, but also a wide range of social supports and services designed to enhance social participation.

The Learning Health System for Spinal Cord Injury Initiative is being conducted under the auspices of the Disability and Rehabilitation Team at the WHO, led by Prof Alarcos Cieza, and responding to the need to ensure the universal challenge of access to health care embodied in Goal 3 of the *Sustainable Development Goals*,<sup>5</sup> as well as the specific objectives of the *Global Disability Action Plan 2014–2021 Better Health for All People With Disability*.<sup>6</sup> Operationally, this initiative is a collaborative initiative between WHO, the International Spinal Cord Society, and the International Society of Physical and Rehabilitation Medicine—both of the latter are international organizations in official relationship with WHO—and hosted by the Swiss Paraplegic Research (Nottwil, Switzerland).

The normative framework of the initiative is provided by the WHO–International Spinal Cord Society report, *International Perspectives on Spinal Cord Injury (IPSCI)*,<sup>7</sup> published by WHO on December 3, 2013, World Disability Day. The IPSCI report summarizes the best available evidence on SCI from both the personal and societal perspectives and around the globe. Based on WHO's own *World Report on Disability*, published in 2011,<sup>8</sup> IPSCI takes the next step to focus on a specific health condition and provides concrete and actionable recommendations aimed at improving the lived

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experience of SCI by means of an evidence- and human rights-informed research and policy effort. The IPSCI recommendations focus attention on structural features of the health sector response to SCI, as well as cross-sectorial issues of accessible and empowerment of persons with SCI and their families. Other recommendations focus on employment as a key area of social participation, address negative attitudes toward persons with SCI, and encourage research and improved data collection.

At the core of the initiative is the International Spinal Cord Survey (InSCI), a community survey that will be conducted in 2017 in 28 countries, across 6 WHO regions. Several of the participating countries are currently planning to develop and field national modules focusing on additional issues, for example, participation in sports activities, more focused detail on employment, or the level of social integration and acceptance experienced by the individual. A follow-up survey is proposed for 2022. The survey is fully grounded in the *ICF*, both in terms of the dimensions of the experience of SCI that are covered and the domains upon which the questions are based and also and more fundamentally in terms of the underlying conceptualization of functioning that provides the rationale and inherent structure of the survey. Because of this, InSCI is likely to be the first national-level, health condition-specific survey entirely structured and linked to the *ICF* and implemented across a variety of countries.

The overall objective of InSCI is to identify the factors that explain functioning and well-being of people living with SCI within and across countries in the context of health, health-related, and other social and political systems, policies, services, and care provision and accounting for differences in the health condition of SCI and environmental factors and personal characteristics. The survey will provide comprehensive and comparable information about the lived experience of disability—the perspective of the person. In light of detailed information from each participating country collected and analyzed at the study center at the Swiss Paraplegic Research, the complementary perspective of society will also be developed, comparatively across participating countries.

The scope of the Learning Health System for Spinal Cord Injury Initiative, however, extends beyond these substantial data generation activities, fundamental though they are. In addition, the initiative relies on, and takes the preliminary steps of implementing, a fundamental approach to reforming the societal response to SCI. This is called the learning health system approach, originally proposed and described by the US National Academy of Medicine (formerly the Institute of Medicine) beginning in 2007.<sup>9-14</sup> This approach recognizes that health systems “learn” when they can rely on cyclical dynamics to identify issues, create responses, implement change, observe the consequences, respond to the results of the implementation, and revise and reshape the response: that is, learn from success and failure. A health system can only learn when it has the capacity to identify and understand weaknesses and constraints, successes and innovations, and craft and implement interventions that avoid or mitigate the effects of what does not work and enhance synergies that encourage what does work. In a recent discussion paper, the need for the kind of information InSCI will collect is described as essential for the learning health system approach.<sup>14</sup> It is hoped that the initiative, and

InSCI in particular, will become a model for how health systems can “learn” for other specific health conditions.

