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**ISPRM DISCUSSION PAPERS**

**DEVELOPING THE  
INTERNATIONAL SOCIETY  
OF PHYSICAL AND  
REHABILITATION MEDICINE  
(ISPRM)**



The Non-profit Foundation for  
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# Journal of Rehabilitation Medicine

Journal of Rehabilitation Medicine is an international peer-review journal published in English with ten regular issues per year. It is owned by a Swedish nonprofit organization: Foundation for Rehabilitation Information. Journal of Rehabilitation Medicine was former called Scandinavian Journal of Rehabilitation Medicine, which was founded by Olle Höök in 1968. The name was changed to Journal of Rehabilitation Medicine in 2001.

Journal of Rehabilitation Medicine aims to be a leading worldwide forum for research in physical and rehabilitation medicine, aiming to increase knowledge in evidence-based clinical rehabilitation. Contributions from all parts of the world and from different professions in rehabilitation are encouraged. Original articles, Reviews (including Educational reviews), Special reports, Short communications, Case reports, and Letters to the Editor are published. Clinical studies on rehabilitation in various patients groups, within neurological and musculoskeletal as well as in other relevant rehabilitation areas, reports on physical and behavioural treatment methodology, including rehabilitation technology, development and analysis of methodology for outcome measurements, epidemiological studies on disability in relation to rehabilitation, and studies on vocational and socio-medical aspects of rehabilitation will be considered for publication. The journal emphasizes the need for randomized controlled studies of various rehabilitation interventions, the use of the International Classification of Functioning, Disability and Health (ICF) as a background for reports when appropriate, and the use of modern psychometric methodology in treating and reporting data from ordinal scales.

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# **DEVELOPING THE INTERNATIONAL SOCIETY OF PHYSICAL AND REHABILITATION MEDICINE (ISPRM)**

Jerome E. Bickenbach, PhD, LLB, Joel A. DeLisa, MD, MS, Per M. von Groote, MA, Christoph Gutenbrunner, MD, Andrew J. Haig, MD, Marta Imamura, MD, PhD, Leonard S. W. Li, MD, John L. Melvin, MD, MMSc, Jan D. Reinhardt, PhD and Gerold Stucki, MD, MS



## CONTENTS

<i>Abstract</i>	788
<i>Foreword</i>	
Joel A. DeLisa, John L. Melvin and Gerold Stucki	789
<i>Chapter 1: Achievements and challenges of ISPRM</i>	
Gerold Stucki, Jan D. Reinhardt, Joel A. DeLisa, Marta Imamura and John L. Melvin	791
<i>Chapter 2: ISPRM's way forward</i>	
Gerold Stucki, Jan D. Reinhardt, Per M. von Groote, Joel A. DeLisa, Marta Imamura and John L. Melvin	798
<i>Chapter 3: International non-governmental organizations in the emerging world society: The example of ISPRM</i>	
Jan D. Reinhardt, Per M. von Groote, Joel A. DeLisa, John L. Melvin, Jerome E. Bickenbach, Leonard S.W. Li and Gerold Stucki	810
<i>Chapter 4: A policy process and tools for international non-governmental organizations in the health sector using ISPRM as a case in point</i>	
Jan D. Reinhardt, Per M. von Groote, Joel A. DeLisa, John L. Melvin, Jerome E. Bickenbach and Gerold Stucki	823
<i>Chapter 5: Organizational structures suited to ISPRM's evolving role as an international non-governmental organization in official relation with the World Health Organization</i>	
Per M. von Groote, Jan D. Reinhardt, Christoph Gutenbrunner, Joel A. DeLisa, John L. Melvin, Jerome E. Bickenbach and Gerold Stucki	833
<i>Chapter 6: The policy agenda of ISPRM</i>	
Gerold Stucki, Per M. von Groote, Joel A. DeLisa, Marta Imamura, John L. Melvin, Andrew J. Haig, Leonard S. W. Li and Jan D. Reinhardt	843

## ABSTRACT

**This special issue, with 6 chapters, analyses the role of the International Society of Physical and Rehabilitation Medicine (ISPRM) against the background of international issues in Physical and Rehabilitation Medicine (PRM) and rehabilitation at large.**

**Since its foundation in 1999 ISPRM has established a central office, a membership structure, relations with official journals, and has held a number of successful PRM world congresses. Most importantly, ISPRM has entered into official relations with the World Health Organization (WHO) (chapter 1). ISPRM is now challenged by a number of issues restricting the future growth of the society and its evolution into a professional non-governmental organization (NGO) actively shaping international policies in rehabilitation (chapter 2).**

**The basis for this evolution is a clear understanding of ISPRM's political role in world health. This entails the recognition of ISPRM's humanitarian, scientific, and professional mandate and its position in world society and health policy (chapter 3). Consequently, a structured policy process and a set of suitable policy tools for goal selection, agenda setting, resource mobilization, implementation, evaluation and innovation appear useful (chapter 4). Moreover, ISPRM may consider modifying its organizational structures and procedures in order to enhance its effectiveness, accountability and legitimacy (chapter 5).**

**A thorough review of these issues leads to a comprehensive policy agenda for ISPRM, as presented in the final chapter (chapter 6).**

*Key words:* physical and rehabilitation medicine, rehabilitation, disability, non-governmental organization, organizational development, World Health Organization.

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## FOREWORD

The International Society of Physical and Rehabilitation Medicine (ISPRM) serves as the global agency for Physical and Rehabilitation Medicine (PRM). As a non-governmental organization (NGO) in relation with the World Health Organization (WHO), as an international umbrella organization of PRM physicians, and as a catalyst for international PRM research, ISPRM has a *humanitarian or civil societal*, a *professional*, and a *scientific mandate*. According to its by-laws, ISPRM thus aims to “continuously improve PRM practice and facilitate PRM input in international health organizations with the goal to contribute to optimal functioning and quality of life of people experiencing disability” (1).

Since its foundation in 1999 ISPRM has been increasingly successful in achieving its mission, both within PRM and through its collaboration with the WHO. With its emergence as the pre-eminent international scientific and educational society for practitioners in the field of PRM and its evolving policy role in collaboration with the WHO and the United Nations (UN) system at large, ISPRM is now facing a number of challenges typical for an expanding international NGO.

To address these challenges, the President of ISPRM called for a retreat of the Executive Board, which was held in May 2008 in China. As a result of the retreat an *Organizational Structure Task Force* was appointed. To facilitate the work of the task force and to involve ISPRM’s constituency, a series of discussion papers were mandated and are now published in this special issue on “Developing ISPRM”. The first 2 chapters in this special issue of the *Journal of Rehabilitation Medicine* (JRM) (2, 3) focus on organizational aspects, while the following 4 chapters (4–7) focus on ISPRM’s evolving role from the policy perspective.

The first chapter (2) reviews the history of ISPRM since its foundation in 1999, summarizes current achievements and confronts them with current challenges. The second chapter outlines general approaches to develop ISPRM and how the challenges can be addressed (3). Key aspects include the understanding and positioning of ISPRM within the world architecture of the UN and WHO system and PRM, as well as the need for, and mutual benefits of, developing strong relations with the emerging regional PRM societies. To enhance ISPRM’s scientific mandate, yearly congresses organized by ISPRM’s Central Office based on a defined regional rotation procedure and possibly involving regional societies are discussed. The paper then elaborates on how to promote the field of PRM and to foster a common identity through its official journal and a web of related PRM journals. Finally, approaches to professionalizing ISPRM’s Central Office and overcoming resource restraints are addressed.

The second part of this special issue starts with a chapter on the broader perspective of the world society and health policy depicting the complex world societal situation within which NGOs such as ISPRM have to operate (4). Against this background, the subsequent chapter outlines a policy process

suitable to ISPRM’s evolving role and political mandate (5). The next chapter provides an in-depth analysis of organizational challenges ISPRM faces as an international NGO in official relation with WHO, including legitimate representation of membership, accountability of organizational procedures, and the humanitarian or civil societal mandate to help reach the health-for-all goals as defined by the WHO and the UN (6).

These chapters provide the basis for the final chapter, which summarizes ISPRM’s internal policy agenda in relation to its constituency and its external policy agenda in relation to international institutions, including the WHO, the UN and other NGOs in official relation with WHO (7).

Beyond organizational issues, this special issue emphasizes ISPRM’s particular role in promoting rehabilitation as an essential health strategy and PRM as a crucial discipline in achieving and maintaining optimal human functioning (8, 9). This also includes contributions to the realization of human rights, such as the full participation of individuals experiencing disability in society (10). Since ISPRM’s policy role may be less known to its constituency than the more visible educational and scientific work, this special issue may also raise awareness with regard to ISPRM’s political significance. It is intended to motivate collaborative efforts towards achieving ISPRM’s mission. This will enhance ISPRM’s capacity to contribute to the creation of a political and economic environment that allows PRM physicians globally to provide suitable services along the continuum of care, across health conditions and over the life-span. This will, on the one hand, create benefits for people experiencing disability in terms of more effective and inexpensive rehabilitation services all over the world. On the other hand, the individual PRM physician will profit from an increased social, political and economic recognition of the area.

In this context, it is important to recall the added value that ISPRM’s political action creates for its national and individual membership. Within PRM, only ISPRM can work in co-operation with other international professional organizations and global intergovernmental agencies such as WHO towards an international policy agenda that recognizes the need for an enhancement of the rehabilitation strategy and the role of PRM. ISPRM thus complements efforts of national and regional societies to foster the conditions suitable for PRM physicians’ work at the inter-regional and international level. Most importantly, ISPRM’s policy can contribute to a political and economic environment that allows PRM physicians to provide timely and effective care worldwide and in favour of people experiencing disabilities. ISPRM’s policy role can also contribute to a more coherent understanding of PRM’s field of competence.

All PRM physicians (9, 11, 12), physicians applying the rehabilitation strategy (8), health professionals and researchers in PRM and functioning and rehabilitation at large (13, 14) are called upon to contribute to making ISPRM more visible, effective and efficient, and economically and socially relevant.

These efforts will, on the one hand, in the light of ISPRM's humanitarian mandate, enhance the organization's capacity to contribute to the establishment of suitable rehabilitation services and optimal functioning of people experiencing disability worldwide. On the other hand, the coherence and the influence of the profession will be strengthened, including the enhancement of academic rigor and systematic structure in PRM research.

ISPRM members and readers of JRM are invited to contribute to this discussion and the development of a coherent position of ISPRM within the world health policy, by sending letters to the Editor of the JRM, to the corresponding author, or to ISPRM's central office.

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## ISPRM DISCUSSION PAPER

### CHAPTER 1: ACHIEVEMENTS AND CHALLENGES OF ISPRM

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#### SUMMARY

*This paper describes the history of the International Society of Physical and Rehabilitation Medicine (ISPRM). Past achievements and current challenges are outlined. ISPRM has been successful in setting up a central office, attracting individual and national members, holding international congresses, and establishing relations with the Journal of Rehabilitation Medicine (JRM) as the organization's official journal. ISPRM is currently in official relations with the World Health Organization (WHO) and collaborates closely with WHO's Disability and Rehabilitation team. ISPRM, however, also faces challenges with regard to its growth and the realization of its goals. These include boundaries of voluntary leadership, limited economic resources, the need for enhancing the central office, variations in membership, limits of the current congress bidding system and structure, relations with regional societies, and the need to further develop policies within the field of Physical and Rehabilitation Medicine (PRM) and in relation to WHO and the United Nations system. It is concluded that ISPRM must evolve from an organization, of which the main activities are to hold a biennial congress hosted by a member nation and to provide input to WHO on request, into a professional non-governmental organization (NGO). ISPRM should embark on assuming a leadership role in the further development of PRM within the broader area of human functioning and rehabilitation.*

#### INTRODUCTION

With its emergence as the pre-eminent scientific and educational international society for practitioners in the field of Physical and Rehabilitation Medicine (PRM) and its evolving role in collaboration with the World Health Organization (WHO) and the United Nations (UN) system, the *International Society of Physical and Rehabilitation Medicine (ISPRM)* is now facing a number of challenges. In this first chapter of this Special Issue of *Journal of Rehabilitation Medicine* we review the history of

ISPRM and summarize key achievements since its foundation in 1999. We then outline the challenges ahead.

#### HISTORICAL BACKGROUND OF ISPRM

In 1988, a joint meeting of representatives from the International Rehabilitation Medicine Association (IRMA) and the International Federation of Physical Medicine and Rehabilitation (IFPMR) was held in Toronto, Canada. The objective was to commence developing policies in order to coordinate common activities of the 2 organizations and thus avoid duplication. During this session, it was also agreed to delegate representatives into each others' Boards of Governors and to hold international congresses alternately every 2 years. In a second meeting 2 years later, the desire to work more efficiently and effectively and to avoid unnecessary duplication was re-affirmed.

In 1992 it was agreed by executives of IRMA and IFPMR to create an International Task Force to explore the possibility of merging the 2 associations into a single new organization. From the beginning the Task Force faced a number of challenges regarding the planning of a new organization. After identifying and resolving these issues, it was agreed in 1996 to name the new organization the "International Society of Physical and Rehabilitation Medicine" (ISPRM). John Melvin, Philadelphia USA, was designated to become its first president.

In November 1999 all relevant documents were completed and approved. The IRMA and IFPMR agreed to terminate their activities and initiated a new era under the name of the ISPRM.

#### ACHIEVEMENTS 1999–2008

##### *Central Office*

A decision to establish a Central Office was made during the ISPRM Board of Governors Meeting in Athens, Greece, in September 2000. After a voting procedure, the Central Office was established in Assenede, Belgium. It is currently

Table I. Survey of International Society of Physical and Rehabilitation Medicine (ISPRM) national and individual members 2001–09

	2001	2002	2003	2004	2005	2006	2007	2008 to present
Individuals	637	531	565	558	684	1818	2319	2507
National societies	20	21	29	30	43	47	35	33

headed by Werner van Cleemputte, who has made a personal commitment to strengthen rehabilitation.

Among a wide range of activities the Central Office successfully established a membership organization. It administers the ISPRM newsletter and is contributing to the administration of the society's web page. Likewise, the Central Office is instrumental in the organization of board meetings and the ISPRM congresses. The Central Office has also taken an important role in facilitating communication among ISPRM members in various countries and different parts of the world.

#### Membership

The ISPRM is made up of national and individual members. This structure reflects the merging of 2 previous organizations with differing structures and philosophies of membership. The IFPMR had national societies of physicians who specialized in PRM as members. It focused largely on issues related to the establishment and maintenance of a separate medical specialty. The IRMA had individual members and focused on including all physicians who devoted a major portion of their time to rehabilitation. Its members included physicians from other specialties or countries without PRM societies.

The reasons for including individual members are: (i) to enable PRM physicians to join ISPRM even if their country is not yet an official member of ISPRM; (ii) to include other medical specialists concerned with the care of impairments and disabilities in ISPRM; (iii) to enable members to receive benefits and services directly from ISPRM. Having individual members also provides the possibility to recruit individuals

who are willing to take positions within ISPRM and to engage in ISPRM activities on a voluntary, non-remunerative basis. Another reason is that there might be countries, particularly in the developing world, in which no PRM society exists. Indeed, the recruitment of individual members from developing regions may be the spark for the foundation of national and regional societies.

ISPRM had 20 national members and 637 individual members in 2001. Over the years, the national membership has fluctuated between 20 and 47. Individual membership has ranged from a minimum of 531 to a maximum of 2507 (Table I). An important increase in individual members in 2006 is related to the extraordinary commitment of the Italian Society, which decided to pay a lump sum for all its individual members. In the meantime, Australia, Colombia, France, Thailand, Saudi Arabia, Mexico, the 2 Chinese societies, Cyprus, Portugal, Singapore, Venezuela and Uruguay have also made a commitment to pay a lump sum for their individual members. A further increase in the number of individual members is expected with the upcoming decisions of other national societies to do the same.

#### Congresses

The core internal activity of ISPRM, as of any scientific society, is the organization of scientific congresses. Congresses bring scientists together and foster the exchange of ideas as well as the formation of a common identity. They provide an overview of current topics in the scientific community and foster or generate cognitive interests accordingly.

Since 2001 ISPRM has organized international congresses with an ever-increasing attendance, rising from 1192 attendants in Amsterdam (2001) to 1300 in Prague (2003), 1821 in São Paulo (2005) and 2351 in Seoul (2007) (Table II). From a scientific perspective, all of these congresses were highly successful, as documented in the abstract books and proceedings referenced in Table II. Also, the congress locations can be considered well-balanced, with congresses held or planned in the different ISPRM regions.

Table II. Previous and planned International Society of Physical and Rehabilitation Medicine (ISPRM) congresses

Year	City	Host ISPRM nation	Large ISPRM region	ISPRM region	Congress president	Scientific committee chairs	Participants <i>n</i>	Submitted abstracts <i>n</i>	Book of proceedings
2001	Amsterdam	The Netherlands	EMA	Europe	William Peek	Gustaf Lankhorst	1192	912	(2)
2003	Prague	Israel	EMA	Africa & Middle East (Host nation) Europe (Congress location)	Haim Ring	Nachum Soroker	1300	1100	(3)
2005	São Paulo	Brazil	AM	Latin America	Linamara Battistella	Marta Imamura	1821	951	(4)
2007	Seoul	South Korea	AO	Asia & Oceania	Chang-il Park	Tai Roon Han	2337	1192	(5)
2009	Istanbul	Turkey	EMA	Europe	Önder Kayhan	Gülseren Akyüz			
2011	San Juan	Puerto Rico	AM	Latin America	Veronica Rodriguez	William Micheo			
2013	Beijing	China	AO	Asia & Oceania	Zeyi Cao	Zhilan Peng, Youji Feng			

AM: Americas; EMA: Europe, Middle East, Africa; AO: Asia-Oceania.

### Journals

From the start ISPRM recognized the need for an official journal committed to its mission. Most importantly, an official journal serves as a forum for publications relevant to the internal and external policy process described in Chapter 5 in this special issue (1). The official journal also publishes congress abstracts and CME (Continuing Medical Education)-accredited educational articles. *Disability and Rehabilitation* served as the first official journal of ISPRM, from 2001 to 2009, and has expressed interest in being involved with ISPRM in the future. In 2006 the *Journal of Rehabilitation Medicine* became the second official journal of ISPRM, and a 4-year contract has been signed for 2009–12.

### Collaboration with the WHO and the United Nations system

ISPRM achieves its mission not only through activities within the field of PRM but also by facilitating input into international health organizations (Table III). The basis for ISPRM's work with the governmental system of the UN and its agency for health, the WHO, is its official recognition as a partner organization. On 1 February 2008 ISPRM was re-designated as a professional organization in official relation with the WHO by Alex Ross, the Director of the "Programme on Partnerships and UN reforms of the Director General's Office". The WHO team responsible for the liaison with ISPRM is the Disability and Rehabilitation (DAR) team within the department of Violence and Injury Prevention and Disability (VIP) ([www.who.int/disabilities/en/](http://www.who.int/disabilities/en/)) (7).

Since 1999 ISPRM has contributed continuously to the work of the DAR team, as it has to the work of other WHO teams, including the Classification, Terminology and Standards team (CTS) ([www.who.int/classifications/en/](http://www.who.int/classifications/en/)) (8).

### Collaboration with Disability and Rehabilitation team

The basis for ISPRM's collaboration with the DAR is a 4-yearly ISPRM-WHO work plan in line with the DAR action plan (Electronic Appendix I) and the DAR guiding documents (Electronic Appendix I) (9–12). The current ISPRM-WHO work plan for the period 2008–10 outlines the current activities of ISPRM in collaboration with DAR (Electronic Appendix II).

Activities in collaboration with DAR included contributions to technical guidelines, such as the *technical guidelines for medical rehabilitation*, which is still in progress, and *community based rehabilitation* (12).

ISPRM was also closely involved in the initiation and development of the 58<sup>th</sup> World Health Assembly (WHA) resolution on "Disability, including prevention, management and rehabilitation" and the consideration of the International Classification of Functioning, Disability and Health (ICF) as a reference

framework for the resolution that, among other things, states "Recalling the International Classification of Functioning, Disability, and Health (ICF) (11) officially endorsed at the Fifty-fourth World Health Assembly in 2001" (9).

