The Implementation Challenge and the Learning Health System for SCI Initiative

Gerold Stucki, MD, MS, and Jerome Bickenbach, PhD, LLB

Abstract: The paper introduces the *special issue* by linking the International Spinal Cord Injury (InSCI) Community Survey study to the Learning Health System for SCI Initiative (LHS-SCI). The LHS-SCI was designed to respond to the implementation challenge of bringing about policy reform in light of the targeted policy recommendations of World Health Organization's *International Perspectives on SCI* report as well as the call for action of WHO's *Global Disability Action Plan*. The paper reviews the components of LHS-SCI relevant to internationally comparable information, a theory of change to guide for action, and the tools for evidence-informed policy. The interplay between persons, their health needs, and the societal response to those needs provides the foundation for the organization of the LHS-SCI Initiative. Moreover, as the other articles in this *special issue* describe in detail, the rationale, conceptualization, and study design of the InSCI study are also informed by the rationale, and mission, of the LHS for SCI Initiative. The LHS-SCI, and the implementation challenge that motivates it, is responsible for the design of the InSCI study and the overall mission of LHS-SCI to continuously improve the lived experience of people living with SCI around the world through an international evidence- and rights-informed research and policy reform effort.

Key Words: Spinal Cord Injury, Data Collection, Questionnaire Design, Community Survey, Survey Methodology, International Classification of Functioning, Disability and Health

On December 3, 2013 (the International Day of Persons with Disabilities), the World Health Organization (WHO) launched the International Perspectives on Spinal Cord Injury (IPSCI), a joint production of the WHO and the International Spinal Cord Society.[1] The aims of the IPSCI report were to assemble the best available evidence on SCI—epidemiology, services, interventions, and policies—and to bring that together with information about the lived experience of people with SCI as the basis for recommendations for action, consistent with the United Nations' Convention on the Rights of Persons with Disabilities.[2] Following the format and structure of WHO's World Report on Disability (WRD), launched 2 years before,[3] IPSCI not only brought together the state of the art in SCI worldwide epidemiology and reviewed best practices in prevention strategies, health, and rehabilitation service needs and health systems reforms to meet unmet needs, it also delved deeply into domains of the lives of persons with SCI—relationships and adjustment, enabling environments, education, and employment. Like the *World Report on Disability*, IPSCI makes recommendations about that experience (Fig. 1).

The IPSCI and the WRD face an implementation challenge. As the United Nations agency for health, the WHO has an extensive regional and country-level dissemination network to distribute these reports, and it can bring the world's attention to the recommendations they make. Yet, these efforts have proven to be insufficient to bring about at the levels of both policy and practice, reforms that implement the recommendations. It is challenging to find, evaluate, and analyze the best evidence and use it to create recommendations that are relevant and feasible. However, it is even more challenging to bring about change, to make a difference, by implementing the recommendations at the country level. Changing clinical practice with evidence-based clinical guidelines is hard enough. More difficult is implementing recommendations of a global report like IPSCI and WRD: recommendations that are multisectorial, that affect both policy and practice, require coordination between administrative levels, demand buy-in from a wide range of stakeholders, and require change in behavior.

Nonetheless, this is precisely the motivation behind WHO's Disability Global Action Plan 2014–2021.[4] Focusing on the primary objectives of removing barriers to health services, strengthening rehabilitation and enhancing capacity to collect relevant and internationally comparable disability data, the *Action Plan* mandates WHO to identify concrete actions that can realistically achieve these objectives. The *Action Plan* is a call to meet the challenge of implementation.

The Challenge of Implementation

As a general matter, there are three requirements presupposed by this implementation challenge: there is a need for *information*, for a *theory of change* that can structure the implementation project, and for practical *implementation strategies and tools*.

1. <u>Improve</u> health sector response to SCI
2. <u>Empower</u> people with SCI and their families
3. <u>Challenge</u> negative attitudes to people with SCI
4. Ensure that buildings, transport and information are <u>accessible</u>
5. <u>Support</u> employment and self-employment
6. <u>Promote</u> appropriate research and data collection.

FIGURE 1. International Perspectives on Spinal Cord Injury main recommendations.

