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REVIEW

ISCoS–WHO collaboration. International Perspectives of Spinal Cord Injury (IPSCI) report

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Objective: The objective of this study was to describe the projects, the International Spinal Cord Society (ISCoS) has in cooperation with the World Health Organization (WHO) for the benefit of individuals with spinal cord injury (SCI) worldwide.
Setting: International
Methods: Collaboration between ISCoS and WHO can be divided into (A) building capacity for better SCI education and prevention programs; (B) improving classification systems for use of data in SCI research, the International Classification of External Cause of Injury (ICECI), the International Classification of Diseases (ICD) and the International Classification of Functioning, Disability and Health (ICF); and (C) improving the evidence base for SCI through the report, International Perspectives on Spinal Cord Injury (IPSCI). The objectives of the IPSCI report are first to summarize information on SCI, in particular the science and epidemiology, the services, interventions and policies that are relevant and 'the lived experience' of persons with SCI across the full spectrum of life and throughout the world; second, to document all aspects of the science and experience of SCI to identify gaps between what exists and what is required; and third to make recommendations based on this evidence, with a clear perception of feasible goals and targets, that are consistent with the aspirations and goals of inclusion and full participation as expressed in the UN Convention of the Rights of Persons with Disabilities.
Future cooperation: ISCoS and WHO will continue to join forces in areas where they can make the greatest difference, especially in prevention and educational issues worldwide.
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In the year of the fiftieth anniversary of the International Spinal Cord Society (ISCoS), formerly known as the International Medical Society of Paraplegia (IMSOP), it is appropriate to salute the strengthening of the cooperation between ISCoS and the World Health Organization (WHO) for the benefit of individuals with spinal cord injury (SCI) worldwide.

In recent years, projects have been established between ISCOS and WHO to obtain results that can help in prevention, health promotion, treatment, rehabilitation and lifelong follow-up for people who sustain traumatic or develop a non-traumatic SCI.

The aim of this presentation is to give an overview of where we are, and where we would like to proceed.

Background to the International Spinal Cord Society (ISCoS)

IMSOP was founded in 1961 with Sir Ludwig Guttmann serving as the President. In February 1944, Dr Guttmann founded the Spinal Unit at Stoke Mandeville Hospital, Aylesbury, UK. In 1952, he also founded the International Stoke Mandeville Games, and health professionals from many countries who came with their teams to these games began to meet and discuss their clinical work and research. It was decided to start IMSOP with its first official meeting to be held in Stoke Mandeville in 1961. Annual scientific

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Table 1 Location of the Annual Scientific meetings 1992–2011 of the International Medical Society of Paraplegia, since 2001 International Spinal Cord Society. (http://www.iscos.org.uk)

1992 Barcelona, Spain—in conjunction with the Paralympic Games
1993 Gent, Belgium
1994 Kobe, Japan
1995 New Delhi, India
1996 Atlanta, USA—in conjunction with the Paralympic Games
1997 Innsbruck, Austria—joint meeting with the Deutchsprachige Medizinische Gesellschaft für Paraplegie
1998 Iguassu, Brazil
1999 Copenhagen, Denmark—joint meeting with the Scandinavian Medical Society of Paraplegia
2000 Sydney, Australia—in conjunction with the Paralympic Games
2001 Nottwill, Switzerland
2002 Vancouver, Canada—joint meeting with American Spinal Injury Association
2003 Beijing, China
2004 Athens, Greece—in conjunction with the Paralympic Games
2005 Munich, Germany—joint meeting with the Deutchsprachige Medizinische Gesellschaft für Paraplegie
2006 Boston, USA—joint meeting with American Spinal Injury Association
2007 Reykjavik, Iceland—joint meeting with the Nordic Spinal Cord Society
2008 Durban, South Africa—joint meeting with the Southern African Spinal Cord Association
2009 Florence, Italy—joint meeting with Societa' Medica Italiana Paraplegia
2010 New Delhi, India—joint meeting with Asian Spinal Cord Network & Spinal Cord Society - Indian Chapter
2011 Washington, USA—joint meeting with American Spinal Injury Association