Since the endorsement of the resolution by the 58<sup>th</sup> WHA in 2005, ISPRM has advised the DAR with regard to the development of the *World Report on Disability and Rehabilitation*, as requested by the resolution through an ISPRM representative on the advisory committee of the report. A number of active ISPRM members are contributing to the report as authors, reviewers and participants of the regional consultations held by the WHO's regional offices. ISPRM also collaborates closely with DAR in the implementation of the ICF and the ICF Core Sets developed under the auspice of the WHO's CTS team.

### Collaboration with the Classification, Terminology and Standards team

In addition to the work with DAR, ISPRM has closely collaborated with the CTS team in the implementation of the ICF in the health sector and, more specifically, medicine and rehabilitation ([www.who.int/classifications/en/](http://www.who.int/classifications/en/)). The close collaboration of ISPRM with both the DAR and CTS team is mirrored by an increasingly close collaboration between these teams within WHO (Fig. 1). This is in the spirit of the WHA resolution on disability and rehabilitation, which emphasizes the need for "intensifying the collaboration within the organization in order to work towards enhancing quality of life and promoting the rights and dignity of persons with disabilities, inter alia by including gender-disaggregated statistical analysis and information on disability in all areas of work" (9).

From the start of the ICF Core Set project in 2000, ISPRM has been the main collaboration partner for the development of ICF Core Sets, the international tools for the assessment of functioning, disability and health in practice, research, statistics and policy (13–17). Over the years ISPRM has maintained a close relationship with the ICF Research Branch of the German WHO Collaborating Center for the Family of International Classifications (DIMDI) ([www.icf-research-branch.org](http://www.icf-research-branch.org)), which is coordinating the WHO's work for development of the ICF Core Sets. A large number of ISPRM members have attended several ICF training workshops at the ICF Research Branch in Munich, Germany and all over the world, for example, in Italy, Hungary, Turkey, Portugal, Latvia, Slovenia, China, Malaysia and South Africa. The work with the WHO regarding the implementation of the ICF is summarized in 4 current articles (18–21) in the *European Journal of PRM* and a book chapter in the upcoming chapter of a textbook on rehabilitation medicine edited by Frontera et al. (22).

Table III. *Mission of the International Society of Physical and Rehabilitation Medicine ISPRM (6)*

#### Mission

The mission of the International Society of Physical and Rehabilitation Medicine, hereinafter referred to as the Society, is:

1. To be the pre-eminent scientific and educational international society for practitioners in the fields of Physical and Rehabilitation Medicine.
2. To improve the knowledge, skills and attitudes of physicians in the understanding of the pathodynamics and management of disability including impairments.
3. To help to improve the quality of life of people with impairments experiencing disability.
4. To provide a mechanism to facilitate Physical and Rehabilitation Medicine input to International Health Organizations.

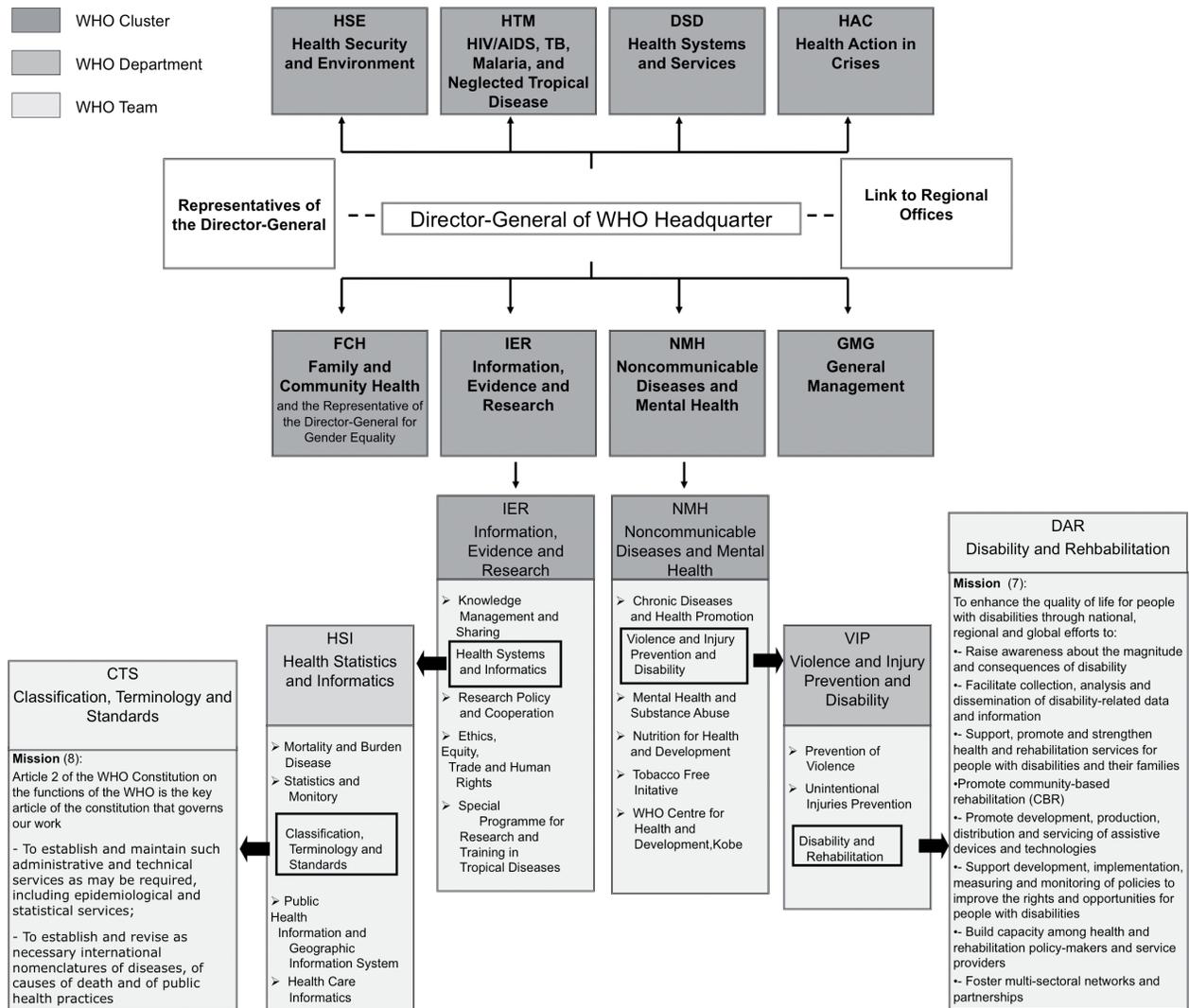


Fig. 1. Structure of the World Health Organization (WHO).

*Collaboration with other WHO teams*

Upon request by the DAR ISPRM has also provided input to a number of other WHO team. ISPRM has, for instance, prepared a description of rehabilitation for the report “Neurological disorders: public health challenges” (23) (Electronic Appendix III).

*Collaboration with the United Nations*

Until now, ISPRM has provided input to and collaborated with the WHO, the UN’s agency for health, but not directly with the UN or other UN agencies, such as the UN Statistics Division (UNSTAT), the UN Educational, Scientific and Cultural Organization (UNESCO) or the International Labour Organization (ILO). Therefore, ISPRM was not directly involved in the process leading towards the UN “Convention on the Rights of Persons with Disabilities” (10). However, ISPRM provided input to the convention’s paragraphs on health (Article 25) and rehabilitation (Article 26) (Table IV) (10) through its collaboration with DAR and its work with the CTS team, who were among the teams representing the WHO.

*International exchanges*

Under the leadership of Mark Young, ISPRM has developed an active exchange mechanism for medical students, trainees and practising physicians as an important part of its educational programme. The comments of those completing these exchanges consistently speak of their value for medical learning and expanded cultural understanding.

CHALLENGES

In the course of the development of its activities within the field of PRM and its collaboration with the WHO and the UN system, the ISPRM leadership has recognized a number of challenges. These need to be addressed to ensure the successful further development of the society. Broadly speaking, the challenges can be grouped into: (i) organizational development; (ii) the role and positioning of the society within the world of PRM; and (iii) policy development.

Table IV. United Nations (UN) Convention: Paragraphs on Health and Rehabilitation (10)

*Article 25 – Health*

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

*Article 26 – Habilitation and Rehabilitation*

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
  - (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
  - (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

*Organizational development*

*Volunteer leadership.* ISPRM is fortunate to have had many effective volunteer leaders to assist it during its formative years, and to have for the future those who have promised to be even more energetic and effective. However, the scope of potential activities available to ISPRM exceeds the time available from volunteers, who must also maintain full-time responsibilities within their own professional lives. The reality of this limitation of available professional talent will continue to place restrictions on what ISPRM can accomplish, and at what rate it can implement changes.

*Economic resources.* As identified in various sections of these papers, ISPRM has had only modest funds available to accomplish its activities. One of its significant challenges will be in developing a plan that results in more resources to accomplish its mission. Incorporated in these papers are ideas on how to increase the availability of funds (1, 24) through organizing some of the ISPRM activities differently. Even so, planning for the future will need to recognize the need for detailed business plans, and the matching of activities to the resources available to accomplish them.

*Central Office.* A major limitation of the functions of the Central Office over the last years has been this limitation of financial resources. While the Central Office was successful in establishing a membership organization, newsletter and web page, it lacked the necessary resources to develop and systematically implement a strategic plan focussing on membership growth, funding activities, and public relations. Because of the current organization of ISPRM congresses by host nations, the Central Office played only a limited role in organizing some

of ISPRM's congresses. Thus, its opportunities to interact face to face with its membership were restricted. Also, the Central Office is currently not involved in the handling of the congress abstracts. Hence, no systematic approach regarding abstracts and congress publications could be implemented.

Over the 9 years of its existence, the Central Office's activities increased dramatically, driving it close to its capacity limit, since ISPRM could not make further monetary investments supporting its organizational growth (24). With the existing limitation, additional work has been contributed by some ISPRM members dedicated to supporting the work of ISPRM. For example, the new ISPRM website is run by a dedicated website committee, with the aim that the website serves as a major source of up-to-date knowledge concerning all aspects of PRM, for the benefit of the general public and rehabilitation professionals around the world. However, clear role delineation is needed to facilitate an effective and efficient functioning of ISPRM.

*Membership.* The fluctuation in the total number of national and individual members creates uncertainty with respect to budgeting and uncertainties during board meetings regarding the eligibility of candidates to hold office. Also, nations who have made a commitment to pay a lump sum for all individual members may feel that the financial burden is shared unequally. On the other hand, the situation must be avoided that all representatives of individual members come from a single, or only a few, national societies.

Related to the fluctuating membership is the limited funding available for the work of the Central Office.

*Congress bidding system and regional representation.* While the ISPRM congresses have been largely successful, the bidding system has raised much concern among ISPRM's membership with regard to the balance of the different ISPRM regions. Regionally balanced congress venues are a core requirement for any international non-governmental organization in official relation to the UN system. Also, from this year on, the ISPRM president is no longer the president of the ISPRM congress. ISPRM is thus challenged to reconsider how it ensures proper communication and involvement of the board with the organizing scientific society from the host country or region.

#### *Role and positioning of ISPRM in the world of PRM*

*Relationship with regional societies.* With its mission to be the pre-eminent scientific and educational international society for PRM, ISPRM is in competition not only with large national societies, e.g. in North America, but even more so with emerging and increasingly strong regional societies. The latter include the Latin American Society of Physical and Rehabilitation Medicine (AMLAR), the newly founded Asia-Oceania Society of Physical and Rehabilitation Medicine (AOSPRM) and the European Society of Physical and Rehabilitation Medicine (ESPRM). Since ISPRM has currently no formal mechanism to work with regional societies with which it shares its constituency it is challenged to define its position in relation to them, e.g. with respect to congresses and official relations with leading international and regional PRM journals.

*ISPRM congresses in the context of regional and sub-regional congresses.* The regional societies, including AMLAR, AOSPRM and ESPRM, as well as sub-regional organizations, including the Mediterranean Forum, hold increasingly large and successful congresses. Through their evolving scientific standards (25, 26), international involvement and ever-increasing attendance rates, the congresses they organize are in clear competition with the ISPRM congresses. Against this background, it is questionable whether the biennial ISPRM congress currently organized by a national PRM society – and thus lacking a constantly developing “social memory” (27) from congress to congress – can serve as main international forum for science and education.

From a more practical perspective, we are now witnessing an “overload” of large PRM congresses. It is unclear whether, and to what extent, funding for an increasing number of major international congresses can be maintained. In the context of the current economic crisis, congress organizers already report difficulties in maintaining recent funding and sponsorship levels. This carries the risk that the field of PRM will lack the focus necessary to rigorously develop its science and practice.

*Relationship with Physical and Rehabilitation Medicine journals.* While ISPRM has successfully established formal relationships with renowned international journals to serve as ISPRM's official journals there are a number of unanswered questions. Should there be 1, 2 or even more official journals?

How should ISPRM handle its relationship with official regional and national journals? Also, the expectations with respect to the official ISPRM journals are currently unclear.

#### *Policy development within the field of PRM and in relation to the UN system and the WHO*

While ISPRM has successfully organized congresses, it has so far not taken a leadership role within the field of PRM and the rehabilitation sciences, e.g. in the definition of the field of competence of the rehabilitation sciences and the profession of PRM. The involvement of ISPRM beyond a few successful projects in the development of policies in relation to the WHO and the UN system at large has been limited. Important policy developments at the regional level have not likely found their way to the international PRM constituency and the WHO. With the exception of educational activities, e.g. in relation to the upcoming ISPRM congress, ISPRM has had a limited role to foster the development of PRM in countries that currently lack rehabilitation services and arguably are most in need of them.

The main reason for this limited international leadership role within the PRM community and in relation to the WHO may be the lack of a formalized internal and external policy process. There is also no systematic mechanism to provide PRM input at the regional level, e.g. to the regional offices of the WHO responsible for developing countries. Another reason for ISPRM's lack of leadership in the policy arena may be that national and regional societies are not likely aware of the unique role and potential ISPRM has with respect to internal and external policy development.

## CONCLUSION

Based on the achievements of its first decade of existence, ISPRM must now evolve from an organization whose main activities were to hold a 2-yearly congress hosted by a member nation and to provide input to WHO on request. The time has come to become a professional non-governmental organization (NGO) that assumes a leadership role in the further development of PRM within the broader area of human functioning and rehabilitation. This requires that ISPRM defines its role and position within the world of PRM and the emerging world society, reviews appropriate policy tools, and develops an internal and external policy process and agenda to meet the demands of its evolving role. Respective approaches we described in subsequent papers of this special issue (1, 24, 28–30).

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#### Electronic Appendices

No	Name of appendix	Available at
I	Disability and rehabilitation WHO action plan 2006–2011 (pdf file).	<a href="http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0438">http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0438</a>
II	WHO/ISPRM collaboration plan for the years 2008–10 (pdf file).	<a href="http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0439">http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0439</a>
III	Extract from the report “neurological disorders” describing the rehabilitation strategy in the context of other public health strategies (pdf file).	<a href="http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0440">http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0440</a>

## ISPRM DISCUSSION PAPER

### CHAPTER 2: ISPRM'S WAY FORWARD

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#### SUMMARY

*This paper outlines approaches to developing the International Society of Physical and Rehabilitation Medicine (ISPRM) and addresses many current challenges. Most importantly, these approaches provide the basis for ISPRM to develop its leadership role within the field of Physical and Rehabilitation Medicine (PRM) and in relation to the World Health Organization (WHO) and the United Nations (UN) system at large. They also address a number of specific critiques of the current situation. A positioning of ISPRM within the world architecture of the UN and WHO systems, as well as the consideration and fostering of respective emerging regional PRM societies, is central to establishing networking connections at different levels of the world society. Yearly congresses, possibly in co-operation with a regional society, based on a defined regional rotation, are suggested. Thus, frustration with the current bidding system for a biennial congress and an intermediate meeting could be overcome. Yearly congresses are also an important step towards increasing the organization's funding base, and hence the possibility to expand the functions of ISPRM's Central Office. ISPRM's envisioned leadership role in the context of an international web of PRM journals complementing the formally defined official journal of ISPRM, regional societies, and so forth, is an inclusive rather than exclusive approach that contributes to the development of PRM journals worldwide. An important prerequisite for the further development of ISPRM is the expansion and bureaucratization of its Central Office, adding professionalism and systematic allocation of resources to the strengths of the voluntary engagement of individual PRM doctors.*

#### INTRODUCTION

With its emergence as the pre-eminent scientific and educational international society for practitioners in the field of Physical and Rehabilitation Medicine (PRM) and its evolving role in collaboration with the World Health Organization (WHO) and the United Nations (UN) system, the International Society of Physical and Rehabilitation Medicine (ISPRM) is now facing a number of challenges. In the first chapter of

this special issue, which aims to involve the constituency in the process of advancing ISPRM, we described the history and achievements of ISPRM since its foundation in 1999 and outlined the current challenges (1).

In order to address these challenges, ISPRM must now evolve into an organization that assumes a leadership role in the development of the field of PRM within the broader area of human functioning and rehabilitation. The objective of this second chapter is to outline approaches as to how ISPRM can achieve this goal. The specific aims of this chapter are: (i) to discuss ISPRM's envisioned future role and position within the world of PRM; and (ii) to describe the development of the Central Office to meet the needs of ISPRM's evolving role.

#### ROLE AND POSITION OF ISPRM WITHIN THE WORLD OF PHYSICAL AND REHABILITATION MEDICINE

ISPRM, as the pre-eminent international society in the field of PRM in official relation with the WHO, is in a unique position to lead and facilitate the worldwide collaboration of scientific organizations, conferences and journals in the field of PRM. Scientific societies, conferences and journals are involved in, sometimes fierce, international competition (2). However, they are also mutually dependent with respect to their common goal to advance their distinct scientific fields. While usually independent and in no formal relationship, scientific societies, journals and conferences should also have an inherent interest in collaborating as long as their specific interests coincide or are at least particularly considered, e.g. in a web of journals (3). In this paper we try to answer the question as to how ISPRM can enhance the current collaboration of PRM societies, conferences and journals.

#### *World architecture of Physical and Rehabilitation Medicine societies*

ISPRM is committed to the UN's fundamental principle of universalism, according to which every individual has the human right to participate in and be a beneficiary of social progress and better standards of life (4). In order truly to embrace this

world societal perspective, it is helpful to act on the assumption of a world architecture, comprising different levels of regional, sub-regional, national and local subunits. Communication and co-operation with the WHO and other institutions of the UN system is facilitated through the orientation of ISPRM towards their subdivision of world regions. Against this background, ISPRM also needs to develop an understanding of its position in the emerging world architecture of PRM societies as well as a vision for its future position. Only then will ISPRM be really capable of leading and facilitating PRM research and practice in collaboration with other PRM institutions worldwide. Table I and Fig. 1 show the current world architecture of PRM from a regional and international perspective in relation to the architecture of the WHO regions.

A number of aspects become obvious from this comparison. First, there are no regional societies in the ISPRM regions of the Middle East, Africa and Northern America. Secondly, there are 2 examples of large regions embracing southern, equatorial and northern parts of the world. The newly founded Asia-Oceanian Society of PRM (AOSPRM) is an example from the PRM perspective, while the Pan-American Health Organization (PAHO) is an example from the WHO perspective. AOSPRM can be considered a model for the development of large regional societies in the other parts of the world. In the future one may accordingly envision a world architecture of PRM with 3 large regions: Asia-Oceania (AO); Europe, Middle East and Africa (EMA); and the Americas (AM).

Three large regional societies working in close collaboration with ISPRM could importantly contribute to the strengthening of PRM from an international perspective. Recognizing also the potential advantages for ISPRM's work, e.g. with respect to the organization of ISPRM congresses as outlined below, ISPRM may consider facilitating the creation of 3 large regional societies. More specifically, ISPRM may, in this respect, closely collaborate with the European Society of PRM (ESPRM) and the Latin American Society of PRM (AMLAR). Through its traditional links and collaboration with the Middle East and the Mediterranean Forum, ESPRM is in a unique position to lead the development towards a large region by reaching out from the northern to the southern hemisphere. AMLAR, a "tried and true" regional society seems ideally positioned to reach out to the northern American countries.