Information

To initiate, monitor, evaluate, and adjust processes of implementation, valid and reliable data are essential. In the case of a global health report like WDR and IPSCI, these data must be relevant to the recommendations being implemented, international in scope, and longitudinal. To be relevant to the IPSCI recommendation, the data must encompass the complete lived experience of SCI, including environmental determinants and personal factor characteristics that explain the functioning and well-being of people living with SCI. In addition to information about the person, implementation requires information about the societal response to the needs of persons with SCI. These data must be international to learn from country-level successes (and failures) in shaping their own societal responses (at the policy level [macro-], the service administrative level [meso-], and the level of clinical and other dimensions of practice [micro-]). Finally, information about the person and societal response must be longitudinal to monitor change in the societal response to track implementation. This is an enormous informational demand, given the technical difficulties of ensuring international comparability.

Theory of Change

The processes of the implementation of complex and multisectoral recommendations will not work if they are fragmented, incoherent, and unsustainable. Implementation science is full of examples of attempts to change systems that failed because the strategy used ignored the potential impacts on other sectors, workforces, or institutions. For this reason, implementation researchers argue for the need to describe pathways for scaling up change to take into account the unpredictable behavior of "complex adaptive systems."[5] Failures can result from the naive assumption that planned actions will have clear consequences, when, at the level of the system, far more complex relationships are at work. What is needed, therefore, is a realistic theory of system change that accounts for feedback loops, patterns of cyclical change, and other properties of complex systems such as those found in health and social sectors.

Implementation Tools

Increasingly, health researchers are recognizing the importance of bringing *research into practice* and have, as a result, become more interested in *knowledge translation*. The rise of implementation science and implementation research is a response to the realization that the promise of *evidence-based medicine* depends on implementation, and so the successful use of implementation tools to change behaviors, both at the clinical level and through policy reform.[6] The WHO has fully invested in implementation research[7] and has taken the lead in developing broad implementation strategies for making clinical and health systems reforms, primarily in low- and middle-income countries.[8] Somewhat lagging behind are implementation strategies for implementing recommendations of world reports, such as IPSCI and WDR,[9] but WHO is aware that the benefits of its guidelines and global reports will never be realized without the application of implementation strategies and tools.

One of the motivations behind The Learning Health System for Spinal Cord Injury (LHS-SCI) Initiative, of which the International Spinal Cord Injury (InSCI) Community Survey is a part, was to respond to this implementation challenge. The underlying rationale, conceptualization, and study design of the LHS-SCI Initiative reflect this motivation. The InSCI study addresses the need for evidence of the lived experience of persons with SCI in the InSCI participating countries. The overall mission of LHS-SCI is broader than this, as it includes processes of evidence- and rights-informed research and policy reform that respond to the implementation challenge.

The LHS-SCI is therefore informed by two major traditions in health research: the familiar tradition of evidence-based medicine, and, from within implementation science, evidence-informed policy. Whereas the former motivates the concern to ensure that clinical practice is governed by the best available evidence, the latter bridges this concern with the need to influence the policy and political domains to make change happen, sustainably, throughout the health system.

THE CONCEPT OF THE LEARNING HEALTH SYSTEM FOR SCI INITIATIVE

Our approach in this paper is to describe the mission, concept, and study design of LHS-SCI in light of the underlying motivation just described. Research initiatives of the ambition, scope, and complexity of LHS-SCI will address many objectives and research questions, but our aim here was to expose the reasoning behind some of the fundamental choices that went into the conceptualization and design of the initiative to provide the full context of the InSCI study, including the rationale for the data model and study design. At the core of the LHS-SCI is the aim of integrating evidence and policy. However,

this integration is not merely the traditional one of bringing evidence to the attention of policy makers; it is also a response to the implementation challenge: the LHS-SCI is embarking on a long-term initiative to create a sustainable, multicountry, integrated implementation strategy that brings together evidence generation, a theory of change, and implementation tools.

Normative Framework

The LHS-SCI initiative begins with a commitment to the recommendations of the IPSCI report. To ensure its success and effectiveness, it was decided to align the initiative with WHO's own research and policy agenda as specified in its *Global Disability Action Plan 2014–2021* and its three objectives:

- To remove barriers and improve access to health services and programs.
- To strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation.
- To strengthen collection of relevant and internationally comparable data on disability, and support research on disability and related services.

As it was produced concurrently with the development of the *Disability Action Plan*, IPSCI also reflects these priorities in its recommendations. Hence, both the *Action Plan* and IPSCI (and indeed, WRD as well) focus on access to services and in particular to rehabilitation services, and emphasizes the importance of collecting internationally comparable data, both on the experience of SCI and the societal response to the needs of persons with SCI. Finally, both the *Action Plan* and IPSCI were shaped by the provisions of the *Convention on the Rights of Persons with Disabilities*, which, among other things, guarantees the rights to accessibility, health, and rehabilitation services, and full participation in education, employment, and community life. Every study design choice, including the selection of domains to be operationalized as survey questions for InSCI and the selection of data items to be collected for the cross-cultural societal response, was motivated by the normative framework created from the merging of these three sources.