Guided by these insights, the Learning Health System for Spinal Cord Injury Initiative proposes to use the multicountry data collection platform in order to generate an analysis of the gaps between the recognized needs for persons with SCI—across the entire lived experience of the condition and taking account of environmental and personal factors and their impact on the experience—and the societal response to these needs. Guided by the specific IPSCI recommendations, and more distally by the human rights set out in the United Nations *Convention on the Rights of Persons with Disabilities*,<sup>4</sup> the initiative will propose an implementation strategy to close the fundamental gap between research and policy change and concrete implementation. This important aspect of the initiative is based on strategies developed and reformed through practical experience and grounded in the current state of the art in implementation science, in particular policy briefs and national stakeholder dialogues. It is anticipated that this phase of the initiative will begin in 2019.

This Special Issue begins by introducing the components of the learning health system for SCI, focusing primarily on the technical aspects of the InSCI survey and its implementation. For context, and to give the reader a sense of the overall scope and full context of the survey, an introduction to the learning health system approach, as applied in this initiative, as well as the implementation strategy of stakeholder dialogues, will also be included. The second part of the issue provides an opportunity for a sample of the participating countries to provide a baseline of the SCI experience in their countries, a brief review of their understanding of the societal response, and a description of their own survey strategy and supplementary national modules.

In the first article in the issue the innovative data model of the questionnaire used for the survey is described in detail. The challenge of collecting internationally comparable data on the lived experience of persons with SCI—data that can then be coordinated with information about the societal response of countries—is addressed, both in principle and technically. The standard balance of survey feasibility and data comprehensiveness is shown to pose a particular challenge in this survey, and the response to this challenge is described.

The first part of the issue ends with the the guiding rationale of the initiative, namely, the implementation challenge and the learning health system (pages x–y). The article reviews the components of the learning health system for SCI, and the role of the InSCI community survey is designed to play in the implementation endeavor, in light of the underlying learning health system approach. The point is underscored here that every aspect of the development of the InSCI survey was motivated, and in some instances specifically designed, to meet the objectives of the initiative as a whole.

Between these 2 end points in the first part, a discussion of the background rationale and the work that is in progress to develop an implementation strategy, grounded in the state of the science, which is tailored to the specific objectives of the initiative is outlined. In this original work, the authors use the resources of argumentation theory to enhance the effectiveness, in a policy implementation context, of the stakeholder dialogue methodology. The resource and training implementation of this

phase of the initiative are also discussed here. In the second article the specific survey methodological features of the InSCI survey are set out in detail. The article describes in detail the design of InSCI as a multinational community survey, grounded in the ICF. The overall aims, guiding principles on sampling strategies, data collection modes, reminder management, and other operational details are elucidated.

The remaining 2 articles set the stage for developing the analytical framework in terms of which data from countries outlining the societal response to SCI population needs will be analyzed during the course of the next 2 years of the initiative. The first of these articles focuses on rehabilitation services, both from the perspective of the provision and the payment of services. Based on the country-level reports and a systematic review of the literature, the article presents a preliminary analysis of the impact of rehabilitation services and payment on the societal response to SCI. These results will help to develop other systems models for comparative purposes as more data, from the InSCI survey and subsequent focused, country-level key informant reports are available from the participating countries. The next article discusses the challenges of analyzing cross-cultural societal responses to SCI, focusing on the basic health and health-related systems. The article describes a preliminary concurrent mixed-methods study to identify key macroeconomic indicators that can be used to describe the social situation of persons with SCI in the 28 participating countries, as well as the general societal response. Data were derived both from existing international sources of country-level macroeconomic information and also from a country template completed by researchers representing the participating country. Preliminary analysis suggests that there is a correlation between the efficiency of the health and social care systems and the extent of a country's investment of those sectors, but shows that unmet SCI need cannot entirely be explained in this manner.

As mentioned, in the second part of this Special Issue, 19 participating countries take the opportunity to describe their SCI experience and societal response prior to the implementation of the InSCI study, in part to provide a baseline for later analysis. The represented countries in this part are China, Germany, Greece, Indonesia, Israel, Italy, Korea, Lithuania,

Malaysia, the Netherlands, New Zealand, Norway, Poland, Portugal, South Africa, Spain, Switzerland, Thailand, and the United States. In each short report, country researchers describe recruitment procedures and other survey implementation issues that are of particular relevance to their country situation. They describe what they hope to learn from their participation in the initiative and, where relevant, outline their anticipated national modules and the research questions they hope to answer.

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