Since there is currently no regional society in the ISPRM region "Middle East and Africa", the evolution of ESPRM

into a tentative European, Middle East, and African Society of PRM (EMASPRM) seems a viable alternative to the creation of regional societies in the Middle East and Africa, which seems unlikely in the near future. Just as AOSPRM, this society may then create 2 committees matched with, and responsible for, the communication with the 2 regional WHO offices within the larger region. Also, many Mediterranean and Middle Eastern countries are already included in the Mediterranean Forum of PRM and are collaborating closely with ESPRM. The envisioned integration of ESPRM with the Middle Eastern and African region also offers the unique opportunity to support PRM physicians in the latter countries with regard to the development of the specialty. This could importantly contribute to overcoming the paradox that PRM is currently least present where it could contribute most. The collaboration of ISPRM and ESPRM in the development of PRM in Africa, the Mediterranean region and the Middle East would also be an important initiative to answer the call of the WHO resolution on disability and rehabilitation "stressing that 80% of people with disabilities, particularly in the child population, live in low income countries and that poverty further limits access to basic health services, including rehabilitation services" (5). Clearly, these regions are most in need of rehabilitation services because of "economic problems, poverty and ongoing social conflicts and wars related to disability" (5). It is also important to note that the integration of Europe with the Middle East and Africa has been a vision of our former president, the late Professor Haim Ring, who was the founder of the Mediterranean Forum. An according development in the spirit of true partnership needs to be fostered from the international level, i.e. ISPRM, in order to avoid any feelings of "being patronized" by the Europeans on the side of Africa and the Middle East.

Since it is unlikely that the USA, Canada and the English-speaking Caribbean countries will organize a regional Northern American society, an alternative would be that these countries join forces with AMLAR, which could evolve into a Pan-American society of PRM (tentatively named American Society of PRM, with the possible acronym AMSPRM). A Pan-American organization would be in line with WHO's regional organization of PAHO and would follow the example of other medical organizations, such as the International Federation of Sports Medicine (FIMS). The integration of the Northern American countries with AMLAR would also be in line with the current paradigm shift in US policy towards increasing international consultation and collaboration on the global level,

Table I. *The world architecture of Physical and Rehabilitation Medicine from regional and international perspectives*

WHO regions	Envisioned ISPRM large regions	Current ISPRM regions	Current regional societies	Envisioned regional societies
The Americas	The Americas (AM)	North America Latin America	na AMLAR	tbd
Western Pacific Asia	Asia & Oceania (AO)	Asia & Oceania	AOSPRM	AOSPRM
The Eastern Mediterranean Africa Europe	Europe, Middle East, Africa (EMA)	Africa & Middle East  Europe	na  ESPRM	tbd

na: not applicable; tbd: to be defined; ISPRM: International Society of Physical and Rehabilitation Medicine; ESPRM: European Society of Physical and Rehabilitation Medicine; AMLAR: Latin American Society of Physical and Rehabilitation Medicine; AOSPRM: Asia-Oceanian Society of Physical and Rehabilitation Medicine; WHO: World Health Organization.

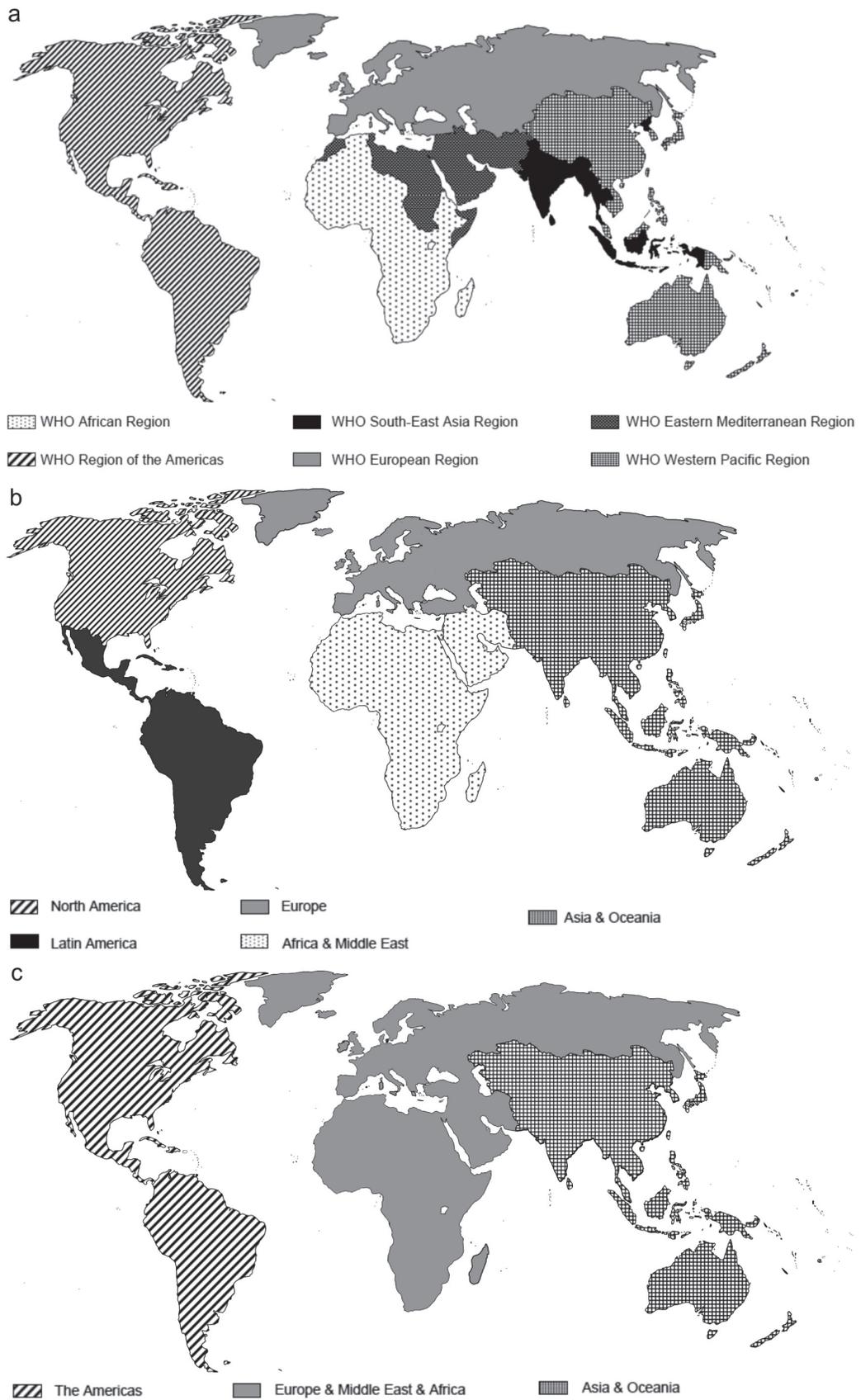


Fig. 1. World regions from the perspectives of: (a) World Health Organization (WHO); (b) International Society of Physical and Rehabilitation Medicine (ISPRM) at present and, (c) envisioned ISPRM large regions.

e.g. within the UN system (6), and the development of a new vision of shared continental interests in collaboration with Latin American countries (7). The integration of the Northern American region with AMLAR could importantly increase the involvement of one of the most active and powerful national PRM societies, the American Academy of PRM (AAPMR) in the regional and hence international arena. This would importantly strengthen the regional and international PRM perspective both within the Americas and globally.

The proposed naming and abbreviation of the envisioned large regional societies are oriented towards the model of AOSPRM, which includes AO as the initial letters, for the included regions Asia and Oceania, S for Society, and PRM for the scientific field. This is because the systematic use of this model would contribute to the development of a common identity for PRM worldwide and easy recognition by international institutions, including the WHO and other non-governmental organizations (NGO).

While ISPRM cannot implement the suggested developments towards 3 large regional societies, it can develop and share its vision of an international PRM architecture, which it considers most suitable for the development of the field. To facilitate such a development it could also redefine its regions, moving from currently 5 regions to 3 large regions. It could further develop formal ties with the large regional societies. In this context it could redefine its current concept of regional vice-presidents, e.g. by providing the large regional societies with the possibility to nominate candidates or even elect the regional ISPRM presidents from members of the regional boards. The idea that ISPRM's vice-presidents should, at the same time, be members of the executive board of the respective regional society seems a preferred option in light of the fact that currently all regional vice-presidents from regions where a regional society exists are members of the respective regional board.

Whether or not ISPRM should develop formal relationships with regional societies is open to debate. A first step may be the development of working procedures for key common activities, such as the organization of joint congresses, as described in a following section.

Although ISPRM may implement its activities to facilitate 3 large international regions, it will need to be pragmatic in its relationships with national and regional societies in order to maintain a fully international presence. Co-operative relationships require that all parties see value in their participation. ISPRM cannot alienate significant national or regional organizations through imposing its vision on them without losing their representation. The ISPRM strategies will need to emphasize persuasion, inclusion and, in all likelihood, gradualism.

#### *ISPRM congresses*

ISPRM's vision is to organize the leading international congress in PRM with respect to scientific quality and attendance. To achieve this goal, ISPRM must overcome the challenges outlined in the first chapter of this special issue (1) and must develop a loyal and engaging participant base through a sus-

tained effort over time. This requires a number of changes in the organization of future ISPRM congresses. They include yearly instead of biennial congresses organized under the scientific and administrative leadership of ISPRM together with a host nation, and, possibly, in collaboration with a relevant regional society. Respective joint committees with representatives of ISPRM, the national host society and the regional society need to be established 2 years ahead of a congress.

*Yearly meetings.* ISPRM cannot develop a profile in each single member nation through congresses organized by a host nation. It could, however, develop a profile in its large regions. This would seem important, since many, if not most, individual members are more likely to attend a meeting within their region than an international meeting held in another, often distant, region, associated with high travel costs. This point has been clearly visible in the previous congresses, where the majority of attendants came from the host country and the respective region. In contrast, the international attendants came mainly from a relatively small group of internationally active members.

A prerequisite for the development of a profile in the regions is a regular presence of ISPRM in each region. Unfortunately, this is not possible with a biennial congress to be held in one out of 5 regions. Not considering variations resulting from the bidding process, ISPRM is currently present in each of its 5 regions only every tenth year.

To enhance ISPRM's presence in the regions it seems preferable to hold an ISPRM congress every year and to rotate systematically within the 3, currently virtual, large ISPRM regions. This would allow individual members to attend an ISPRM congress in their region every third year and hence to develop a loyalty with the congress. As shown in Table III of the first chapter of this special issue (1), the switch to yearly ISPRM congresses would be possible from 2014 onward.

*Joint meetings in collaboration with a regional society and a national society.* A move of ISPRM towards yearly congresses to be held in the 3 large regions potentially intensifies the competition with international congresses organized by regional and sub-regional societies (1). It thus seems crucial to clarify the relationship of ISPRM with the relevant regional societies.

A most attractive solution would be yearly ISPRM congresses in collaboration with regional societies in a triennial rhythm. Since there is only one regional society in Asia-Oceania, the partner would be AOSPRM. In the large region of Europe, Africa and the Middle East, ESPRM, together with relevant national societies from the Middle East and Africa and sub-regional organizations, could serve as the host regional society for this large ISPRM region. In the large ISPRM region of the Americas, the regional society AMLAR could, together with the relevant national societies of the Northern American region, serve as collaboration partner for the triennial ISPRM meeting organized in the Americas. If, as envisioned and following the model of AOSPRM, 2 large regional societies would emerge for Europe, Middle East, Africa and the Americas,

ISPRM could in the future collaborate with these societies in a triennial rhythm.

The main advantage of joint ISPRM-regional society meetings hosted by a national society is the strengthening of both the regional societies and ISPRM. The regional society benefits from a triennial international scientific exchange and international lecturers as well as a worldwide attendance. ISPRM benefits from a broad attendance of ISPRM individual members and non-member PRM physicians from the region who are loyal to their regional society meeting.

To strengthen both ISPRM and the regional societies, the regional societies might decide to move to yearly congresses as well. Besides the ISPRM world congress hosted together with a particular regional society according to the suggested rotation, ISPRM may be present at the 2 other regional congresses that year in a special ISPRM session.

The organization of ISPRM congresses in collaboration with regional societies and hosted by a national society is a major challenge. However, because of the new situation of having presidents who are not at the same time the organizers of ISPRM congresses, ISPRM is, in any case, faced with the challenge to develop suitable procedures with regard to communication and collaboration with the host nation. Therefore, it seems timely to develop a concept involving respective hybrid organizational structures and procedures. There are a number of principles that ISPRM must in the future consider in the organization of congresses in collaboration with a host nation and possibly a regional society.

#### *Principles for ISPRM involvement in congress organization.*

ISPRM's mission to organize the leading international congresses requires that ISPRM takes the lead in their scientific and administrative organization. Up till now the national host and not ISPRM carried the financial burden. ISPRM thus had to accept that it only had a consulting role with respect to the scientific programme and the financial and practical congress organization including the financially relevant registration procedures and industrial exhibition. In the future, ISPRM should consider taking primary responsibility for the scientific and administrative organization. When ISPRM will carry at least part of the financial risk it will have a say in the sharing of the gains.

With regard to the scientific organization, it is suggested that ISPRM in the future establishes joint scientific committees chaired by an ISPRM representative and involving in addition the same number of members representing ISPRM, the national society hosting the congress, and, if applicable, the collaborating regional society. The number of committee members designated by each partner should not exceed 15, and hence 46 members in total including the chairperson provided by ISPRM. Since the committee members designated by ISPRM are the holders of a "collective" or "social" memory (8, 9) and carry the experience from one congress to the next, it is important that ISPRM designates its scientific committee members for a period of several years in a "roll-over" procedure. ISPRM could, for example, elect 5 new members to its scientific committee every year in the case of a committee consisting of 15 members and a term of 3 years.

To ensure accountability with regard to the scientific content it is suggested that ISPRM develops and adopts a topic list that is altered only every few years to include emerging topics or exclude topics of decreasing importance or interest. The definition of a congress topic list contributes to a coherent definition of the field of competence as discussed in chapter 6 of this special issue (10). In light of the envisioned collaboration with the regional societies in the yearly congress, it should be developed in close collaboration with the regional societies AOSPRM, AMLAR and ESPRM. A first version of a topic list for the next ESPRM congress in 2010 in Venice, developed under the auspices of ESPRM (11), may serve as a starting point.

In addition to a congress topic list it would seem important to develop a common basic structure for international PRM congresses to ensure that both, clinically and research-oriented congress participants can count on an attractive programme covering all relevant areas over the years. Based on first suggestions (12), it would again seem useful to develop an internationally conforming basic structure in collaboration with the regional societies.

With regard to the administrative organization, it is suggested that ISPRM should in the future organize the abstract submission process and handle the registration of congress participants together with the national host and in collaboration with the regional partner society. This will ensure continuity with regard to the scientific evaluation of abstract submissions and the possibility of ISPRM's Central Office communicating with its membership at the congress; its only possibility to interact face-to-face.

The handling of these functions will require ISPRM to develop its Central Office accordingly, as described below. Conversely, the organization of sessions, invitations and reimbursements of speakers and exhibitions in the future could also be the responsibility of the national host society. With regard to financial agreements, it is suggested that all partners, be it ISPRM and a host society or, ISPRM, a host society, and, possibly, a regional society receive a similar share from a defined part of the income generated through the congress.

As sponsorship of the congresses by industry is needed to break even, it is advised that a specific congress sponsorship committee should be set up for the recruitment of sponsors for the congress. With yearly congresses, it will become easier to convince sponsoring companies and to continue respective collaborations on a long-term basis. Presently each congress has to start from scratch again. ISPRM should have an important role in this sponsorship committee and provide its chair.

The evolution from the current decentralized model of congress sponsorship to partnerships will require that ISPRM has sufficient resources to accommodate to the risks of losses as well as congress operations. This may require an incremental strategy, perhaps first emphasizing the value of consistency of scientific content from congress to congress (11, 12).

ISPRM's involvement in both the scientific and sponsorship committee would ensure the society's scientific legitimacy by the means of consistency with the Policy and Procedures document (13) and organizational accountability in terms of funding, as outlined in an accompanying paper (14).

## Journals

*Web of Physical and Rehabilitation Medicine journals.* Together with scientific societies and conferences, journals are instrumental in the development of scientific fields. Journals in particular have an important role in the dissemination of research. The publication and discussion of the results of scientific studies are essential in promoting the research process in the direction of a constant approximation of truth in the scientific community and the stimulation of new research questions. Through the breadth and depth of the publications, journals also importantly contribute to a common understanding of a scientific field or "field of competence". In doing so, the visibility of the scientific field from outside is enhanced and identification from inside the field is facilitated (3, 15).

With respect to their common goal, to develop and maintain a distinct scientific field, societies, journals and conferences are mutually dependent. Therefore, a society must decide whether and how it will collaborate with journals of major relevance for its constituency. Beyond organizing "meet the editor" sessions at ISPRM congresses, ISPRM is challenged to define its role in the emerging collaboration of journals sharing its mission.

It is thus suggested that ISPRM considers taking the lead in the development of an international web of journals, building on an initiative by ESPRM for the European region. ESPRM has formalized its relationship with European journals which share its vision, to strengthen the field of PRM within Europe and internationally. ESPRM is envisioning a "web" of journals that collaborate in concert. Through its initiative, ESPRM by no means intends to interfere with the highly competitive scientific publication process of "original work". Researchers will and should publish their research in the most suitable journal irrespective of a particular journal's collaboration with scientific societies such as ESPRM or ISPRM. ESPRM does, however, hope that the envisioned web will contribute to the strengthening of the journals in such a way that they become scientifically more competitive and will attract an increasing number of the best papers in the future (3).

A web of journals can also facilitate the publication of papers that are considered not primarily "scientific", but which are essential for the development of the field of competence. Papers of immediate relevance for the development of the field of competence include guidelines and standards as well as discussion and policy papers developed in collaboration with ISPRM, regional or national PRM societies (10, 16). The same holds true for educational articles, which must find an appropriate forum on the international, regional, language or sub-regional area or national level.

The envisioned web is also intended to facilitate the publication of articles that are of primary relevance internationally, for a specific region, language or sub-regional area, or country. Examples are papers on rehabilitation and health services provision, as well as case studies on rehabilitation care in the context of national or regional healthcare systems. Other examples are language validations of measurement instruments that are typically of interest and relevance to a national or language sub-regional area, but not necessarily to a regional or international readership.

Finally, ISPRM, together with the regional societies, can contribute to the scientific standards for journals by collaborating in the development of standards for the planning of studies and grants and the reporting of studies based on the ICF and the harmonization of author's instructions, as described in more detail in this special issue (10).

There are numerous journals of potential relevance for the field of PRM. The reasons for this are the highly interdisciplinary orientation of rehabilitation and the broad field of functioning and rehabilitation research, ranging "from the cell to society" (17). While it would be possible to develop a far-reaching web of journals in the area of human functioning and rehabilitation (15), it seems preferable to adopt the approach by ESPRM and to develop a web of journals that are clearly dedicated to PRM. Table II shows the current list of journals collaborating in the European web of PRM journals. Tables III and IV show tentative lists of PRM journals in the Asia-Oceanian region and the American region.

*Formal relationships.* If ISPRM decides to follow the model of ESPRM it would need to formalize relationships with individual journals, taking into account the varying scope of each journal and the current level of international competitiveness. ISPRM would accordingly opt for the re-designation of its official journal, the *Journal of Rehabilitation Medicine* (JRM) for administrative and organizational issues, and the fostering of a truly international highly competitive journal. It would then formalize its relationship with journals that publish articles both in English and national languages under consideration of their international scientific competitiveness. All journals that aim to establish official relations with ISPRM would need to fulfil the first 4 out of the 6 criteria shown in Table V. Journals fulfilling all 6 criteria would be "published in association with ISPRM", while journals fulfilling at least 4 criteria would be "endorsed by ISPRM". Editorial boards are selected by the journals on pure scientific grounds and the members do not represent any organization. An appropriate arrangement of the contacts between the organizations and the journal would therefore be to have special contact persons with the specific role of discussing principles for the collaboration between the journal and the organization, including publication of statement papers and educational reviews.