Learning Health System

As mentioned, the successful integration of evidence and policy presupposes a theory of change for implementation across both the health sector and health-related sectors such as education and employment. The decision was made to use the notion of the "learning health system" as the theory of change that would be the blueprint for the study design.

Starting in 2007, the American Institute of Medicine (IOM) released the first of a dozen workshop reports and studies on the urgent need for better clinical health research and fundamental systems' reforms to put that research into practice.[10] The term *learning health system* was used to describe a health system that *learns* through the application of *cyclical dynamics* for identifying issues, creating responses, implementing change, observing the consequences of the change, revising and reshaping that response: in short, a health system that learns from its successes and failures. A learning health system has the capacity to identify and understand—at the level of clinical practice,

administration of services, and overall, national health policy—weaknesses and constraints and develop and implement changes that avoid or mitigate the effects of what does not work and encourage what does work.

The United States, like all high-resource countries, faces the *health care imperative* of improving health care outcomes while reducing health care costs.[11] The United States spends considerably more per capita on health care than any other Organization for Economic Cooperation and Development country, but its population health care outcomes (eg, life expectancy) are well below the average in these countries.[12] Whereas some of the problems facing the United States are not readily transferable to other countries, much of what the IOM recommended in these reports is easily applicable to nearly all middle- and high-resource countries:

- In light of the increasing evidential complexity of modern health care, it is essential to narrow the research-practice divide for clinical decision support;
- National health care quality improvement process and data architecture are essential for a health care system to "learn" from successes and failures;
- Health care systems must take full advantage of the opportunities created by technological improvements in computing, information services, and connectivity;
- Patients, families, and communities must be better involved in health care;
- A "continuous improvement" culture of care must be created for systematic problem solving, the application of operational models that encourage and reward sustained quality and improved patient outcomes, and strong leadership.[12]

The path to a "continuously learning health care system," in short, incorporates two infrastructural improvements. The first concerns information. It has been said that the learning health care system is the natural development from evidence-based medicine[13] in that whereas the latter advocated the need for practice to be informed by the best evidence, the former addresses the persistent problem of getting that evidence to actually change practice. Getting the right information to inform health care services is a matter of research methodologies and strategies,[14] exploiting the untapped value in translational and comparative effectiveness research,[15] and implementing electronic health records to benefit from large clinical and administrative data sets.[16] Of importance here, although not developed in the IOM reports, is the further need to ensure that health care outcomes reflect what actually matters to people, namely, the level of functioning in their daily lives.

The other infrastructural reform required for the learning health system is less technical, and considerably more challenging. A health care system learns when feedback loops between research and practice are strengthened so that research questions can be refined for timeliness and relevance to clinical decision making, and clinical data can be managed so that clinical success and failure can be monitored for lessons learned. The vision of the learning health care system is "one in which science and informatics, patient-clinician partnerships, incentives, and culture are aligned to promote and enable continuous and real-time improvement in both the effectiveness and efficiency of care."[17] To achieve this requires health care system remodeling along

several axes: engaging and empowering patients to ensure strong patient-clinician partnerships; creating financial and other incentives that are aligned with continuous improvement; and creating a continuous learning culture sustained by leadership committed to continuous improvement. All of this requires powerful implementation strategies to bring stakeholders together to develop a health care system remodeling plan and timetable.

As a theory of change, the learning health care system has been called "an enormous interdisciplinary challenge incorporating behavioral psychology, communication science, implementation science, behavioral economics, policy science, and organizational theory."[18] Effective change also depends on leveraging the expanded capacity of digital infrastructures, data collection, and innovative statistical and research techniques. Finally, change also requires a sustained application of implementation science to remodel the health care system at all levels: policy, service administration, and clinical practice.[19]

The LHS-SCI Initiative is an application of the learning health care system approach to the case of SCI and the experience of living with SCI. It is hoped that this initiative can become a model for health system redesign for other health conditions and to meet the growing needs of an aging population. The initiative provides the unique opportunity for stakeholders from the participating countries to learn from each other's successes and to build both research and policy capacity toward the implementation, at the national level, of a learning health care system.