Table 2 International Spinal Cord Society (ISCoS) affiliated societies 2011 (http://www.iscos.org.uk)

Association Francophone Internationale des Groupes d'Animation de la Paraplégie (AFIGAP)
American Paraplegia Society (APS)
American Spinal Injury Association (ASIA)
Australian and New Zealand Spinal Cord Society (ANZSCoS)
Asian Spinal Cord Network (ASCoN)
Chinese Association of Rehabilitation for the Disabled Society of Spinal Cord Injuries (CARDP-SOSCI)
Deutchsprachige Medizinische Gesellschaft für Paraplegie (DMGP)
Dutch-Flemish Spinal Cord Society (DUFSCoS)
Japan Medical Society of Spinal Cord Lesions (JASCoL)
Nordic Spinal Cord Society (NoSCoS)
Southern African Spinal Cord Association (SASCA)
Spanish Society of Paraplegia (SEP)
Latin American Society of Paraplegia (SLAP)
Romanian Spinal Cord Society
Societá Medica Italiana di Paraplegia (SoMIPar)
Spinal Cord Society—Indian Chapter
Turkish Society of Spinal Cord Diseases (TrSCD)

meetings were held at Stoke Mandeville Hospital, except during paralympic years, when they were held in the country hosting the Games. IMSOP changed its name to ISCoS (http://www.iscos.org.uk) in 2001 to signal its broader objective, that is, from paraplegia to all health aspects related to the spinal cord.

From 1979, the ISCoS scientific meetings have been held in different countries (Table 1) to support and encourage a global network, as well as to better understand the global perspective on SCI issues. As seen in Table 1, meetings have been held in most continents, often jointly with local country or regional SCI organizations or in conjunction with the paralympic games. In addition, there are regional meetings around the world supported by the Society.ISCoS serves as an international, non-political and non-profit making association that aims to (http://www.iscos.org.uk):

- study all potential topics relating to traumatic and non-traumatic SCI;
- work in close collaboration with other national and international organizations to encourage the most efficient use of available resources worldwide;
- contribute to scientific exchange by collecting and disseminating information through publications, correspondence, exhibits, regional and international seminars, symposia, conferences and so on; and advise, encourage, guide and support the efforts of those responsible for the care of people with SCI;
- encourage research in the field of SCI by means of awards to authors with the best platform presentations and posters and to young investigators proferring original papers for publication in *Spinal Cord*;
- advise, encourage, guide and support, and where appropriate facilitate the coordination of the education and training of medical professionals and professionals allied to medicine related to patients with SCI; and
- encourage the creation of affiliated societies worldwide (see Table 2).

To support membership from low-income countries, ISCoS keeps its membership fee comparatively very low, especially considering that it includes 12 issues of the journal *Spinal Cord* a year. In addition, the society subsidizes both membership and attendance of annual scientific meetings for professionals from the developing world.

Collaboration between ISCoS and WHO

Building capacity for better SCI service

Educational workshops. Both ISCoS and WHO encourage educational efforts with respect to the prevention, treatment, rehabilitation and follow-up of people with SCI in those low- and middle-income countries where resources are scarce. With this in mind, ISCoS vice-presidents and members of the Educational Committee, in cooperation with local organizers in Nepal, India, Thailand, South Africa, Brazil and elsewhere have conducted international and regional educational workshops for SCI teams. The workshops were conducted for nurses, physiotherapists, occupational therapists, psychologists, social workers, as well as doctors, to facilitate the multidisciplinary approach when working with people with SCI in terms of prevention, best treatment, rehabilitation and lifelong follow-up to prevent secondary complications.

Prevention symposium. For many years, ISCoS has made it a high priority to include a prevention symposium in its program for the annual scientific meetings. Some of these symposia have been co-sponsored by WHO, to increase awareness and the potential impact in the region and country where the meeting was held. Themes for these symposia have included prevention of road traffic accidents, construction industry, mining, violence, falls (including among older people), sporting injuries, including rugby and horseback riding, diving into shallow water and so on. There has also been a focus on natural disasters, such as earthquakes.