*Official journal.* ISPRM is in the unique position that, since 2006, it has relied on the well-established JRM as its official journal. While the JRM is not owned by ISPRM, it is run by an independent non-profit foundation and published independently of a commercial editor. JRM would welcome a representative of ISPRM as an observer in meetings of its foundation. It sees itself as an international journal based in Sweden covering all aspects of PRM. While already highly international with respect to its editorial board, JRM is committed ultimately to involve scientists on parity from all 3 large ISPRM regions.

Based on its positive experience with the publication of the abstracts from the first AOSPRM congress in 2009 and the ESPRM congress in 2009, JRM is committed to publishing the abstracts from ISPRM or joint ISPRM/regional societies

Table II. *European journals in Physical and Rehabilitation Medicine considered for the European Society of Physical and Rehabilitation Medicine (ESPRM) journal initiative in alphabetical order (3) †*

Official name	English subtitle	Former name	Main language	Country of origin	Other languages	Abbreviation	Publisher	Owner	Societies*	URL (http://)
Annales de Réadaptation et de Médecine Physique	Intended	–	French	France	English	Ann Readapt Med Phys	Elsevier	SOFMER	SOFMER	www.elsevier.com/wps/find/journaldescription.cws_home/505808/description#description cre.sagepub.com
Clinical Rehabilitation	–	–	English	UK	–	Clin Rehabil	SAGE Publications	SAGE Publications	BSRM VRA	www.minervamedica.it www.ejprpm.org
European Journal of Physical and Rehabilitation Medicine	–	Europa Medicophysica	English	Italy	–	Eur J Phys Rehabil Med	Edizioni Minerva Medica	Edizioni Minerva Medica and Italian Society of Physical and Rehabilitation Medicine	ESPRM SIMFER MPPRM EEFIAP TSPRMS	
Fizikalna i Rehabilitacijska Medicina	Intended	–	Croatian	Croatia	English	Fiz Rehabil Med	CSPRM	CSPRM	CSPRM	
Journal of Rehabilitation Medicine	–	Scandinavian Journal of Rehabilitation Medicine	English	Sweden	–	J Rehabil Med	Foundation of Rehabilitation Information	Foundation of Rehabilitation Information	ISPRM	www.medicaljournals.se/jrm
Medicina Fisica e Reabilitação	Intended	–	Portuguese	Portugal	English French Spanish	–	SPMFR	SPMFR	SPMFR	
Physikalische Medizin, Rehabilitationsmedizin und Kurortmedizin	Journal of Physical and Rehabilitation Medicine	–	German	Germany	English	Phys Med Rehab Kuror	Thieme-Verlag	Thieme-Verlag	DGPMPR ÖGPMPR	www.thieme.de/fz/physmed www.thieme-connect.de/ejournals
Romanian Journal of Physical and Rehabilitation Medicine	–	Revista de Recuperare, Medicină Fizică și balneologie	English	Romania	Romanian	Ro J Phys Rehabil Med	“Carol Davila” University Press. Bucharest	SRFMR	SRFMR	

\*Some journals may also have relationships with other organizations than shown in the table (e. g. Journal of Rehabilitation Medicine is also the official journal of the Physical and Rehabilitation Medicine Board of the European Union of Medical Specialists (UEMS) and the European Academy of Rehabilitation Medicine).

†Additional European journals, e. g. from Spain and Turkey, are currently also under consideration.

BSRM: British Society of Rehabilitation Medicine; CSPRM: Croatian Society of Physical and Rehabilitation Medicine; DGPMPR: Deutsche Gesellschaft für Physikalische Medizin und Rehabilitation; EEFIAP: Hellenic Society of Physical and Rehabilitation Medicine; ESPRM: European Society of Physical and Rehabilitation Medicine; ISPRM: International Society of Physical and Rehabilitation Medicine; MPPRM: Mediterranean Forum of Physical Medicine and Rehabilitation; SIMFER: Italian Society of Physical and Rehabilitation Medicine; SOFMER: Société Française de médecine physique et de réadaptation; SPMFR: Sociedade Portuguesa de Medicina Fisica e de Reabilitação; SRFMR: Societatea Medicină Fizică și de Recuperare; VRA: Nederlandse Vereniging van Revalidatieartsen; TSPRMS: Turkish Society of Physical Medicine and Rehabilitation Specialists; ÖGPMPR: Österreichische Gesellschaft für Physikalische Medizin und Rehabilitation.

Table III. *Asia-Oceanian journals in Physical and Rehabilitation Medicine in alphabetical order*

Official name	English subtitle	Former name	Main language	Country of origin	Other languages	Abbreviation	Publisher	Owner	Sponsored by	Societies	URL (http://)
Asia Pacific Disability Rehabilitation Journal	-	-	English	India	-	-	National Printing Press	Sponsored by Action for Disability Cordaid	Action for Disability Cordaid	Action for Disability Cordaid	www.aifo.it/english/resources/online/apdrj/journal.htm
Chinese Journal of Physical Medicine and Rehabilitation	-	Chinese Journal of Physical Medicine	Chinese	China	English abstract	-	Chinese Journal of Physical Medicine and Rehabilitation Editing Committee	Chinese Medical Association Medical School of Hua Zhong Science & Technology University	Chinese Medical Association	CSPRM	www.cjpmr.cn/zhwl/WEB/InitialPage.aspx
Chinese Journal of Rehabilitation	-	-	Chinese	China	-	-	Chinese Electronic Periodical Services	China Disabled Persons Federation Chinese Rehabilitation Society	China Disabled Persons Federation	CARDP	www.zgckkf.com/
Chinese Journal of Rehabilitation Medicine	-	-	Chinese	China	English abstract	-	Chinese Electronic Periodical Services	Ministry of Health, China Chinese Rehabilitation Society	Ministry of Health, China Chinese Rehabilitation Society	Chinese Association of Rehabilitation Medicine	www.rehabi.com.cn/ch/index.aspx
Chinese Journal of Rehabilitation Theory and Practice	-	-	Chinese	China	English abstract	-	Chinese Electronic Periodical Services	China Disabled Persons Federation Chinese Rehabilitation Society	China Disabled Persons Federation	CARDP	www.ertc.com.cn/trsweb/search.wct?channelid=8583
Clinical Rehabilitation Tissue Engineering Research	-	Chinese Clinical Rehabilitation	Chinese	China	English	-	Chinese Journal of Clinical Rehabilitation Press	Chinese Rehabilitation Research Center	Chinese Rehabilitation Medical Association	CARM	en.zgckkf.com/sites/English/List_2025_9463.html
Japanese Journal of Rehabilitation Medicine	-	-	Japanese	Japan	English abstract	Jpn J Rehabil Med	JARM	JARM	JARM	JARM	www.soc.nii.ac.jp/jarm/
Journal of Thai Rehabilitation Medicine	-	-	Thai	Thailand	English	J Thai Rehabil Med	Suthin Publisher, Chiangmai	The Royal College of Psychiatrists of Thailand	TRMA	TRMA	www.rehabmed.or.th
The Journal of Korean Academy of Rehabilitation Medicine	-	-	Korean	Korea	English abstract	J Korean Acad Rehabil Med	KARM	KARM	KARM	KARM	www.karm.or.kr

CARDP: China Association of Rehabilitation of Disabled Persons; CARM: Chinese Association of Rehabilitation Medicine; CJRTP: Chinese Journal of Rehabilitation Theory and Practice; CJPMR: Chinese Journal of Physical Medicine and Rehabilitation; CSPRM: Chinese Society of Physical Medicine and Rehabilitation; JARM: Japanese Association of Rehabilitation Medicine; KARM: Korean Academy of Rehabilitation Medicine; TRMA: Thai Rehabilitation Medicine Association.

Table IV. American Journals in Physical and Rehabilitation Medicine in alphabetical order

Official name	English subtitle	Former name	Main language	Country of origin	Other languages	Abbreviation	Publisher	Owner	Societies	URL (http://)
Acta Fisiátrica	—	—	Portuguese	Brazil	English abstracts	Acta Fisiatr	Divisão de Medicina de Reabilitação Hospital das Clínicas, University of São Paulo School of Medicine	Divisão de Medicina de Reabilitação Hospital das Clínicas, University of São Paulo School of Medicine	—	www.actafisiatrica.org.br
American Journal of Physical Medicine & Rehabilitation	—	—	English	USA	—	Am J Phys Med Rehabil	Lippincott Williams & Wilkins	AAP	AAP	www.amjphysmedrehab.com/
Archives of Physical Medicine and Rehabilitation	—	—	English	USA	—	Arch Phys Med Rehabil	Thomson Reuters	Elsevier	ACRM	www.archives-pmr.org/
Boletín de Rehabilitación Médica	—	—	Spanish	Venezuela	—	Bol Rehabil Méd	Ministerio de Sanidad y Asistencia Social, Departamento de Rehabilitación Médica	—	—	—
Jornal do Fisiatra	—	—	Portuguese	Brazil	—	—	ABMFR	ABMFR	ABMFR	www.fisiatria.org.br/
Medicina de Reabilitação	—	—	Portuguese	Brazil	English abstracts	Med Rehabil	ABMFR	Centro de Estudos e Pesquisa Medicina de Reabilitação	AMLAR ABMFR SPMFR ASCEP	—
PM&R	—	—	English	USA	—	PM&R	Elsevier	AAPM&R	AAPM&R	www.pmrjournal.org/
Reabilitar	—	—	Portuguese	Brazil	—	—	—	—	—	—
Rehabilitación: enfoque integral de la discapacidad	—	—	Spanish	Argentina	—	—	—	—	—	—
Revista Argentina de Rehabilitación	—	—	Spanish	Argentina	English abstract	—	SAMFYR	SAMFYR	SAMFYR	www.samfyr.org/revista_argentina2.php?td=12
Revista Colombiana de Medicina Física y Rehabilitación	—	—	Spanish	Colombia	English abstract	—	ASCMF&R	ASCMF&R	ASCMF&R	ascmf.homesite.com/publicaciones.html#anchor_15
Revista Medicina Física e Reabilitação	—	—	Portuguese	Brazil	—	—	SPFMR	SPFMR	SPFMR	www.spmfr.org.br/revista.asp
Revista Mexicana de Medicina Física y Rehabilitación	—	—	Spanish	Mexico	English	Rev Mex Med Fis Rehab	SMMFR	SMMFR	SMMFR	www.medigraphic.com/espanol/e-hms/e-fisica/em-mf.htm

AAP: Association of Academic Physiatrists; AAPM&R: American Academy of Physical Medicine and Rehabilitation; ABMFR: Associação Brasileira de Medicina Física e Reabilitação; ACRM: American Congress of Rehabilitation Medicine; AMLAR: Latin American Society of Physical and Rehabilitation Medicine; ASCEP: Associação de serviço à criança Excepcional; ASCMF&R: Asociación Colombiana de Medicina Física y Rehabilitación; SAMFYR: Sociedad Argentina de Medicina Física y Rehabilitación; SMMFR: Sociedad Mexicana de Medicina Física y Rehabilitación; SPFMR: Sociedade Paulista de Medicina Física e Reabilitação; SPMFR, Sociedade Brasileira de Medicina Física e Reabilitação.

Table V. *Criteria for the collaborations of journals in Physical and Rehabilitation Medicine with the International Society of Physical and Rehabilitation Medicine (ISPRM) (3). Fulfilment of all 6 criteria qualifies for "publication in association with ISPRM", fulfilment of the first 4 criteria qualifies for "endorsed by ISPRM"*

Criteria	Description
I	Publications in English (It is possible to publish articles in other languages if an English abstract is provided)
II	English title or subtitle referring to the medical specialty Physical and Rehabilitation Medicine (It is possible to carry a title or subtitle in another language)
III	Involvement in the editorial board of at least 2 ISPRM scientists named by the journal in consultation with ISPRM
IV	Provision of space for ISPRM relevant information
V	Impact Factor should exist
VI	Citation in relevant databases such as Medline

hosted by an ISPRM member country in the future. JRM is also committed to publishing a reasonable number of discussion and policy papers concerning ISPRM's internal and external policy process, as described in accompanying chapters of this special issue (10, 16). These papers would be reviewed in order to meet the scientific standards of the journal.

The JRM is currently not an open access journal. However, it provides free access to its articles after one year. In addition, it provides open access to selected reviews, special reports and educational articles. More importantly, all individual members of ISPRM have immediate access to the electronic version of the journal. To benefit as many individual members as possible worldwide, it is therefore important to encourage national societies to negotiate a flat fee for all its individual members.

#### DEVELOPMENT OF THE CENTRAL OFFICE

One of the most important organizational challenges to ISPRM is to further develop its Central Office. In order to meet the challenges set out in the first chapter of this special issue, it is suggested that ISPRM strengthens its Central Office in order to make it an even more important and supportive part of ISPRM's development efforts and goal attainment (1).

##### *General principle*

The general principle behind this development is the change from voluntary engagement of charismatic persons to bureaucratic authority (14, 18). Clearly, this pre-supposes higher financial investment.

*Additional professional staff.* Ideally, in the future the manager or central executive officer (CEO) of ISPRM who should have experience in PRM as well as in professional management is supported by additional staff. This should be, on one hand, vertically integrated middle management and assistants to whom specific fields such as public relations and tasks in relation to ISPRM's strategic plan (16, 19) may be delegated, and horizontally integrated consultants with expertise in specific areas of PRM.

*Financing change – a first step.* A first step towards financing such a bureaucratic expansion of the Central Office might be, as mentioned above, to place the organization of ISPRM congresses and the administration of subsequent fees into ISPRM's, i.e. the Central Office's, hands. Also, ISPRM membership of national societies might in the future be limited to combined membership, so that all national societies would have to pay a lump sum for their individual members (1). In addition to the financial advantages, this would spread the ISPRM mission within a large number of individual members, e.g. through open access to ISPRM's official journal.

##### *Key duties of the Central Office*

In addition to the envisioned involvement of the congress organization, a set of key duties of the enhanced Central Office would exist. These would be centred on membership management and liaison and fundraising activities.

*Membership management and liaison duties.* A key duty would be to enhance membership management, including the collection of membership fees and the recruitment of national and individual members worldwide.

Additionally, the Central Office would foster liaison with other PRM societies, other professional organizations in official relation with the WHO, such as the World Federation for Occupational Therapy (WFOT), as well as government representatives. This would link the development of ISPRM's activities directly to the agendas of other key players (20).

*Public relations and fundraising.* Another key duty would be the representation and presentation of ISPRM and its activities to international media, thus communicating the society's visions and goals to a global audience (21).

Finally, and elementary in bolstering the growth of ISPRM's influence in the future, the Central Office would – in close collaboration with the board, ISPRM's sponsorship committee, and its educational and development fund envision, compile, and manage the strategic plan, including fundraising activities, in particular the creation of new funding streams.

These new funding streams into ISPRM from private or public sources would, on one hand, be used to finance ISPRM's internal organizational tasks and activities. On the other hand, these new streams would be redirected to support projects in possible global public private partnerships (GPPP) with the goal of delivering rehabilitation services in developing countries (22). ISPRM may, in the future, facilitate such projects by offering consulting with regard to their implementation, supervision and monitoring of standards (10).

##### *Preliminary objectives and first tasks of the enhanced Central Office*

In order to build and maintain such a pivotal organizational structure 2 preliminary objectives are at hand: firstly, to employ additional management and public relations experts via professional recruitment; secondly, to create new and readjust current funding streams to establish a sufficient Central Office budget for the challenges ahead. Then, a sequence of important tasks can be managed.

*Central contact database.* The first task of the Central Office management would be to set up a central database of all existing and new PRM relevant networking contacts, including regional and international, individual and institutional contacts in the private and public realm.

These include: all national and regional PRM societies, other international, regional and national NGOs relevant to PRM including other health professional societies (20) and disability advocacy organizations, governments, government ministries and institutions, health experts from different political parties, private companies, existing GPPPs (22, 23), social movements postulating the establishment of rehabilitation services, interest groups, and the mass media.

*Public relations network.* Secondly, a public relations network would be set up (24). To this end, a set of appropriate networking tools would be defined. Among these are face-to-face contacts, telephone calls to private and public contacts, e-mail, posters and presentations, speeches, specially organized ISPRM venues (congresses, meetings, lunches, dinner speeches, open-spaces, fundraising venues), sponsorship, etc. Since different communication tools involve different levels of media richness, i.e. types of information (e.g. emotions, content, pictures) which can be exchanged, each tool or combination of tools may be used for specific communication goals (25, 26).

*Management of ISPRM presence at relevant venues.* Thirdly, according to the ISPRM strategic plan, the Central Office would review relevant venues worldwide where ISPRM should be present. Public relations activities (27) are to raise aware-

ness within the world society and nation states necessary for the acquisition of new funding streams (28).

Relevant venues may include PRM congresses and scientific meetings, international and national trade fairs, exhibitions, public and closed government sessions and consultations at the international, regional, sub-regional, national, and local level, as well as private venues sponsored by companies relevant to PRM.

ISPRM's Central Office would also organize new kinds of venues to present ISPRM's activities and discuss these with different groups. Discussion forums (open spaces) and expert meetings with representatives from media, politics, the private sector and other interest groups such as disabled persons organizations (DPOs), development projects, capacity building initiatives, and so forth, would be held.

At all of the above-mentioned venues members of the Central Office's public relations team and ISPRM regional representatives would make direct face to face contact and create new networking links and concrete agreement on new partnerships towards a boundary-less enterprise (29). These joint partnerships may be contracted sponsorship agreements, joint programme agreements, joint public relations initiative agreements and many more. At the centre of these networking initiatives would, of course, be the planned yearly congresses organized by ISPRM itself.

## CONCLUSION

The outlined approaches for developing ISPRM address many challenges. They provide the basis for a respective decision process within the responsible bodies of ISPRM (Table VI).

Table VI. Summary of issues and decision points on "developing International Society of Physical and Rehabilitation Medicine (ISPRM)"

Issues	Decision points
Enhancing the ISPRM policy process and agenda	Establishing a systematic internal policy process in relation to the PRM constituency Establishing an external policy process in relation to WHO, other professional organizations and NGOs Systematic development of quadrennial policy agendas for the internal and external policy process Systematic development of the networking in relation to the external policy process through participation and initiation of relevant meetings
Professionalization of the Central Office	Organization of the ISPRM congress through the ISPRM Central Office Generation of the funding necessary for the professionalization and expansion of the Central Office through the income generated by the organization of yearly ISPRM congresses and development of a sponsor network Co-ordination of the internal and external policy process and planning of the policy agenda through the Central Office staff Participation and initiation of relevant meetings in relation to the external policy process through the Central Office staff in collaboration with ISPRM officials
Enhancing ISPRM congresses	Move to yearly ISPRM congresses (earliest possibility, 2014) Systematic rotation of the congress location in the 3 large regions Asia/Oceania, Europe/Middle East/Africa, Americas Organization of the ISPRM congresses by its Central Office Co-operation in the ISPRM congresses with the regional societies AOSPRM, ESPRM and AMLAR
Enhancing PRM journals	Nomination of JRM as ISPRM's only official journal Observer role of ISPRM's Central Office in the non-profit foundation running JRM Publication of articles relevant for the internal and external policy process in ISPRM's official journal (JRM) Fostering of PRM journals worldwide through the facilitation and collaboration with webs of journals in the 3 large regions
Establishing collaborations with the regional societies	Co-operation with the regional societies AOSPRM, ESPRM and AMLAR in the yearly ISPRM congress Facilitation of the evolution of current regional societies towards large regional societies in Europe/the Middle East/Africa and the Americas Nomination of the regional ISPRM vice presidents by the regional societies AOSPRM, ESPRM and AMLAR

PRM: Physical and Rehabilitation Medicine; JRM: Journal of Rehabilitation Medicine; NGO: non-governmental organization; ISPRM: International Society of PRM; ESPRM: European Society of PRM; AMLAR: Latin American Society of PRM; AOSPRM: Asia-Oceanian Society of PRM; WHO: World Health Organization.