The Informational Base: Person and Society

The LHS-SCI Initiative builds on a preexisting informational base for SCI. The evidence from the IPSCI report, supplemented by evidence from the WRD, provides a broad base of information about all aspects of the lived experience of SCI. Although the best research evidence available supports generalization about international perspectives on SCI, in many regions of the world, the gaps in evidence are substantial. We know almost nothing about the epidemiology of SCI across the African continent, for example.

Fortunately, more granular data about the lived experience of SCI are available from the community survey conducted in the context of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) in 2012,[20] results of which have been analyzed and recently published.[21] The SwiSCI community survey was based on the conviction that the goals of the societal response to the needs of persons with SCI, with regard to rehabilitation services and social interventions, must be that of improving what matters to people, namely, optimizing functioning and participation in all aspects of community life. This conviction reflects the understanding of functioning in WHO's *International Classification of Functioning, Disability and Health* (ICF), which conceptualizes functioning and decrements in functioning, or disability, as the outcome of a complex interaction between a person's health condition and environmental and personal factors.[22]

The ICF provides the shared framework for both the SwiSCI survey and the LHS-SCI Initiative. Moreover, the ICF conceptualization of functioning structures the evidence collected for both IPSCI and WRD and is presumed by the WHO *Disability Action Plan* as well. In particular, the third objective of the *Plan*, to strengthen the collection of internationally comparable data on disability, is currently being implemented through the development and piloting of the Model Disability Survey (MDS).[23] The MDS is based on the ICF conception of functioning and uses a set of ICF domains that have been shown to be adequate for a complete description of functioning, both from the perspective of the intrinsic health capacity of the individual and his or her performance in actual environments. As described in detail in other papers in this *special issue*, the MDS was used as one of the sources of questions for the InSCI survey.

The ICF is fundamental to the LHS-SCI for another reason. The LHS-SCI Initiative follows the SwiSCI study in its commitment to the view that the lived experience can only be expressed in the ICF notion of functioning and that all data collected and used for the initiative must be based on the ICF domains and model of functioning. Thus, the SwiSCI community survey collects information on all of the ICF components—health condition, impairments, activities and participation, and environmental and personal factors—as does the MDS.

The information base provided by the InSCI evidence and SwiSCI data will be augmented during the course of the initiative by the InSCI community survey. As the parameters for both SwiSCI and InSCI surveys are described elsewhere, it need only be emphasized here that InSCI collects data about the person, and the person's lived experience of SCI, in an ICF-based data model. The overall objective of InSCI is to identify determinants of functioning, health, and well-being of people living with SCI within and across countries in relation to health and social service, systems, and policies. This will be done taking into account individual differences in the experience of health conditions, environmental factors, and personal characteristics. The collaborating countries cover the six WHO regions and represent countries with different stages of economic development, different political regimes and health systems, thereby providing the basis for comparison.

International Spinal Cord Injury data capture the determinants of functioning and participation. However, to get the complete picture of the interaction between the person and society, information about the overall societal response to the health and health-related needs of persons with SCI needs also to be collected. These data describe all state actions (and inactions) that have a direct impact on people's lives and their lived experience of SCI.

Information about the societal response will come from country profiles in which relevant quantitative and qualitative information about the general current socioeconomic state of the country is described. Of particular interest is how the health system operates with respect to SCI in general and the lived experience of SCI in particular. In addition to these profiles, the societal response analysis for LHS-SCI will develop a consolidated comparative analysis of the societal response to SCI based on these data and supplementary information collected from international sources. The goal of this analysis was to identify patterns of unmet needs to formulate policy recommendations designed to strengthen the capacity of these systems to meet these needs.

The combination of information about the person and, in particular, the health and health-related needs of individuals experiencing SCI, and information about the societal response to those needs captures the essential person-society interplay that is at the heart of the health sciences. Arguably, the evolution of the health sciences and, in particular, the astounding breadth and depth of interdisciplinary of health research is a recognition that the interplay between persons and their needs, and the societal response to those needs is at the core of what we now understand to be the aim of the health sciences.[24]

The information base for the LHS-SCI Initiative, both existing data sources and those that will be arise during the course of the initiative, is both qualitatively broad and quantitatively extensive, providing a rich source of data for a wide range of comparative analyses. All participating countries will benefit not only from a more in-depth understanding of their own situation but also from a fully comparative understanding of the situation of other countries from which lessons can be learned. In the context of the LHS-SCI Initiative, these data will provide the essential informational base for the implementation of the normative framework provided by the IPSCI recommendation, the *Disability Action Plan* objectives, and the *Convention on the Rights of Persons with Disabilities*. This leads to the next component of the LHS-SCI Initiative.