Improving classification systems for use of data for SCI research

The international classification of external cause of injury (ICECI). ICECI classifies how injuries occur and is designed for use in international injury prevention. It forms part of the WHO Family of International Classifications (WHO-FIC), and maps to the 9th and 10th revisions of the International Classification of Diseases,[1] as well as the 11th revision that is now in progress.

The core module of the ICECI uses several axes (intent, mechanism, object/substance, place, activity, alcohol use and drug use), supplemented in the additional modules with other axes (violence, transport, place, sports and occupational), all of which helps in the development of effective prevention strategies. These axes serve different coding requirements and resources by operating on three levels of coding detail.[2]

The ICECI provides an extension to the current ISCoS-endorsed International SCI Core Data Set[3] for centers, regions and countries who wish to develop detailed policy relevant to SCI prevention. From April 2003, when the ICECI Coordination and Management Group (ICECI-CMG) took over responsibility for the development of the Classification, ISCoS has been an active participant. In 2006, ISCoS helped to establish an ICECI Spinal Cord Injury Working Group, which in recent years has been engaged collaboratively in evaluating the content validity and inter-rater reliability of the ICECI in a variety of injury scenarios using a computerized system. This project assesses whether computerized data entry is as effective as paper-based systems, and evaluates the effect of training on coding of injury scenarios (http://www.iscos.org.uk).[2] This project significantly simplifies training for units that require this information, and provides an accessible platform for data collection available through the ISCoS website. Additional work done in this area include the integration of the International SCI Core Data Set[3] and the ICECI into computerized data entry software, the development and trial of a regionalized software version for the Asian Spinal Cord Network (ASCON) and the training of coders through ISCoS affiliated scientific meetings.

This project is part of the International SCI Data Sets initiative[4] and the ISCoS Prevention Committee.

International Classification of Diseases (ICD). 'The ICD is the global standard to report and categorize diseases, health-related conditions and external causes of disease and injury in order to compile useful health information related to deaths, illness and injury (mortality and morbidity)… Countries use it to compile basic health statistics and to monitor health spending (http://www.who.int/classifications/icd/ICDRevision/en/index.html).'

WHO collaborates through various topic advisory groups with all interested parties, of which ISCoS is a partner, during the update and revision process for specific issues. 'A Revision Steering Group oversees the overall revision process. An internet-based workspace will document systematic reviews that obtain evidence from analysis of available data (http://www.who.int/classifications/icd/ICDRevision/en/index.html).'

As the design of the ICD has a direct impact on health care and influences public health programs, prevention, reimbursement and treatment, ISCoS became involved in the current revision of the ICD-10. ISCoS has been fortunate to be incorporated in the work both in relation to the orthopaedic part related to spinal injuries (associated to the Musculoskeletal Topic Advisory Group) and other parts of the classification, in particular neurological severity, which may have relation to the spinal cord injured individuals.

International Classification of Functioning, Disability and Health (ICF). ISCoS and WHO, by means of a cooperative agreement between WHO and the ICF Research Branch of the German Collaborating Center, led in the development of the ICF Core Sets for SCI in a 3-year, multi-method process.[5,6] The project consists of four worldwide studies conducted in all WHO regions from 2006 to 2008, concluding with an ICF Core Set Consensus Conference held in 2008 in Nottwil, Switzerland. The Core Set for SCI indicates that essential

categories for a multidisciplinary description of SCI requires categories for all components of the ICF, body functions and structures, activities and participation and environmental factors.

ICF categories relevant for SCI were identified by means of an empirical study, a systematic review of outcomes and measures used in SCI research, an expert survey, and focus groups and semi-structured interviews with persons with SCI.[6–11] Consensus about items to be part of a *Comprehensive* and of a *Brief ICF Core Set* for SCI in the *Early post-acute* and *Long-term context* were reached in the ICF Core Set Consensus Conference.[7,9] Subsequent field testing has been carried out to validate this first version of ICF Core Sets for SCI.