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## ISPRM DISCUSSION PAPER

### CHAPTER 3: INTERNATIONAL NON-GOVERNMENTAL ORGANIZATIONS IN THE EMERGING WORLD SOCIETY: THE EXAMPLE OF ISPRM

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#### SUMMARY

*Using the International Society of Physical and Rehabilitation Medicine (ISPRM) as a case in point, the paper describes the complex world societal situation within which non-governmental organizations (NGOs) that address health issues have to operate. In particular, as an international organization in official relation with the World Health Organization (WHO), ISPRM is confronted with a variety of responsibilities and a true world health political mandate. The accompanying rights need to be played out in relation to its own internal member organization and external allies. The theory of the world society and the current situation are briefly reviewed. The role of international NGOs within the world health polity, rehabilitation and Physical and Rehabilitation Medicine (PRM) is highlighted, whilst special emphasis is placed on NGOs in official relation with WHO. Functions, dysfunctions and challenges of international NGOs operating in the health sector are discussed. Against this background, key approaches to enhance ISPRM's political role are analysed. These include transparent and accountable development of the organization, the differentiation between internal and external policy relations, the harmonization of organizational structures and procedures, the consequential use of political structures available to influence WHO's agenda, and the identification of other policy players of major relevance to PRM in order to build strategic alliances with external partners and to enhance ISPRM's membership base.*

#### INTRODUCTION

The notion that health is mainly a matter of chance, one's genetic endowment and personal lifestyle has slowly been complemented by the view that everyone has the right to the highest attainable level of health, or more simply, "the right to health" (1, 2). This is clearly seen in the various World Health Organization (WHO) initiatives promoting 'health for all' (3),

i.e. the right to health care and other conditions necessary for good health on an equal basis with others, for example access to food and clean water (4). Moreover, the United Nations Millennium Development Goals (5) and many UN treaties and declarations of human rights (2,4,6,7) may be cited. The rationale for such a right is that health, unlike other elements of human well-being, is not only a good thing in itself, it is instrumental to every life plan or aspiration that an individual might have (8). Moreover, health is increasingly conceived as being contingent on environmental factors at the micro, meso and macro level (9), including products, services and policies, of which the modification may facilitate the realization of rights to health (10–12). Health is herein increasingly understood broadly as a matter not merely of the absence of disease, but of optimal human functioning (10, 13, 14). This rephrasing of the often questioned WHO health definition (15–17) makes the link between health and disability explicit and provides a framework for classification and measurement (18, 19).

In the area of functioning and disability, we currently face a paradigm shift from a medical and charity approach to a "human-rights approach to disability" (6, 20). Sparked by the social model of disability (21), the focus has shifted from special to equal treatment and full social inclusion (22–24) of people with disability (25). This has recast the basic aim of rehabilitation as an essential health strategy of achieving and maintaining optimal human functioning (26), which in turn is closely linked to quality of life and – in the human rights context – to social inclusion and full participation of individuals experiencing disability (6, 25). Within rehabilitation, Physical and Rehabilitation Medicine (PRM) plays an essential role in implementing this fundamental strategy (26–28).

At the same time, rehabilitation in general, and PRM specifically, must operate against the background of persistent world social and political issues. These include continuous discrimination against persons with disabilities (6), the lack of adequate rehabilitation services, particularly in low and middle income countries of the world (6, 29, 30), conflicting defini-

tions and standards of PRM (27, 28, 31, 32), and the absence of adequate research capacity in disability and rehabilitation (33, 34). Non-governmental organizations (NGOs) can play a major role in addressing these worldwide problems, complementing the efforts of international governmental organizations (IGOs), and counterbalancing the self-interest of nation states and private enterprises (35–37).

As an international NGO of physicians (7) in official relation with WHO (38), the International Society of Physical and Rehabilitation Medicine (ISPRM) clearly has a humanitarian or civil-societal (36, 39, 40), a professional (27, 41) and a scientific (33, 34) mandate to addressing the obstacles to realizing the right to health and taking responsibility for its larger constituency. The three mandates are interlocked and include contributions to the establishment of rehabilitation services worldwide (29, 30), the development of PRM as a coherent and globally-recognized profession (27, 28), and the building of international research capacity in human functioning and rehabilitation (41, 42). Internationally, ISPRM is one of the professional health organizations that has put these global issues on its agenda (43) and has gone on record to contribute to realistic solutions (44).

Pivotal to the success of ISPRM in this endeavour is an explicit, systematic and transparent delineation of policies suited to exert influence from an international perspective. A necessary prerequisite for this is a realistic understanding of the current world societal situation and ISPRM's position in the world health policy. Without awareness of the complexities of the world situation, it would not be possible to identify policy tools with which ISPRM could make a constructive impact on health policy (45), or to develop those policy processes and organizational structures (45, 46) that ISPRM could use to define and implement its policy agenda (43).

The aim of this paper is to develop a comprehensive understanding of, firstly, the position of international NGOs in the world society at large, and the world health polity, rehabilitation and PRM in particular, and, secondly, of key approaches to how ISPRM can enhance its weight in health policy.

The specific objectives of this paper are: (i) to describe briefly the basic features of the current world societal situation; (ii) to describe the role of NGOs in general and of ISPRM in particular; (iii) to discuss potential functions and dysfunctions of NGOs within the world health system; and (iv) to outline basic approaches to address respective challenges. These include: (a) the set-up of a transparent and accountable discourse on ISPRM's structures and processes; (b) the differentiation between internal and external relations; (c) the harmonization of ISPRM's structures and procedures with WHO; (d) mechanisms to influence WHO's agenda; (e) the identification of other key external actors within the world health policy of major relevance to ISPRM; and (f) toe-holds to enhance ISPRM's membership base.

### BASIC FEATURES OF THE CURRENT WORLD SOCIETAL SITUATION

Although this is obviously not the place for a complete description of the current world societal situation, a few fundamental

observations may set the stage. Clearly, in today's world there are global resource dependences (47) and an uneven distribution of power and influence within global policy. There are also enormous inequalities of health and functioning around the globe (11, 30). At the same time, there are augmented opportunities for international NGOs such as ISPRM to intervene and contribute solutions.

The most obvious source of these opportunities is the global interconnectedness of communications, accompanied by a growing permeability of national boundaries with regard to economic, political, social and scientific exchange (48–50). This global interconnectedness of communications, actions and resources may be viewed as the essence of what has been labelled the world society (24, 51, 52). These, and related developments such as a world mass media system (53, 54) and global telecommunication and information technologies such as the internet (55), have contributed to what amounts to a world culture (56–58), or even a worldwide civil society based on universal humanitarian values (7, 8, 20, 40, 59, 60). The WHO Civil Society Initiative (CSI) (39, 61) is but one manifestation of this world culture.

### World health system

Clearly, a world health system has emerged in recognition of global health risks, such as infectious diseases, environmental pollution, and poverty (62, 63). We are witnessing the development of global health governance (64) to deal with these global threats to health. Moreover, many behaviours and factors formerly not considered as relevant to health are now being seen as determinants of health, and thus as issues for future interventions and policies (65, 66). This is, for instance, expressed by a new understanding of functioning and disability (6, 10, 13, 14). The distinction of functioning and disability classifiable with WHO's ICF is herein orthogonally positioned to the classical distinction between health and ill-health (health condition in the language of the ICF) classifiable with WHO's International Classification of Diseases (ICD). So, for example, the prevention of health conditions in disabled persons becomes a public health issue (26, 27, 67, 68). In relation to the other rehabilitation professions and other medical strategies, PRM has a particular role within the health system in promoting functioning as well as diagnosing and treating health conditions (Fig. 1).

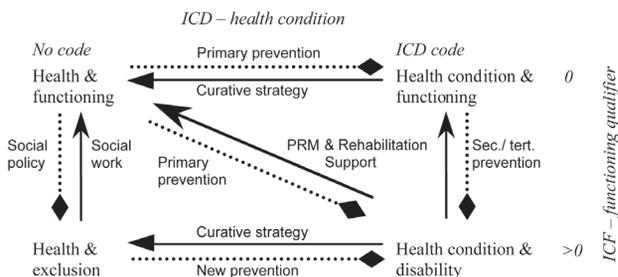


Fig. 1. Two different codes of the health system: health condition and functioning as targets of different health strategies. ICD: International Classification of Diseases; ICF: International Classification of Functioning Disability and Health; PRM: Physical and Rehabilitation Medicine.

On the level of the society, every decision, for example, whether to invest in coal-fired power plants, to promote sports or to balance the budget, once viewed as purely national economic or political issues, may now be conceived of as issues with direct health consequences and potential global impact (65).

At the organizational level, there are growing tendencies towards global diffusion and convergence of organizational structures and standards, such as WHO's ICF, arising from world cultural rationality (51, 56, 69–71). In organization sociology, this phenomenon has been labelled institutional isomorphism (70, 72). Examples of these tendencies are shifts within the legitimacy management of international NGOs that are related to the increased expression of universalism of human rights, such as the right to health.

#### *Global health inequalities*

By no means have these developments towards global connectedness and the convergence of values and aspirations disturbed the underlying inequalities of resources and unequal realizations of those values and aspirations such as health. Arguably, some developments, such as globalized capitalism or global health risks, have produced and enhanced many of the inequalities between world regions and social strata (73, 74). Others, such as the UN Convention on the Rights of Persons with Disabilities, are prescriptions rather than descriptions, which are actually articulated by international institutions *because* a great part of the world population is *de facto* excluded from their realization. Their impact is, nonetheless, global in nature: a particular state may disapprove of them and pretend to ignore them, but in the long run not taking notice is almost impossible. Many “ignored” international initiatives come back to state parties through “home grown” social movements (51) or prominent ambassadors. At the same time, different local cultures, including different cultural constructions of disability (75), continue to exist in the world society (76). These views sometimes struggle with world cultural imperatives (77), sometimes lead to different pathways of implementation and innovation. The latter is accounted for in the world cultural concept of diversity (57, 78), the former makes negotiations under the banner of “cultural sensitivity” inevitable (20).

#### *Rehabilitation systems and low resourced settings*

The World Health Assembly (WHA) Resolution 58.32 stresses “that 80% of people with disabilities, particularly in the child population, live in low-income countries and that poverty further limits access to [...] rehabilitation services [...]” (30). Against this background, the call of the UN Convention that “States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services” seems a Sisyphean task. The UN Convention explicitly recognizes “the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in

developing countries [...]” (6). ISPRM as a global PRM society is clearly addressed by these calls.

Very few data are available on rehabilitation services in low resource settings. Haig et al. (29), for instance, show that in Sub-Saharan Africa virtually no rehabilitation services are available. This means that even middle- and upper-class Africans cannot access medical rehabilitation. Obviously, there *is* a demand but *no* supply. The most difficult and important challenge, however, lies in addressing the needs of the many poor persons living with disabilities in low-resourced settings. ISPRM is thus called upon to make a two-fold contribution. On the one hand, the establishment of a market for rehabilitation services may be facilitated, while, on the other hand, markets need to be made accessible to the poor by fostering efficient service provision and compensating market failure through NGO and government provision of services or subsidies.

A major problem, also identified during a May 2008 meeting of WHO DAR (Disability and Rehabilitation) and professional rehabilitation organizations, including ISPRM, the World Confederation of Physical Therapists (WCPT) and the World Federation of Occupational Therapists (WFOT), is the “high level of migration from less developed countries (brain drain)”, meaning “that trained professionals leave their countries for higher salaries and better recognition”, as documented in the meeting minutes (79).

Against this backdrop, the potential role of international NGOs in health and rehabilitation is clear but challenging. There is a need to address inequalities of health and functioning and dysfunctions of current economic and political systems within the world society, while simultaneously accounting for cultural diversity. At the same time, world societal structures need to be utilized to reach this objective.

### THE ROLE OF NGOS IN THE WORLD SOCIETY AND WORLD HEALTH POLITY

Worldwide, a constantly increasing number of NGOs or Civil Society Organizations (CSOs) have taken on roles and participated in achieving tasks once managed exclusively by states and international state initiatives (56, 61, 80, 81). NGOs are beginning to play a major role in bridging the gap between formulated policy principles and social and political reality (36, 80). They often expand beyond national boundaries and many are expected to uphold civil rights principles and world societal public interests against powerful trans-national business interests, national self interest, and conflicts between rich and poor areas (35, 80, 82).

NGOs may be defined as non-state organizations comprised of private individuals or associations that are organized on a non-profit and voluntary basis to achieve a common purpose. They operate at the local, national or international level, i.e. NGOs with a global membership and/or global scope of activities (35, 39, 56, 80, 83). According to WHO, NGOs (also CSOs) “include [...] groups that represent consumers and patients, associations with humanitarian, developmental, scientific and/or professional goals and not-for-profit organi-

zations that represent or are closely linked with commercial interests” (84). Mixed goals NGOs, such as ISPRM, herein need to be aware of potential conflicts of interest between professional, humanitarian and scientific goals (85, 86), and may be challenged by purely humanitarian NGOs, such as disability rights organizations (87). The non-profit nature of NGOs leads to a “non-distribution constraint”, i.e. surplus generated cannot be distributed to individuals in control of the NGO, but must be retained, reinvested (e.g. in a central office, research projects, or service provision) or granted to other NGOs (37).

*NGOs in official relation with WHO*

In the world health polity, NGOs in official relation with WHO, such as ISPRM, are of major political relevance in reaching “health-for-all” goals (84, 88). ISPRM’s main external policy focal point is, and inevitably must be, the WHO and its policy agenda.

Through official relations with WHO, health-related NGOs are shifted from the periphery to the centre of the world health political system. They become subject to a defined set of rules and are eligible for the use of formal communication pathways with intergovernmental entities (24, 84, 88).

Fig. 2 shows the increasing number of formal relations of WHO with NGOs.

Protracted informal procedures are necessary to become an NGO in official relation with WHO. The following criteria for the admission of NGOs into official relations with WHO apply: (i) the main area of competence must be in line with WHO’s purviews; (ii) the NGO shall “centre on development work in health or health-related fields”; (iii) shall not pursue commercial interests; and (iv) “the major part of its activities shall be relevant to and have a bearing on the implementation of the “health-for-all” strategies [...]” (84, 88). When accredited, the NGOs have specific privileges, including the attendance of WHO meetings and duties such as the dissemination of WHO information. Table I summarizes WHO’s principles for official relationships with NGOs.

NGOs in official relations are reviewed by WHO every 3 years. Based on this review, decisions on the continuance of

the relationship are made (88). ISPRM thus needs to constantly evaluate its own agenda and activities in the light of this scrutiny and deliver respective reports to WHO.

*Functions of NGOs in the world health system*

To understand ISPRM’s role in the world health system, it is helpful to differentiate between varying NGO functions.

*Enhancement of public goods and creation of social capital.* It has been highlighted that international NGOs are key players in the mobilization of transnational support for the enhancement of public or collective goods (37), otherwise exposed to the moral hazard (89) of global private corporations and short-term power interests (80, 82, 90) fostering adverse selection (91). This means that asymmetric information in favour of corporations or state parties may lead to quality deficits in goods and services provided and finally to a market of “lemons”(91), i.e. an underprovision of health-related goods and services at the highest possible quality level. International NGOs may thus play a vital role in compensating market as well as government failure (37). Moreover, because of their greater community involvement (92), they can be considered as generators of global social capital (37, 60, 93–95), i.e. stable networks of cooperation and collaboration in a community or region (96). This may lead to a particular effectiveness “in areas of health intervention that demand social action, public advocacy, or innovative and community-based responses to health problems” (35). In this light, it becomes obvious why “many IGOs originated as the result of [international] NGO activity”, for instance UNESCO (78). Also, their world citizen character provides international NGOs with an outstanding role in monitoring the activities of IGOs, nation states and private corporations (80).

*Contribution to world public opinion.* International NGOs are specialists in the compilation and dissemination of documents and opinions on political issues recognized worldwide (97) such as poverty, landmines, torture, death penalty, and globalization itself. Many international NGOs thereby make extensive use of the possibilities of global mass communication and the internet. They, thus, importantly influence the world media and policy agenda (45, 98) and contribute to what might be called “world public opinion” (80). NGOs have the potential to spark social movements (60, 80) addressing specific health issues such as functioning and disability.

*Resource mobilization, fast response, and health service provision.* NGOs provide health technologies, expertise, human dedication and monetary resources not available to governments (61, 82). International NGOs appear to be much more flexible and faster in responding to international social problems than governmental administrations (80, 90, 99). They are particularly seen as innovators and value creators in financing and health service provision (82, 90).

More concretely speaking, NGOs can serve the function of service provision, for instance managing a hospital in a low resource setting (92). They can act as a supporter of other

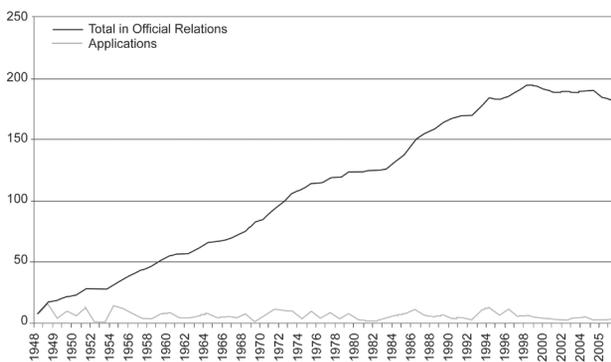


Fig. 2. Non-governmental organization (NGO) applications to official relation with the World Health Organization (WHO) since 1948. Source: WHO Civil Society Initiative (CSI).

Table I. Excerpt of the World Health Organization (WHO) policy principles governing official relations with non-governmental organizations (NGOs)

NGO/CSO	Civil Society Organizations (CSO):
Definition	“The increasingly accepted understanding of the term CSOs is that of non-state, not-for-profit, voluntary organizations formed by people within the social sphere of civil society” (1). NGO: “The term NGO is also commonly used to describe non-state, not-for-profit, voluntary organizations” (1).
Objective	“The objectives of WHO’s collaboration with NGOs are to promote the policies, strategies and programmes [of WHO]; to collaborate with regard to various WHO programmes [...]; to implement these strategies; and to play an appropriate role in ensuring the harmonizing of intersectoral interests among the various sectoral bodies concerned in a country, regional or global setting” (2) “to strengthen mutually beneficial relations at global, regional and national levels in ways that improve health outcomes, strengthen health actions and place health issues on the development agenda” (3).
Official relation	“WHO recognizes only one category of formal relations, known as official relations [...]. All other contacts, including working relations, are considered to be of an informal character” (2). “The establishment of relations with NGOs shall be an evolving process proceeding through a number of separate stages [...].” (2). “The Executive Board shall be responsible for deciding on the admission of NGOs into official relations [...].” § 2 (2). “the Board’s Standing Committee on Nongovernmental Organizations [...] shall consider applications submitted by NGOs [...] and shall make recommendations to the Board; § 4.2 (2). “The Board, through its Standing Committee [...], shall review collaboration with each NGO every three years and shall determine the desirability of maintaining official relations”; § 4.6 (2). “The Board may discontinue official relations if it considers that such relations are no longer appropriate or necessary [...]”; § 4.7 (2).
Prerequisites	“The main area of competence of the NGO shall fall within the purview of WHO. Its aims and activities shall be in conformity with [...] the Constitution of WHO, shall centre on development work in health or health-related fields, and shall be free [...] commercial or profit-making nature. The major part of its activities shall be relevant to and have a bearing on the implementation of the health-for-all strategies [...]”; § 3.1 (2). “The NGO shall normally be international in its structure and/or scope, and shall represent a substantial proportion of the persons globally organized [...]”; § 3.2 (2). “The NGO shall have a constitution [...], an established headquarters, a directing or governing body, an administrative structure at various levels of action, and authority to speak for its members through its authorized representatives. Its members shall exercise voting rights in relation to its policies or action”; § 3.3 (2). “Thus, organizations eligible for admission into official relations are [...] international NGOs with a federated structure (made up of national or regional groups or having individual members from different countries), foundations that raise resources for health development activities in different parts of the world, and similar bodies promoting international health”; § 3.4 (2). “In exceptional cases a national organization [...] may be considered for admission into official relations related work”; § 3.5 (2).
Privileges	“The privileges conferred by official relationship shall include: (i) the right to appoint a representative to participate, without right of vote, in WHO’s meetings or in those of the committees and conferences convened under its authority [...] this representative at the invitation of the chairman of the meeting or on his acceding to a request from the organization, shall be entitled to make a statement of an expository nature [...] (ii) access to non-confidential documentation and such other documentation as the Director-General may see fit [...] (iii) the right to submit a memorandum to the Director-General, who would determine the nature and scope of the circulation.”; § 6.1 (2). In the event of a memorandum being submitted which the Director-General considers might be placed on the agenda of the Health Assembly, such memorandum shall be placed before the Executive Board for possible inclusion in the agenda of the Assembly”; § 6.2 (2).
Responsibilities	“NGOs shall be responsible for implementing the mutually agreed programme of collaboration and shall inform WHO [...] if for any reason they are unable to fulfil their part [...]”; § 7.1 (2). “NGOs shall [...] to disseminate information on WHO policies and programmes”; § 7.2 (2). “NGOs shall collaborate [...] in WHO programmes to further health-for-all goals”; § 7.3 (2). “NGOs shall [...] collaborate with the Member States where their activities are based in the implementation of the national/regional/global health-for-all strategies”; § 7.4 (2).
Consequences for regional and national members	“These NGOs [regional or national NGOs affiliated to international NGOs in official relations with WHO] are, by definition, in official relations with the WHO Regional Office(s). They shall develop and implement a programme of collaboration with the regional and national levels of WHO to ensure implementation of health-for-all strategies at the country level”; § 5.1 (2). “Privileges similar to those stated above shall normally be accorded to national/regional NGOs having working relations with WHO regional offices [...]”; § 6.3 (2). “A national organization which is affiliated to an international NGO covering the same subject on an international basis shall normally present its views through its government or through the international NGO [...]”; § 6.4 (2).

organizations’ initiatives, e.g. community-based rehabilitation programmes, by collecting funds, managing operations and liaison tasks of partners (92, 99–101).