Implementation Tools: Policy Briefs and Stakeholder Dialogs

As a theory of transformation action, the LHS is grounded in the need for the best clinical and research evidence for evidence-informed health policy making and an essentially participatory, multistakeholder process of implementation of research into practice. Implementation science is the natural source of this second mechanism, although much of implementation research is also focused on the nontrivial need to package information in a manner that is accessible to all stakeholders.[25] The LHS-SCI Initiative proposes to use the state-of-the-art implementation tools for application at the national level for each participating country. These tools are policy briefs and stakeholder dialogues.

The policy brief is a concise, accessible, but 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, informed by all available data including the complete informational base that will be provided by the LHS-SCI Initiative and developed by country collaborators who can integrate their understanding of the specific political and cultural context for policy making in their country. The policy brief will include, based on a comparative analysis from other LHS-SCI collaborating countries, three or four policy reform options that address the issue raised. Although the preparation of a successful policy brief, relevant to the actual situation of the national setting, is a challenging task,[26] it is an essential preliminary step for the implementation mechanism of stakeholder dialogue.

A stakeholder dialogue is a structured communication process or a dialogue where representative stakeholders work collaboratively toward a common understanding and reach agreement about a practical, step-by-step implementation strategy designed to address and solve the issue fully described in the policy brief. The dialogue is guided by a moderator who facilitates the interaction and stimulates participants to clearly express their positions and, using the policy brief as the basis, provides evidence and arguments for their position. The dialogue closes when (*a*) there is agreement over a course of action or (*b*) there is no agreement and either (i) there is need for a second stakeholder dialogue to foster agreement or (ii) more research is needed, as there is a lack of evidence to agree on a best solution. A full description of the version of stakeholder dialogue to be used in LHS-SCI, as well as a theoretical justification for the process, is provided in a paper in this *special issue*.

Research and Policy Capacity Program

A goal of the LHS-SCI and the final component of the concept of the initiative involves the perceived need to develop policy and research capacity across the network of participating countries. The research center in Nottwil will be the source of technical assistance for the initiative, including implementation tools. Capacity building will be achieved through a two-part policy and research capacity effort.

Scientific Capacity Building

The LHS-SCI Initiative requires a new kind of health researcher, one who appreciates that health systems and service research must be a cooperative endeavor involving multiple stakeholders and demands new skills and expertise including, in particular, implementation science. The research center in Nottwil, in collaboration with the academic institutions of the participating countries, will initiate and seek funding for a research scientist program that will bring in young researchers interested in developing the skills and capacity for a learning health system. LHS-SCI will also conduct short educational courses in protocol development and other interdisciplinary teaching modules focusing on the components of the LHS-SCI Initiative.

Management of Standardized Health Information

The LHS-SCI will lead in the development of data standards for structured reporting and, where appropriate, the collection of new multipurpose health information. This is fundamentally a collective goal, as it is impossible for any single researcher to be able to overcome the barriers to acquiring, and maintaining, relevant and comparable health information. What is required is the integrated participation of all LHS-SCI academic institutions as well as the additional resources of the WHO. This will require health information standardization and a health data warehouse.

The LHS-SCI will develop and propose national data standards in collaboration with the WHO, suitable to comprehensively describe both the health and functioning of persons and populations as well as the components of the health system as a foundation for sustainable decision making in national health care systems. Information about individual and population health includes, but extends beyond, basic medical or biological information to encompass information about the lived experience of a person with a health condition. Information about how a person's health plays out in their lives, how it, in interaction with the person's physical, interpersonal, and social

environment, helps or hinders the individual to live the kind of life and achieve the goals and aspirations he or she seeks is crucial for input into the learning health care system.

Finally, since data that are not available are data that cannot be used, it is central to the LHS-SCI goal of providing tools for the enhancement of communication between policy, research, and practice in national health care systems that access to relevant and usable health data. This requires standardization and the capacity to make data collected from a variety of health settings, registries, and administrative sources using a variety of data collection tools and methods that is comparable. In a next step, an accessible storage platform needs to be created so that data can be readily, efficiently, and cost-effectively disseminated.