The on going validity work for *ICF Core Sets* for SCI is an inclusive and open process. Anyone who wished to actively participate in this process was invited. Individuals, institutions and associations can be formally associated as partners of the project.[6]

Improving the evidence base for SCI

International Perspectives on Spinal Cord Injury (IPSCI). ISCoS and WHO, with the coordination provided by Swiss Paraplegic Research (SPF), have come together to produce an unique volume on SCI. IPSCI not only aims to capture, to the greatest extent possible, perspectives from high, medium and low resource parts of the world, and to do so in light of the best available evidence, but also, reflecting the model of functioning and disability in the WHO's ICF, to capture the complete lived experience of SCI. Finally, IPSCI is informed by the 'moral compass' of the UN's *Convention on the Rights of Persons with Disabilities* (CRPD) that sets out the obligations of state parties with regard to the implementations of human rights, as these play out in all domains of life and living for persons with disabilities.

IPSCI seeks to provide up-to-date and evidence-based information about the full range of issues, services and interventions of relevance to traumatic SCI and non-traumatic spinal lesions. Chapters include current information about causes and prevention programing, about the basic epidemiology of SCI around the regions of the world, as well as a general description of the principles of medical and rehabilitation clinical interventions. Other chapters survey the systems and services that are available and needed for SCI, and the assistive technology needs and availability. Finally, IPSCI looks at the lived experience of SCI by first surveying the features of a person physical, human-built, attitudinal, social and political environment that either facilitate or hinder the individual in participating in all aspects of life. IPSCI includes two chapters on education, employment and sports, as well as family and community life. The aim throughout is to identify needs, best practices in serving needs and gaps that exist between what is currently available and what is required, taking into account the differences between regions with low and medium resource levels compared with those areas of the world with high resources.

IPSCI can only benefit from the thought that has gone into both the process for developing and the content of the WHO World Report on Disability. The insights from that report will inform both the content and the organization of IPSCI, in light of its explicit objectives. IPSCI is fortunate to be able to rely on a wealth of experience in all aspects of SCI—from medical interventions, to rehabilitation strategies across all settings, to community-based social responses—as well as from dedicated SCI researchers.

The primary objectives of the report can therefore be summarized as follows:

1. To assemble and summarize information on SCI, in particular the science and epidemiology, the services, interventions and policies relevant to the lived experience of persons with SCI across the full spectrum of life and throughout the world.
2. To document the evidence base for all aspect of the science and experience of SCI, and thereby to identify gaps between what exists and what is required.
3. To make recommendations based on this evidence with a clear perception of feasible goals and targets consistent with the aspirations and goals of inclusion and full participation expressed in the UN Convention of the Rights of Persons with Disabilities.

IPSCI draws on a widespread network of contributors and organizations in the field of SCI. Professional organizations such as the International Society of Physical and Rehabilitation Medicine (ISPRM), the World Confederation for Physical Therapy (WCPT), the World Federation of Occupational Therapists (WFOT) are closely involved. Representatives at all levels include people with SCI, who are authors and contributes, as well as organizations such as Disabled People Organization's (DPO's), Disabled Peoples International (DPI), Paralyzed Veterans of America (PVA) and the European Spinal Cord Injury Federation (ESCIF). These organizations will all have a central role in disseminating and implementing the recommendations made in IPSCI. After publication of IPSCI, a follow-up project will facilitate, monitor and evaluate the knowledge transfer process and its impact.

Future cooperation

ISCoS and WHO will continue to work for the benefit of individuals with SCI worldwide. This will happen with cooperation in the areas where the two organizations can jointly make the greatest difference: data collection, prevention, health system strengthening and human resource development in line with the recommendations of IPSCI. These will in particular concentrate on low- and middle-resource countries, where the needs are greater.

Much can be accomplished in the future with the ISCoS and WHO joining forces for the benefit of people with SCI.

Conflict of interest

The authors declare no conflict of interest.

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