Professional international NGOs such as ISPRM are also able to support initiatives by formally approving programmes

in form of certifications (45). Their expertise can help funnel the attention of nation states toward such partners, initiating new funding streams. In addition, their function as an international advocacy organization helps to promote primary and grass-root healthcare concepts (80, 90, 92).

*Advocacy of minority and powerless majority groups.* A major element of government failure is the orientation of democratic governments towards the majority or the “median-preference voter” (37). Non-democratic governments, on the other hand, may design policies for a predominant minority. Against this backdrop, NGOs may act as advocates of powerless minority or majority groups (102). In the case of advocacy, a professional physicians’ organization, such as ISPRM, needs to be cautious. Consultant doctors are in unique positions of power and are generally well-paid members of any society, implying a careful reflection of majority and minority positions in society (103).

*Facilitating transnational research.* As research organizations, international NGOs may serve the function of evidence collection with regard to best practice in different resource settings (104). This automatically brings macro and meso level environmental factors (9) into the research equation, e.g. through comparative analysis (105) or culturally sensitive meta-analysis or systematic reviews (106). In highly rationalized societal systems, such as health research or medicine, international NGOs may even be attributed greater authority than states, IGOs, or international corporations, giving them “a quasi official status in world society” (80). Examples are the Institute of Medicine (IOM) (107) or the Cochrane Collaboration for systematic reviews on healthcare interventions (108). It is, however, also important to note that some NGOs may be rather selective about health research and dissemination of findings and contribute to increasing knowledge gaps.

*Societal division of labour and professionalization.* NGOs representing a particular profession, such as ISPRM, have a pivotal function in defining the field of competence of the profession in question (109), describing appropriate education and training curricula (41), setting standards of knowledge and skills needed for professionalism (110), and drafting the division of labour with related professions (111). They also are of particular importance in prescribing ethical codes of professional conduct. Violation of such codes may then even go ahead with an exclusion from the profession, possibly backed by executive state powers (80). International NGOs play an additional role in the international standardization of professional requirements and ethics. On the international level, important future partners of ISPRM thus may be, for example, the International Standardization Organization (ISO) and the International Labour Organization (ILO) of the UN system. International NGOs may furthermore foster professionalization and moral conduct by designing “awards to recognize moral exemplars” (80).

*Linking different societal sub-systems.* NGOs are quite flexible in crossing borders of the societal division of labour. They are capable of linking perspectives from different societal areas, e.g. the linkage of environment, economy, health and development through a comprehensive approach towards water supply in developing regions (36). NGOs, moreover, bring players from different societal spheres together, encouraging comprehensive problem-oriented discourses (112). NGOs,

and particularly international NGOs with their supplementary transnational view, serve as structural couplings between different societal sub-systems that usually follow their own logic (113). In a sense, ISPRM can thus be considered as a typical international NGO dovetailing scientific, professional, and humanitarian motives and approaches.

*Successful initiatives.* Successful initiatives of international NGOs in the health sector have been described primarily with regard to counteracting negative external effects derived from corporate practice, e.g. in tobacco control, distribution of pharmaceuticals, treatment access, and breast-feeding (82). Also their roles in vaccination programmes delivered through global private public partnerships (GPPP) (99–101, 112) and guideline development (114) have been highlighted.

#### *Dysfunctions and challenges of international NGOs*

The legitimacy, effectiveness and efficiency of international NGOs in addressing health issues and providing services have also been questioned, for instance under the label of voluntary failure (37).

*Lack of formal authority.* International NGOs often have no formal authority flowing from democratic, legal, bureaucratic or religious sources (56, 80). Moreover, they may not even be known or have a standing in the regions in which they want to operate, which may be the case with ISPRM in low resourced settings.

*Philanthropic bias.* Health-related NGOs may be biased because of conflicts of interest resulting from different levels of knowledge, influence, and resources of their partners (99). This may entail the neglect of the interests of low resource regions and minorities (35). Conversely, NGOs may focus exclusively on a particular minority group, leading to neglect of other stakeholders (philanthropic particularism) (37). Since they are often dominated by actors from the north-western hemisphere, NGOs may also act upon incorrect assumptions about the implementation capacities of developing countries (philanthropic amateurism) (37, 60, 80, 90), leading, for instance, to unsustainable health systems and brain drain of health professionals when the NGO withdraws its financial support (115, 116). International NGOs may be motivated not only by humanitarian concern, but also by a sense of mission regarding questionable ideologies (philanthropic paternalism) (37, 90). Since international NGOs provide collective goods they also face the problem that people may use services although they are not in need, or that former donors withdraw their donations because others have contributed in larger amounts than in the past (37, 117). This leads to difficulties in addressing the underprovision of services (philanthropic insufficiency) (37).

*The moral entrepreneur’s dilemma.* In the course of their dependency on fundraising, NGOs face the dilemma of the “moral entrepreneur” (118), insofar as they must continuously show that they contribute to the solution of the problems they

address, although at the same time the problem still exists or is even more exigent than before.

*The charity dilemma.* Related to the moral entrepreneur's dilemma is a problem that may be called the charity dilemma. Charitable organizations that contribute to the inclusion of minorities in healthcare and beyond often need to depict the minority that will benefit from the organization's activities as suffering and helpless. With the help of this strategy sympathy can be aroused in potential donors and financial donations promoted. However, this marketing strategy itself contributes to the minority status of the group and may have negative effects on societal attitudes towards group members, such as people with disabilities. In a word, it may be disabling (119).

*The professional standards dilemma.* Professional standards and guidelines lead to the exclusion of those from the profession who do not adhere to the standards (111). High professional standards may be indeed desirable but may also produce systematic biases at the cost of professionals in low resource settings where professional training does not exist or does not have the form it has in developed countries. The dilemma may, however, be dissolved by introducing "minimal" and "gold" standards at the same time, whilst employing signature procedures for the "gold" standard (45).

#### KEY APPROACHES IN ENHANCING THE POLITICAL ROLE OF ISPRM

For ISPRM to fulfil its humanitarian, professional and scientific mandate, it is essential to understand these issues. Taking into account the situation of low resource settings, for instance, is a normative expectation expressed by WHO (35, 39, 82, 88) and is a crucial part of ISPRM's work with WHO (79, 120).

So, in order to avoid being a paper tiger, the management of legitimacy (121) and the development of effective working relations are inevitable.

Key approaches in this respect are: (i) to set up a transparent discourse on how to further develop ISPRM's organizational structures and policy relations; (ii) to differentiate between internal and external policy relations and in the latter case between input and output; (iii) to harmonize organizational structures and procedures in the light of the collaboration with WHO; (iv) to consequently use existing structures to influence WHO's policy agenda; (v) to identify other main external policy actors of potential relevance to joint initiatives and strategic alliances; and (vi) to develop a strategy to enhance membership.

#### *Transparent and accountable development of ISPRM's policy*

An explicit description, evaluation, and discussion of appropriate formal organizational and policy relations (46) and tools (45) are a necessary starting point to foster ISPRM's political power. The transparency of related discussions and developments is a must in international politics. This will provide

ISPRM members and its global constituency with traceable information on these issues, thereby increasing their accountability for decisions (122, 123). In return, this discussion will enhance group cohesion and shared identification with ISPRM's visions and goals. On an inter-institutional and external level, this discourse will increase ISPRM's legitimacy as an organization (70, 124), one capable of meeting international standards of law and policy. More specifically, ISPRM's standing with WHO and the UN system will be enhanced. It will also help the organization to withstand scrutiny in the light of funding accountability and legal requirements (125, 126). In addition, it is hoped that this discussion will create a culture of open exchange and questioning within ISPRM, which in turn will lead to an improvement in its underlying structures and processes and enhance their efficiency, effectiveness and internal legitimacy (97).

#### *Differentiation between internal and external policy relations*

Organizations such as ISPRM are social systems that link membership to certain codes of conduct, e.g. those stated in the constitution, bylaws, or work contracts. Members are, for instance, expected to follow orders from people in certain positions regardless of their personal opinions. This connection of membership with expected conduct makes it possible to reproduce behavioural patterns on the side of the members in accordance with the purposes and rules of the organization in question (113, 127–129). In contrast with families, organizations are not an end in themselves but pursue goals in their external environment (124), such as "rehabilitation-for-all" in line with the WHO health-for-all initiative. Organizations thus differentiate between internal (self-reference) and external relations (other-reference). The former refer to the organization's members, e.g. national PRM societies, which may be seen as an internal environment. The term "internal environment" stresses the fact that, from an institutional perspective, an organization can never be in complete control of its members and sub-divisions. These often follow their own agendas and interests in micro-political arrangements and coalitions sometimes diametrically opposed to the organization's goals. External relations aim at influencing (output) or accommodating to (input) relevant corporate or individual actors within the external environment (113), e.g. influencing a WHO resolution vs accommodating to a UN convention. An organization's constituency normally includes members as well as non-members. The organization's relations to its constituency are thus partly internal and partly external.

It is suggested that ISPRM defines the structure of its policy process along similar lines and differentiates between an internal and external policy process and structure (45, 46).

#### *Harmonization of internal and external structures and procedures*

When deciding on the development of organizational relations, ISPRM's choices are constrained to pre-existing norms of its organizational environment. Moreover, ISPRM's choices directly affect its member societies on a national and regional

level. Besides such pressure towards institutional isomorphism (56, 70–72, 80), harmonization of internal and external structures and procedures can be seen as a powerful political means. By measures of synchronization with, for instance, WHO, the organization’s legitimacy (70) and its attractiveness to new members and potential collaboration partners, including state parties, may be enhanced.

More specifically, this means that compatibility with WHO’s goals needs to be secured by adapting to WHO’s programmes on the one hand and influencing its agenda on the other. In addition, a mimicry of WHO’s structures enables ISPRM and its member societies to appropriately communicate with WHO’s bodies at all world levels. Indeed, regional and national member societies of an international NGO in official relation with WHO are themselves “by definition, in official relations with the WHO Regional Office(s). They shall develop and implement a programme of collaboration with the regional and national levels of WHO to ensure implementation of health-for-all strategies at the country level” (88). This signifies that collaboration of ISPRM with regional and national societies so that they meet WHO expectations is desirable for ISPRM as well as the societies in question. Explicitly, WHO places emphasis on the “harmonization of intersectoral interests among the various sectoral bodies concerned on a country, regional or global setting” through WHO-NGO collaboration (88).

Finally, an orientation towards other successful medical societies assures that respective public expectations are met. For example, the publication of clinical guidelines is not merely a matter of taste for an international medical society.

*Enhancing external impact: influencing WHO’s agenda*

One of ISPRM’s most powerful tools to influence the world health policy agenda is the right to submit a statement of an expository nature in the forefront of a WHO meeting and to submit a memorandum to WHO’s Director General, who then decides on the nature and scope of its circulation (45, 88). An ISPRM representative can additionally be at a WHA session in question and make a statement, thus backing ISPRM’s effort to influence the global health policy agenda. Although ISPRM does not have the right to vote in WHO meetings, it thereby has the potential to influence the agenda, as has been shown in the case example of the WHA Resolution provided elsewhere (38).

An equally important means to influence the agenda and decisions of WHO is the consultation with state parties entitled to vote in the WHA. ISPRM’s relationships to national governments mediated through national and regional PRM societies is thus of central importance to ISPRM’s external policy.

By means of coalition building with other NGOs in official relation with WHO, additional value can be attached to a particular request. ISPRM and its allies can cumulate their rights to send memoranda to WHO and make statements at the WHA. Other NGOs might also have good relations with governments in favour of the initiative in question, bringing an ally eligible to vote into the equation.

Fig. 3. shows different pathways by which political influence can be exerted on WHO.

*Identification of other main external actors and seeking alliances*

Apart from WHO, other external actors relevant to PRM and rehabilitation at large are to be accounted for in ISPRM’s drive to become the world-leading PRM representative.

First of all, these are other actors within the UN system. These actors, and their relationships to each other are depicted in Fig. 4. Actors of potential interest to ISPRM, for funding possibilities or complementary fields of competence, have been highlighted.

Procedures similar to the ones depicted above in relation to WHO may be used to influence the global health agenda of other institutions of the UN system. Also, an official relation with some of these institutions may be pursued by working closely together with the UN Non-Governmental Liaison Service (NGLS) in Geneva (130).

Secondly, there are other NGOs, such as Rehabilitation International (RI), in official relation with WHO that share ISPRM’s humanitarian, professional and scientific goals. Others may overlap with ISPRM’s field of competence, such as the World Federation of Occupational Therapists (WFOT), and further can be seen as complementary to ISPRM’s expertise, such as Disabled Persons Organizations (DPOs). The Electronic Appendix I shows selected organizations in official relation with WHO. It is indicated whether the society pursues health for all, professional, and/or scientific goals, if it is health condition specific or not, and if it may be a relevant source of fundraising.

Thirdly, the same should be done for NGOs in official relation with other relevant entities of the UN system, e.g. the International Labour Organization (ILO).

Fourthly, other relevant world societal actors need to be identified through literature and internet searches as well as the mass

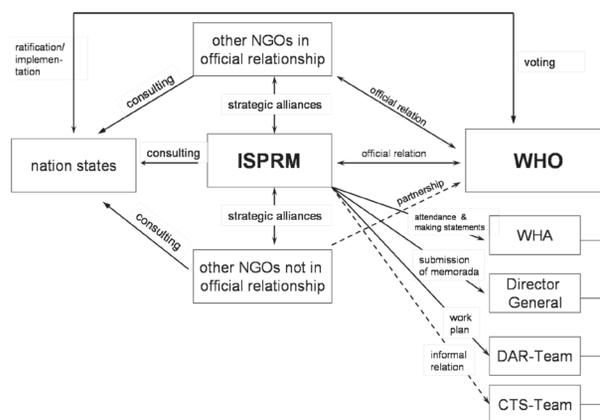


Fig. 3. Pathways of political influence on the World Health Organization (WHO) by a non-governmental organization (NGO) in official relation. CTS: Classification, Terminology and Standards; DAR: Disability and Rehabilitation; ISPRM: International Society of Physical and Rehabilitation Medicine; WHA: World Health Assembly.

# The United Nations System

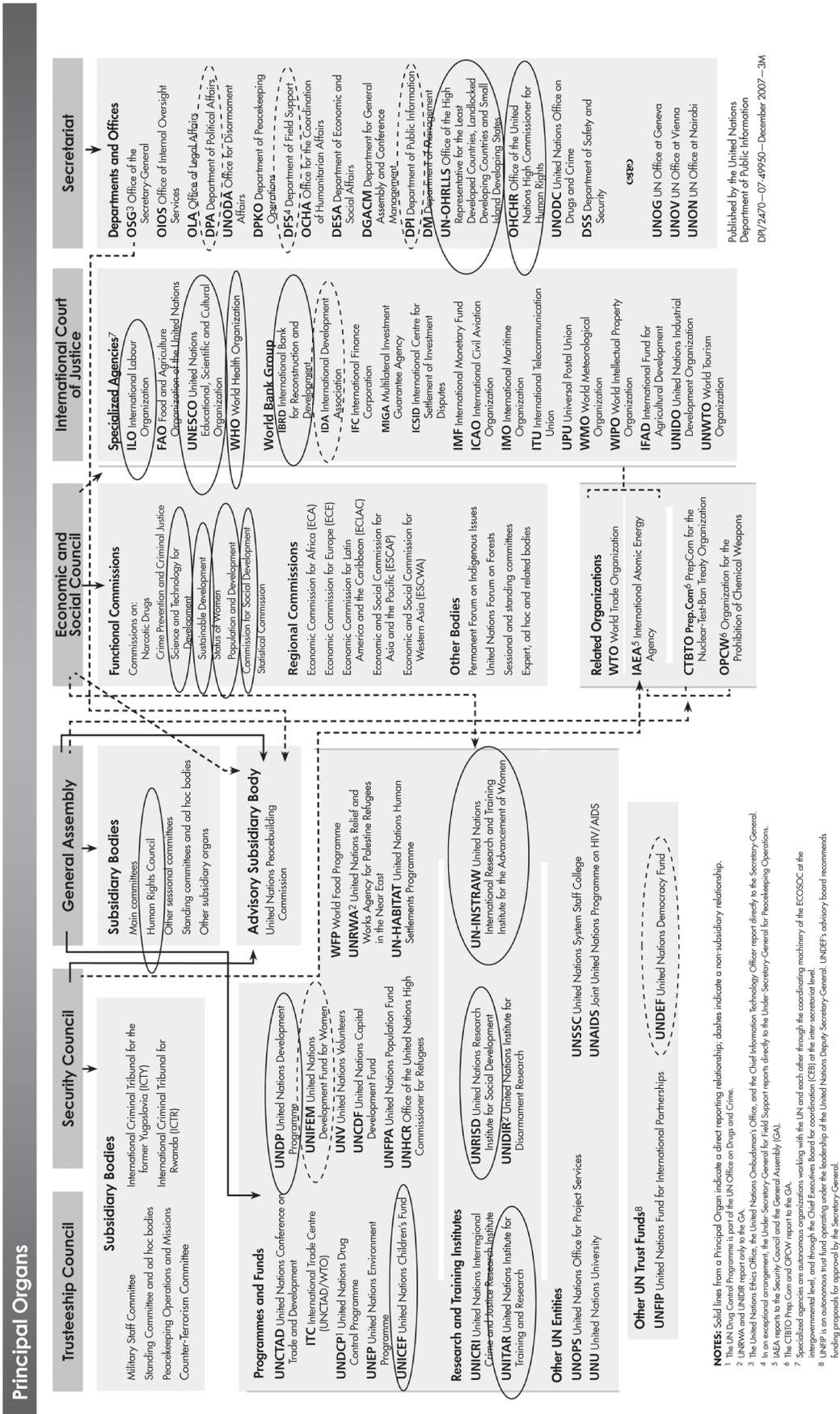


Fig. 4. United Nations system, highlighting potential partners for the International Society of Physical and Rehabilitation Medicine (ISPRM). Source: www.un.org/aboutun/chart\_en.pdf (modified).

media. These could encompass the Red Cross, Health Forum, Development Forum, Millennium Goals Circus, Club of Rome, Global Fund, OECD and so forth. The International Red Cross, for example, entertains a physical rehabilitation programme addressing rehabilitation issues in low resourced settings (131).