CONCLUSION

It has been our aim to place the InSCI study in the context of the broader LHS-SCI Initiative and show that the initiative is motivated by the need to implement the targeted policy recommendations of WHO's IPSCI. The implementation challenge can be broken down into the need for relevant and internationally comparable information, the need for a theory of change that provides guidance for action, and the identification and application of implementation tools to ensure evidence-informed policy. Responding to the interplay between persons and their needs and the societal response to those needs, LHS-SCI Initiative includes a normative framework, a theory of action, a complex informational base capturing data on both the person and societal response, an implementation strategy, and an attempt to secure sustainability through capacity development. As the other articles in this Special Issue describe in detail, the rationale, conceptualization, and study design of the InSCI study is also informed by the rationale and mission of the LHS-SCI.

REFERENCES

1. World Health Organization: *International Perspectives on Spinal Cord Injury.* Geneva, WHO, 2013
2. United Nations: *Convention on the Rights of Persons with Disabilities.* G.A. Res. 61/106; 2007. Available at: http://www.un.org/esa/socdev/enable/rights/convtexte.htm. Accessed December 4, 2016
3. World Health Organization: *World Report on Disability.* Geneva, WHO, 2011
4. World Health Organization: *Global Disability Action Plan 2014–2012: Better Health for All People With Disability; 2015.* Available at: http://www.who.int/disabilities/actionplan/en/. Accessed December 4, 2016
5. Paina L, Peters DH: Understanding pathways for scaling up health services through the lens of complex adaptive systems. *Health Policy Plan* 2012;27:365–73
6. Lavis JN, Catallo C (eds): *Bridging the Worlds of Research and Policy in European Health Systems.* Copenhagen, WHO Regional Office for Europe, 2013
7. World Health Organization, Alliance for Health Policy and Systems Research: *Implementation Research in Health: A Practical Guide.* Geneva, WHO, 2013
8. 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
9. Nilsen P, Ståhl C, Roback K, et al: Never the twain shall meet?—a comparison of implementation science and policy implementation research. *Implement Sci* 2013;8:63
10. National Academies Press (US): *The Learning Healthcare Series.* Available at: http://www.nap.edu/catalog/13301/the-learning-health-system-series 2009. Accessed December 4, 2016
11. Institute of Medicine: *The Healthcare Imperative: Lowering Costs and Improving Outcomes: Workshop Series Summary.* Washington, DC, The National Academies Press, 2010
12. Institute of Medicine: *The Learning Healthcare System: Workshop Summary.* Washington, DC, The National Academies Press, 2007
13. 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
14. Institute of Medicine: *Evidence-Based Medicine and the Changing Nature of Health Care: Meeting Summary* (IOM Roundtable on Evidence-Based Medicine). Washington, DC, The National Academies Press, 2008
15. Institute of Medicine: *Learning What Works: Infrastructure Required for Comparative Effectiveness Research: Workshop Summary.* Washington, DC, The National Academies Press, 2011
16. Institute of Medicine: *Clinical Practice Guidelines We Can Trust.* Washington, DC, The National Academies Press, 2011
17. Institute of Medicine: *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America.* Washington, DC, National Academies Press, 2013
18. Foley T, Fairmichael F (eds): *The Learning Healthcare Project.* Available at: http://www.learninghealthcareproject.org/section/evidence/25/50/professor-charles-friedmaninterview 2015. Accessed December 4, 2016
19. Gardner W: Policy capacity in the Learning Healthcare System comment on "Health Reform Requires Policy Capacity". *Int J Health Policy Manag* 2015;4:841–3
20. Stucki G, Post MW: The Swiss Spinal Cord Injury (SwiSCI) Cohort Study. *Am J Phys Med Rehabil* 2011;90:S1–96
21. Bickenbach J, Tennant A, Stucki G: Describing the lived experience of Swiss persons with spinal cord injury. *J Rehab Med* 2016;48:117–243
22. World Health Organization: *The International Classification of Functioning, Disability and Health.* Geneva, WHO, 2001
23. World Health Organizations: Model Disability Survey. Available at: http://www.who.int/disabilities/data/mds/en/. Accessed December 4, 2016
24. Stucki G, Rubinelli S, Reinhardt JD, et al: Towards a common understanding of the health sciences. *Gesundheitswesen* 2016;78:e80–4
25. Lavis JN, Catallo C, Permanand G, et al: Communicating clearly: enhancing information-packaging mechanisms to support knowledge brokering in European health systems. *Policy Summary 7 (BRIDGE Series)* 2013; WHO EURO and European Observatory on Health Systems and Policies
26. Moat KA, Lavis J, Clancy SJ, et al: Evidence briefs and deliberative dialogues: perceptions and intentions to act on what was learnt. *Bull World Health Organ.* 2014;92:20–8