ISPRM's relationships with other IGOs and NGOs need to be based on mutually agreed terms and conditions to reach outcomes that are and are perceived to be beneficial (45). These relationships can be alliances and partnerships between 2 entities or jointly with multiple partners in form of a Global Private Public Partnership (99). ISPRM can join forces with a national NGO, for example, representing persons with disabilities in leading a campaign to influence a health ministry's agenda. A private company could be included to provide necessary funds for the campaign.

ISPRM can, in addition, establish an advisory agreement with intergovernmental organizations such as the European Union, on how to implement standards and guidelines into the national health systems. ISPRM could reach such a consultative status by sending representatives to relevant IGO hearings and consultations, offering its expertise and network as input and resource.

Similarly, fostering interlocking directorates (45, 132), by including representation of ISPRM on advisory or supervisory boards of other NGOs, IGOs and private corporations, is a step towards forging future coalitions and fostering advantageous relationships.

#### *Scaling up the organization: enhancing membership*

A major internal task in enhancing ISPRM's political influence lies in broadening its basis. A prerequisite is the identification and establishment of new internal relations to PRM societies worldwide.

As outlined above, along with the responsibilities of an organization in official relation with WHO, certain arguably beneficial rights are also passed to ISPRM. These have far-reaching implications, not only to ISPRM as the liaison representative to WHO on the global level, but also to national and regional societies that are automatically recipients of such rights. Their own expertise will be sought and actively called upon, adding to the societies' authority and influence as communicator and facilitator of health policy provisions. In order to broaden ISPRM's membership basis these advantages have to be clearly communicated. Regional societies need to be promoted (45, 133) and a procedure for official relations with ISPRM developed. Together with these regional actors, all national PRM societies and, where no society exists (29), initiatives worldwide should be identified and convinced to join ISPRM. The Electronic Appendix II contains a preliminary list of national PRM societies within different world regions. This provides the basis for efforts in enhancing ISPRM's membership.

#### CONCLUSION

This paper depicts a complex, sometimes contradictory and confusing, world societal situation within which ISPRM has to operate. In particular, as an international organization in of-

ficial relation with WHO, ISPRM is confronted with a variety of responsibilities, but is also endowed with a world health political mandate.

Against this background, further steps towards ISPRM becoming an influential and central player within the world health polity at large and rehabilitation in particular include the elaboration of a policy process and respective policy tools suitable for ISPRM's projects (45) as well as the review of ISPRM's current organizational structures (46), as provided in subsequent papers in this special issue. On this fundament, ISPRM's policy agenda (43) can then be built.

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#### Electronic Appendices

No	Name of appendix	Available at
I	Selected NGOs in official relation with WHO (pdf-file).	<a href="http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0441">http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0441</a>
II	List of PRM societies and selected related institutions worldwide (pdf-file).	<a href="http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0442">http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0442</a>

## ISPRM DISCUSSION PAPER

# CHAPTER 4: A POLICY PROCESS AND TOOLS FOR INTERNATIONAL NON-GOVERNMENTAL ORGANIZATIONS IN THE HEALTH SECTOR USING ISPRM AS A CASE IN POINT

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## SUMMARY

*The politics of international non-governmental organizations (NGOs) such as the International Society of Physical and Rehabilitation Medicine (ISPRM) serve the function of selecting and attaining particular socially valued goals. The selection and attainment of goals as the primary function of political action can be structured along a policy process or cycle comprising the stages of strategic goal setting and planning of strategic pathways, agenda setting, resource mobilization, implementation, evaluation and innovation. At the various stages of this policy process different policy tools or instruments, which can be used to influence citizen and organizational behaviour in the light of defined goals, can be applied. The objective of this paper is to introduce and describe policy tools of potential relevance to ISPRM with regard to different policy functions and stages of the policy process.*

that can be used to influence citizen and organizational behaviour in the light of defined goals (2). The selection and attainment of goals as the primary function of political action (3–5) can be structured along a policy process or cycle. At the various stages of this policy process different policy tools can be applied.

The objective of this paper is to introduce and describe policy tools of potential relevance to ISPRM with regard to different policy functions and stages of the policy process.

The specific objectives are: (i) to review the societal function of political systems; (ii) to describe different stages of the policy process of international NGOs in terms of a designated policy cycle; (iii) to discuss various policy tools suitable for the goal selection, agenda setting, resource mobilization, implementation and evaluation of international NGOs, such as ISPRM.

This outline can serve as a long-term strategic framework and a future reference for ISPRM.

## INTRODUCTION

The International Society of Physical and Rehabilitation Medicine (ISPRM) operates within a complex space of international negotiations and power relations, where international governmental organizations (IGOs) and non-governmental organizations (NGOs), nation states and private companies compete (1). In this situation, ISPRM as an international NGO in official relation with the World Health Organization (WHO) clearly has an international political mandate to realize professional, scientific and humanitarian development goals within the realms of Physical and Rehabilitation Medicine (PRM) and rehabilitation at large (1). Along the process of developing and implementing policies, a set of policy tools is at the disposal of international NGOs operating within the health sector. Policy is mainly about getting individual and corporate actors to do things they otherwise would not have done, or to enable actors to do things they might or could not have done otherwise (2). Against this backdrop, policy tools can be seen as instruments

## FUNCTIONS OF POLICY AND THE POLICY CYCLE

Deriving from classical sociological theory, political systems mainly serve the procedural function of goal selection and attainment (3–5). Against this backdrop, organizations are even seen as social systems specializing in the attainment of particular goals (4, 6). Furthermore, they also fulfil other (latent) functions, such as the integration of different coexisting activities and networks (6). Following a newer version of sociological systems theory (7), integration may be conceived as the mutual reduction in degrees of freedom in the organization itself and in internal and external environmental systems (1, 7). For example, by defining the core competencies of a PRM physician or by building alliances with local rehabilitation services initiatives in developing countries, ISPRM makes a commitment to these standards and activities and, at the same time, sets an agenda and rules, towards which other internal or external actors need to orientate. Through latent pattern maintenance (3, 6, 8) and continuity of an organization's policy

through symbolic action, the organization creates a common identity and collective memory (9).

The organization’s own procedures and applied policy tools are also generators of perceived internal and external effectiveness, cohesion, trust, confidence (10) and legitimacy (4, 11). For example, an ISPRM discussion paper may be seen as a policy tool, as it outlines current policy initiatives as well as their expected effects, reinforces common identity, and enhances the legitimacy of ISPRM’s activities through transparent dialogue (12, 13).

Following the chronology of the policy process yields a policy cycle, along the different stages of which policy tools may be structured. Against the background of environmental factors and the organization’s own structures, the policy process commences with strategic goal selection derived from the organization’s vision and mission and the assessment of the situational opportunity structure. In the following sections, strategic pathways to goal attainment are defined. These can be divided into agenda setting, resource mobilization, implementation, evaluation and, finally, readjustment of the strategy and innovation activities, which impact on the environment and may even lead to organizational change (Fig. 1).

In the phases of goal selection, agenda setting and resource mobilization, most policy tools are non-specific, in that they are both applicable to internal and external policy procedures (1). At the implementation stage, however, internal policy tools aimed at ISPRM’s members can often be distinguished from tools designed for external policy relations (1, 14).

### GOAL SETTING

The first, and most important, task of any organization is the negotiation and formulation of goals. This goal setting process is led by a collection of motives, themselves fused by institutional memory, experience, views, perception of role and role expectations from members, partners and competitors as well as the larger constituency; e.g. ISPRM will not be expected to build cars or drill wells. ISPRM hereby defines its vision (15) as the general purpose of the organization (what we want), for example rehabilitation for all. The realization of the vision

can thus, in terms of decision theory (16, 17), be seen as the decision problem (4). A vision is not realized yet and it is not exactly clear how it can be realized in the future. Conversely, its mission (15) is understood as the core activities of the institution (what we do); for instance, fostering the development of rehabilitation in low resource settings. It can thus be understood as the general preferences of the organization.

### Strategic goals and development of strategic pathways

On one hand, *strategic goals* are derived from the organization’s vision and mission, yielding a hierarchy of preferences and sub-goals (4, 16, 17). On the other hand, the opportunity structures presenting themselves to the organization need to be analysed (18) (Fig. 1). This should involve an assessment of the current state of affairs, the calculation of available and additionally needed resources, and a time budget. Strategic goals are thus more concrete than vision and mission, but are still long-term goals of the institution. An example would be the development of guidelines for the approval of community-based rehabilitation (CBR) projects within the next 2 years.

Strategic pathways, in turn, state sequences of actions of the institution that are compatible with its mission and that shall be undertaken in the light of the perceived opportunity structure in order to reach a strategic goal; for instance: (i) the assignment of a task group; (ii) the review of existing and planned CBR projects; (iii) the creation of a respective database; (iv) contact with local decision makers and involved organizations; (v) involvement of the latter in the design of a certification process, and so forth.

Vision and the mission of an organization can only be changed if its identity is altered as well. Once formulated, they thus have a long-standing validity. Strategic goals and pathways can be adapted more easily and are valid for a time frame of approximately 2–4 years (presidential term). On strategic pathways towards strategic goals the institution’s internal and external goals can in turn themselves be broken down into smaller operational units; namely waypoints or milestones and tasks assigned to a schedule, e.g. first, second and final draft of a guideline (19). Concrete suggestions for ISPRM specific strategic goals and pathways, ISPRM’s policy agenda, are presented in an accompanying paper in this special issue (20).

When selecting strategic goals and pathways, ISPRM may, as an organization in official relation with WHO (1, 14, 15, 20), orientate towards the WHO agenda. This is facilitated through ISPRM’s right to attend sessions of WHO governing bodies (1, 21, 22). Surprisingly, this possibility is currently used by only one-third of the NGOs in official relation with WHO (23).

### Identification of options: assessment of state of affairs, resources and time frame

Against the background of the organization’s hierarchy of preferences, goal setting starts with an assessment of a given situation or setting and its challenges, for instance through the exploration of the state of affairs in literature reviews, e.g. on CBR in low resource settings, or expert consulting, e.g. through

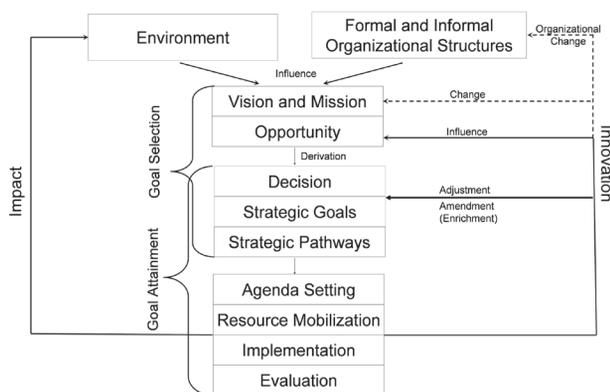


Fig. 1. Policy cycle.

interviews with the directors of respective rehabilitation programmes. This then leads to the identification of alternative options for action, e.g. ISPRM letters of support vs supervision or approval of existing community-based rehabilitation initiatives (certification) vs starting own initiatives, and expected consequences. In a trade-off, these options are then weighed with the organization's hierarchy of preferences, perceived uncertainties in the environment and available resources (internal vs external financing) in connection with a desirable time frame in relation to the perceived urgency of the goal. For example, is adequate funding for visiting CBR settings in developing countries available and are there ISPRM members who are willing and able to engage in such activities? The resulting decision focuses on the best and realistic alternatives. The actual project management (19) follows. It begins by breaking down the vision and mission into strategic pathways. These include scheduled milestones towards strategic goals, such as the development of a checklist for the approval of community-based rehabilitation projects. Strategic pathways in policy usually include an agenda setting strategy, efforts to mobilize resources, an implementation, and a monitoring and evaluation strategy. It is important to note that, from the beginning, indicators and means for the evaluation of goal attainment need to be considered and defined. This can be, for example, done with a balanced scorecard concept including predefined quantitative and qualitative measures (24).

#### AGENDA SETTING COMMUNICATION

An opus entitled "The Making of Rehabilitation. A Political Economy of Medical Specialization, 1890–1980" (25) concludes with a chapter on "The Fall from Power" of Physical Medicine and Rehabilitation (PRM). One physiatrist is quoted with the following remark: "To be blunt, it is much easier to obtain visibility and acceptance with academic colleagues and medical students as a specialist in sports medicine or in the diagnosis and management of ambulatory patients with muscle diseases, than as a manager of rehabilitation services to the same patients". Unfortunately, much of this is still true.

Therefore, the dedication of appropriate communication tools for setting the internal and influencing the external media, public and policy agenda (26, 27) is not a "soft" matter of taste, but of utmost importance. Whilst goal selection is a matter of values on the one hand and of opportunity on the other, combining both through decision analysis, agenda setting is a matter of communicating the selected goals and related issues.

ISPRM must seize the window of political opportunity opened through the World Health Assembly (WHA) Resolution on Disability and Rehabilitation (28), the United Nations (UN) Convention on the Rights of Persons with Disabilities (29), and the increasing significance of transnational collaborations involving IGOs and international NGOs (1) to place and consolidate rehabilitation on the global health agenda.

The primary function of agenda setting communication is the integration of communications and activities of organizational subunits, partner organizations and allies. By focusing on specific topics and actions, the degrees of freedom of systems

in the internal and external environments are reduced (7). For example, by bringing the importance of disability issues onto the public agenda respective political action may be triggered. At least in democratic states, political actors have little chance of ignoring media and public agenda items given their interest in being (re-)elected (26, 27). Corporate or individual actors within the internal or external environment of the organization reward this specialization with higher degrees of perceived accountability and eligibility of the organization to address these topics and perform respective tasks (13). Another function of agenda setting communication is to create collective identity (30) and social memory (9). This leads, in turn, to a gain in internal legitimacy. International NGOs are moral entrepreneurs (31) "whose primary concern is enacting, codifying, modifying, and propagating world cultural structures" (32), meaning internationally agreed upon principles, such as the International Classification of Functioning, Disability and Health (ICF), or access to rehabilitation for all people experiencing disability. Legitimacy of an international NGO is herein at least as important as its cost-effectiveness or efficiency (4, 11, 32).

Agenda setting tools are diverse in nature as their purpose is tailored to serve specific communication pathways. These encompass oral and written communication as well as direct and indirect communication in face-to-face interactions and information transfer by technical media such as e-mail or television, respectively. Also, media for individual communication comprising a defined group of recipients, e.g. ISPRM members, need to be distinguished from mass media, which aim at a previously unknown circle of mostly unrelated recipients (dispersed audience) (33), e.g. the larger constituency of ISPRM. Agenda setting tools include publications in scientific journals as well as newspapers, television, World Wide Web and so forth, statements before WHO governing bodies, congresses and meetings as well as public relations initiatives.

#### Publications

The publication of documents allows an international NGO to shape the international discourse on political issues including the perception of problems through observers relevant to the issues in question (34). In this context, *definitions and conceptual descriptions*, e.g. of disability (29, 35–37) or the area of PRM and rehabilitation (38, 39) are pivotal to an internationally consistent and coherent development of PRM and beyond. By disseminating them, discourses are created that "systematically form the object of which they speak" (40). Moreover, conceptual descriptions may reconcile different viewpoints within an area (34) and allow tailored definitions for specific purposes (38, 39).

*Different types of publications.* Memos, statements and comments are short items informing and replying to specific measures and activities laid out in brief. State of the art, discussion and position papers are long items with in-depth analysis and argument design from the constituency at large and, in the case of position papers, from institutional bodies eligible to speak with authority. These are mainly published in scientific journals

as the main mass medium of an international professional and scientific society (15, 41, 42). However, publications in the wider mass media, e.g. in the form of newspaper interviews, are also possible and desirable.

*ISPRM position, discussion and state-of-the-art papers.* Besides information on its official website, ISPRM should place emphasis on the publication of related issues in journals relevant to the PRM community and other stakeholders. In this context, one can distinguish between ISPRM position papers and discussion papers. Position papers are official statements of the board of ISPRM and are published on behalf of the board in the official journal of ISPRM. ISPRM discussion papers, such as the paper at hand, are statements of ISPRM members or other scholars commissioned by the board of governors, the president's cabinet or council, the executive or other committee. They may be published in ISPRM's official journal, another PRM journal or any other journal suitable for the topic, sometimes reaching out beyond ISPRM's constituency.

Also, state of the art papers in areas that ISPRM has identified to be of major relevance for its policy agenda, e.g. on CBR in developing countries, are instruments for setting the agenda. They can be based on literature reviews or expert consultations and need to be planned in the long run, including the identification and invitation of appropriate author teams. Publication in ISPRM's official journal (*Journal of Rehabilitation Medicine*) would be appropriate. An alternative is publishing international reports or perspectives on certain issues or conditions relevant to PRM in edited books. An example from the WHO is the World Report on Disability and Rehabilitation (43). State of the art papers may also play a role in the goal selection process outlined above.

#### *Submission of memoranda and statements to the World Health Organization*

The submission of memoranda to the WHO Director General and placing statements before WHO governing bodies such as the World Health Assembly (WHA) is a powerful agenda setting tool at the disposal of international NGOs in official relation with WHO (1, 15, 42). A WHO analysis (23) shows that this policy tool is not widely used. From 1998 to 2002 for instance, only 20.6% of the NGOs attending a WHA session made a statement before this body. Also, the use of this policy tool varies strongly between individual NGOs. Whilst one NGO placed 10 statements over the period 1998 to 2002, 18 NGOs did this only once. An example of an ISPRM statement is given in an accompanying paper in this special issue (15). It seems advisable that such statements are prepared by the publication of discussion and position papers that they may then refer to.

#### *Congresses and meetings*

Congresses and meetings of internal institutional bodies, such as the Executive Board, and of mixed internal-external working groups are policy tools of first rank. They allow the identification and preparation of upcoming issues, the recruitment of members and the deployment of information to the PRM community. They evoke inter-regional exchange and

obligation in less resourced regions. Congresses spark scientific and political co-operation and alliances on the international, regional, sub-regional, national, and local level. The envisioned future of ISPRM world congresses has been outlined in an accompanying paper in this special issue (42).

#### *Public relations initiatives*

As congresses and meetings assure face-to-face interaction in order to produce scientific exchange and organizational development, so too do public relations (PR) initiatives assure that a wide array of relevant audiences is reached face-to-face or by mass media. PR activities of international societies try to embrace the dilemma of breaching global boundaries whilst addressing a local constituency and individuals alike (44). The mass media should be used both to review relevant trends in news and their impact and to then trigger public interest in the core field of competence of ISPRM. Interest can be created by personalizing the agenda using prominent ambassadors (26) speaking for ISPRM and its goals. They may be placed on the ISPRM website, in interviews printed or screened as part of mass media's news coverage of societal or PRM relevant events. Making the public aware of ISPRM's activities can also be achieved by advertisements in digital and print mass media.

## RESOURCE MOBILIZATION

The mobilization of resources is a necessary prerequisite of goal attainment (4). It is prepared by agenda setting in terms of interest management, i.e. the creation and concretization of interests to donate resources, such as money or technology, to the NGO (45) and the motivation to voluntarily engage in the NGO's activities on the side of the members (46). "The basic building block for [international] NGOs is the interested individual" (47). As far as financial resources are concerned, many different strategies, apart from member fees, are available to an international NGO in order to mobilize appropriate resources (48). We want to highlight event-oriented fundraising, co-funding, and sponsoring. Clearly, funding from industries contributing to ill-health and disability, such as the tobacco industry, or to armed conflicts, such as the weapons industry, will not be accepted by ISPRM.

#### *Event-oriented fundraising*

PRM congresses, particularly ISPRM's world congresses (15) can be used for event-oriented fundraising (49), for which representatives from PRM relevant industries and foundations are invited. Industrial exhibitions as well as lectures on innovative PRM products and technology including drugs are desirable and need to be fostered in order to acquire new funding possibilities from the health industry. Public and private foundations dedicated to addressing world problems in the health sector and beyond can be induced to attend an ISPRM conference by providing opportunities to discuss PRM issues in the light of more general global and regional developments. This can be done by means of brain trusts or specific panels. Specifically, event-orientated fundraising (48) activities constitute a

win-win situation for an organization in terms of utilization of media coverage and reaching fundraising goals.

#### *Co-fundraising and cross-subsidization*

The regional connectedness and knowledge of ISPRM's members allows ISPRM to perceive relevant health topics, make them part of the policy agenda and, in turn, identify good cause for action, resource allocation and development initiatives. These good causes can be used as trigger topics, funnelling public interest through ISPRM as the responsible intervening organization. For example, ISPRM may decide to support CBR projects in developing countries in a joint effort with regional and national societies. ISPRM may offer know-how in consultations and its name as the internationally pre-eminent PRM organization. It may also guarantee appropriate supervision of the assignment of funding streams. If clearly communicated to potential donors, the funds raised can then be used in part for ISPRM's work, e.g. 20%, and in part for the project in question. Potential donors might not see why they should subsidize a professional organization's get-togethers, but if this organization is attributed to building rehabilitation hospitals or CBR services in a developing region, then the donors might consider funding such initiatives.

A related topic is cross-subsidization, meaning that an NGO may charge higher prices for some goods and services, e.g. for the certification of rehabilitation hospitals in high resource settings. The surplus can then be used to lower the price for other goods and services or to provide the same goods in low-resource settings (50).

#### *Sponsoring and cause-related marketing*

Sponsoring is an attractive tool for the assurance of continuously available financial measures. It includes contractual arrangements between one or several private companies and the NGO in question. As a reward for providing finances or technology for the organization's activities, the sponsor's logo may be placed on the organization's website or the sponsor may be allowed to advertise its products at events or in publication organs of the NGO. Sponsors, however, need to be reviewed and chosen with care, otherwise a loss in credibility of, and trust in the organization is highly probable. Trust is difficult to gain but easy to lose (51).

An interesting idea is the linkage of sponsoring and cause-related (52) or social marketing (53), i.e. gaining a sponsor for a specific project in conjunction with a wider marketing and fundraising strategy.

## IMPLEMENTATION AND APPLICATION

Once goals have been negotiated, the pathways to goal attainment selected, an agenda set and communicated internally and externally, then a set of tools and measures help to implement the approved amendments to existing, and the creation of new standards, procedures and structures.

In the end, it lies in the hands of elected officials and bodies with their authority to decide on policy proposals for internal

and external application (14). They vote – or reach agreement by others means deemed appropriate to pass legislation – on the adoption of standards and guidelines, and confirm goals of their organization's agenda. These policies are then expressed, at one end of a formal scale, in an amended constitution, law or bylaw or, at the other end, via publication in the minutes of a respective session.

Implementation activities constitute the original value creation of an international NGO. The value added may be based on the production of goods such as research results, the delivery and distribution of goods and services, and the dissemination of goals, codes of conduct and information.

Implementation strategies start with the assignment of tasks and the allocation of the mobilized resources, which can be done in designated work plans. Such plans can be agreed upon with other organizations, making their elements mandatory and excluding other issues. The example of the ISPRM-Disability and Rehabilitation (DAR) work plan (20) is provided in an accompanying paper of this special issue.

In the following sections, internal and then external policy implementation tools are presented.

#### *Adoptions, endorsements, and recommendations*

Although in official WHO terminology, ISPRM cannot formally adopt conventions, resolutions, or standards such as the ICF as it is expected from states, it is suggested that an adoption should nonetheless be possible from the internal perspective. External goals and standards such as the UN Convention (29) may thus be adopted by vote at relevant ISPRM bodies such as the Board of Governors – ISPRM's Assembly of Delegates (14). The publication of the voting results in minutes of the sessions as decision papers, e.g. on ISPRM's website, thereby ensures transparency with regard to the constituency at large. Respective modifications of the bylaws may then follow. Likewise, references to such international standards can be made in a preamble to the bylaws. The strongest case of an adoption is such an integration of the statement in ISPRM's guiding documents, i.e. By-Laws and Policy Principles, whilst the weakest case is an ISPRM position statement published on ISPRM's website. ISPRM can then bring its members also to ratify these documents so that they are obliged to make respective amendments to their By-Laws as well.

Also, new internal standards, such as ICF Core Sets (54, 55) or minimal standards for PRM doctors and facilities, as well as technical guidelines, such as guidelines for the education of PRM specialists (56) can be *endorsed* by ISPRM's Board of Governors. They need to be published in a wide range of international, regional and national journals, including translations into different languages. For ISPRM's external constituency, as well as other groups within the external environment, such as state parties or other medical societies, they obtain the character of *recommendations*.

#### *Ratifications through International Society of Physical and Rehabilitation Medicine members*

Standards and guidelines adopted or endorsed by ISPRM may become more or less binding for ISPRM's membership,

which is expected to ratify them. Apart from the exclusion of members from the organization or monetary penalties, ISPRM has, however, no formal *sanctions* at its disposal to enforce such ratification.

*Signatures.* To legitimately represent an international NGO in official relation with the WHO, ISPRM must be accessible to all. Resource limitation in some regions and countries can, however, hinder participation in the implementation of international health standards as required by ISPRM and alienate potentially interested parties.

It may thus be advisable to employ a signature process similar to that of the UN. Also, this process will allow the consideration of the specific situation of low resource countries in which the will to implement standards may be present but the means might not be available in the near future. Furthermore, it may be possible to differentiate between signatures that signify a general commitment to the standard and those implying an obligation to implement the standard within a given time frame. In the latter case, some countries may decide to sign the standard or guideline not immediately but after a clarification of the resource situation and the mobilization of resources. ISPRM may grant a generous time frame, say 30 years, within which the signature may be submitted without the need for formal sanctions. Signing societies may, however, be obliged to implement the standard or guideline within a shorter period of time, say 4 years. Perhaps motivated by the desire to be at the forefront of an innovation (57), societies from high resource countries may decide to sign immediately, whilst other societies will have the opportunity to postpone the signature in accordance with their resource situation. Signatures as a means to facilitate ratification have the important advantage that they lead to a self-commitment of the signing parties, making the deviation a matter of cognitive dissonance (58).

#### *Regional agency*

It is nowadays commonplace in sociological theory that power is not a zero sum game (5). A powerful principal, e.g. ISPRM, is able to delegate tasks to powerful agents and set incentives so that these tasks are accomplished in the principal's sense (59, 60).

ISPRM will thus have little chance of success in implementing its long-term policy goals without the help of powerful regional and national agents (59). ISPRM can, for instance, adopt the UN Convention on the Rights of Persons with Disabilities, or endorse ICF Core Sets for vocational rehabilitation, and recommend their use. Ultimately, an initiative for the application of any ICF Core Sets in everyday practice or for the access to rehabilitation services will need to leave the global policy level and influence grass-root life situations, interactions and behaviours. It is thus of ISPRM's utmost interest to strengthen regional and national PRM societies.

Existing regional ISPRM member society structures (regional agencies) can be used to create new, and utilize existing, regional contacts and networks including both official governmental bodies and other NGOs or grass-root social movements as well

as the private economy. It must be clear, however, that ISPRM cannot directly work with governments that are not democratically legitimized and that contribute to disability by suppressing part of their population. ISPRM would not place itself in a situation where it could be seen to be endorsing these regimes. Indirect links might, however, be carefully considered in order to help populations in need of PRM expertise.

The ISPRM regional and national members may implement ISPRM's policies by establishing formal relationships with other regional or national NGOs or in a Global Private Public Partnership (GPPP) (61–63). Examples include consultation contracts with rehabilitation hospitals, health service providers and health ministries to implement ICF (64, 65), the delivery of training tools to local health professionals (66), certification programmes (47) for hospitals and services, the monitoring of standards and implementation of guidelines (47), and the evaluation of health service delivery (47, 67). Such regional and national agency can be furthered by ISPRM's adoption or endorsement of standards and guidelines, which then can be referred to by the projects in question, by letters of support, by consultation contracts with ISPRM and by ISPRM certification programmes. Of particular importance are regional PRM societies, since they may function as a mediator between ISPRM and national or local PRM initiatives. It is thus advised to allow the affiliation of regional PRM societies as ISPRM members (14).

Regional agency can also help ISPRM link agenda setting and fundraising goals in the form of the above-depicted co-fundraising.

Regional vice presidents of ISPRM (68) hereby serve as a direct link between the regional societies and ISPRM via interlocking directorates (14, 69). They may promote ISPRM's agenda goals, communicate its decisions and activities to national societies, encourage national societies within the region in question to remain or become members of ISPRM as well as be figureheads in the recruitment of individual members. Their involvement in ISPRM congress organizations can strengthen ISPRM's regional ties and enhance the identification of the regional societies with the topics set by ISPRM.

Organizational challenges are evident when thinking towards the future of this regional cooperation in terms of real subsidiarity or partial delegation, supervision and legal liabilities, budgetary accountability, knowledge transfer (including tacit knowledge), empowerment of regional institutions, and cultural diversity and sensitivity.

#### *Approval and certification*

In order to support regional, national and local PRM institutions and projects, ISPRM may decide to design an approval process and certification programme (47). The institutions and projects may be reviewed by ISPRM officers with regard to their adherence to ISPRM standards and guidelines. ISPRM certification may facilitate fundraising for the regional, national or local project. In turn, ISPRM may, as mentioned above, in the case of high resource settings receive a salary for the certification or be granted part of the raised funds.

### Networks

Sustainable networks with other public and private, profit and non-profit organizations are central to ISPRM's political influence and performance. Organizational networks can be seen as collective entities governed by a common goal and/or leadership structure (69, 70). They establish their own organizational structures, both constraining and enabling joint activities (69, 70). In general, networking or hybrid organizational arrangements between market and hierarchy can be transaction cost saving (71). For NGOs, they are often the only alternative for collective action. In many cases no possibility for vertical integration is given, no market for the products or services exists, or economic or ethical "market failure" is probable (50), e.g. when the price of medicines makes them unaffordable in the low resource settings most in need of them.

Networks are, moreover, generators of social capital (72) and may produce a win-win situation in terms of the mobilization of resources and complementary know-how balancing mutual resource dependencies (73). In particular, sustainable networking arrangements create trust (74) and enhance the flow of information from the larger environment (75). Furthermore, feedback from networking partners on relations with the constituency or other institutions constitute a "third party" situation fostering a more objective perspective on the organization's activities (76).

Different forms of informal and formal networks exist, but this will not be discussed in detail here. For an overview, see: (69, 70). We do, however, highlight some selected networking arrangements below.

In the context of all organizations, various informal networks exist in the form of (web-based) forums, informal working groups comprising individuals from different organizations and the like. In the long run, a formalization and institutionalization of networking relations may ensure a greater sustainability of the networking arrangement.

*Bridging groups.* Bridging groups comprised of members of different organizations committed to the attainment of a common goal or the solution of a particular problem, are an instrumental tool in starting up more formal network structures. They provide basic information on the situation in particular settings and on other participants of potential relevance. In particular, they create personal trust, sparking confidence (10) in the development of joint systems approaches. Since, for instance, in Sub-Saharan Africa no PRM societies or adequate services appear to exist (77), the set-up of a bridging group including African physicians and policy players as well as ISPRM representatives seems desirable.

*Interlocking directorates.* Interlocking directorates (69) or advisory boards with other institutions are one interesting means of fostering information flows, taking into account other organizations' perspectives, and making personal contacts that can be of utmost importance in the light of fundraising goals. As ISPRM may want to send its officials into the supervisory or advisory boards of other organizations relevant to human functioning and rehabilitation, it may also decide to create its own supervisory

board or advisors' council inviting influential advisors from related fields (14). Of particular importance to ISPRM seems to be input from disabled persons and their advocacy organizations (78). This holds all the more true since we undoubtedly face a paradigm change from a medical supply model of the needy to a rights-based approach of disability services (35, 79).

*Strategic alliances, joint ventures and Global Private Public Partnership.* Strategic alliances (80–82) can be seen as networks of organizations that formally have agreed upon contributing to the attainment of joint strategic goals by allocating knowledge, resources and manpower to a common strategic pathway. Legally, strategic alliances can, for example, be realized within a designated joint venture. In a joint venture 2 or more parties "pool a proportion of their resources within a common legal organization" (83, 84) in order to pursue joint projects with predefined goals, resource allocation, time schedule and outcome evaluation based on a contract between them (85). Joint ventures appear to be a legal form well suited to the realization of GPPPs fusing the resources of private corporations with the knowledge and moral standing of civil-societal partners (61–63, 86).

## EVALUATION AND INNOVATION

Evaluation means the assessment of the organization's goal attainment. It can be based on retrospective or concurrent evaluation of implementation activities and, in the ideal case, on prospective impact assessment of outcomes such as functioning within the organization's environment (67, 87). Proof of successful problem-solving policies is quite difficult for international NGOs since the success of their global activities may strongly vary across countries. Most importantly, the ultimate ends of international NGOs are non-monetary and qualitative in nature. The implementation of a particular policy may be described, but to measure its success with hard figures in any way can be next to impossible. If ISPRM, for instance, were to help build a CBR programme, it then may be a huge step towards measuring and linking an increase in function in the population to that initiative. Evaluation of goal attainment in NGOs thus often has a ceremonial and ritual character aimed at confirming that one is on the right track (11).

### Indicators

Yet, if evaluation strategies have been prospectively integrated into the organizations' strategic planning, some hard or quantitative as well as soft or qualitative indicators may be available within a balanced score card concept (24). For example, this could be the number of guidelines endorsed divided by the number of planned guidelines, the enhancement of membership in percent, or the satisfaction of the members with ISPRM's work. Fundraising evaluation can help to identify areas where public interest has focused and where it might be heading. A prospective definition of the indicator in question as well as the pursued goal in terms of the same indicator is, however, a necessary pre-condition. Otherwise, self-fulfilling prophecies and *ad-hoc* confirmations of the *status quo* are highly probable.

*Member and consumer feedback: survey and web-based exchange forum*

A regular, say yearly, member survey seems to be an appropriate evaluation tool with which a constant feedback loop regarding the ISPRM membership can be institutionalized. Such a survey should contain some continuously recurring questions in order to assess change within ISPRM’s member attitudes over the course of time. Another part of the questions could, conversely, focus on current problems and decisions at stake.

Also, a forum on the ISPRM website would allow more spontaneous input from member and consumer side. A systematic strategy for the analysis of such data needs to be pre-defined in order to avoid the forum ending up in “much ado about nothing”.

*Innovation: re-adjustment, impact, and organizational change*

Innovation may be based on evaluation procedures, but also on negotiations with internal and external actors, or more spontaneous discussions and the creativity of focal actors.

In most cases, the evaluation of an organization’s goal attainment leads to an adjustment of goals and pathways at the strategic decision level and leaves the organizational vision and structures untouched. Similar re-adjustments may also be stimulated by the organization’s impact on the environment

and respective alterations within the perceived opportunity structure.

In extreme and revolutionary cases, often triggered by the creativity of influential leaders or changes in the balance of power between different member groups, organizational change occurs, eliciting major alterations within the organization’s formal structure and, even more seldomly, within the organization’s vision and mission. In the latter case, a new organization is born.

CONCLUSION

Using the model of a policy cycle comprising the elements of goal selection, agenda setting, resource mobilization, implementation, evaluation and innovation, different policy tools of potential relevance to ISPRM have been introduced and discussed. Fig. 2 provides a detailed overview of how these different policy tools are intertwined along the policy cycle.

The presented policy tools are based on a quite voluntary selection of the authors. Not all of these might be of equal relevance to ISPRM’s activities. Also, there will be many more instruments of assistance in attempting to realize ISPRM’s mission.

The presented overview is, however, a promising starting point for a more systematic policy development of ISPRM.

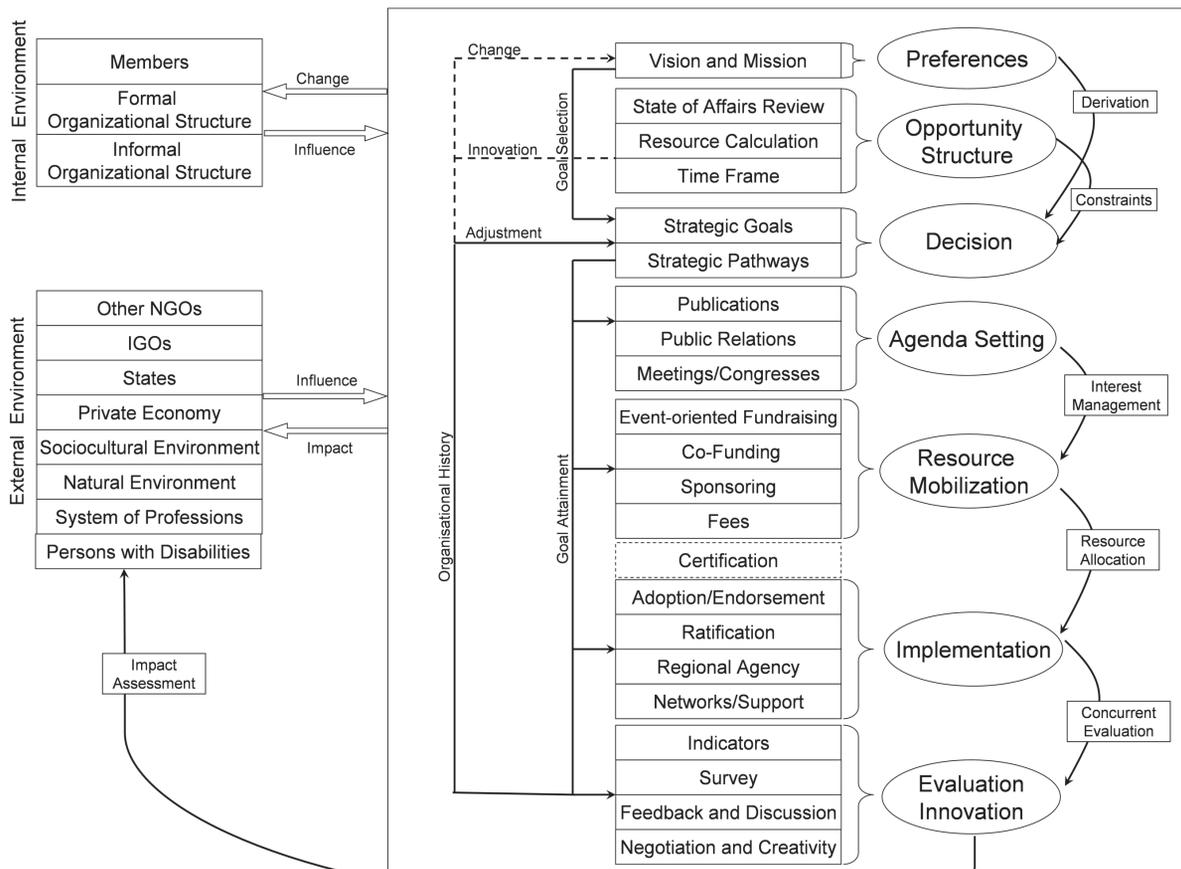


Fig. 2. Policy tools in the policy process. NGO: non-governmental organization; IGO: international governmental organization.

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ISPRM DISCUSSION PAPER

CHAPTER 5: ORGANIZATIONAL STRUCTURES SUITED TO ISPRM'S  
EVOLVING ROLE AS AN INTERNATIONAL NON-GOVERNMENTAL  
ORGANIZATION IN OFFICIAL RELATION WITH THE WORLD HEALTH  
ORGANIZATION

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SUMMARY

*International non-governmental organizations (NGOs) in official relation with the World Health Organization (WHO) face organizational challenges against the background of legitimate representation of their membership and accountable procedures within the organization. Moreover, challenges arise in the light of such an international NGO's civil societal mandate to help reach the "health-for-all" goals as defined by WHO and to facilitate the implementation of the United Nations (UN) Convention on the Rights of Persons with Disabilities. The objective of this paper is to examine how such an international NGO using the International Society of Physical and Rehabilitation Medicine (ISPRM) as a case in point can address these challenges. The specific aims are to analyse ISPRM's structures and procedures of internal organs and external relations and to develop solutions. These possible solutions will be presented as internal organizational scenarios and a yearly schedule of meetings closely aligned to that of WHO to facilitate an efficient internal and external interaction.*

INTRODUCTION

As an international non-governmental organization (NGO) of physicians in official relation with the World Health Organization (WHO), the International Society of Physical and Rehabilitation Medicine (ISPRM) clearly has a humanitarian or civil-societal, a professional, and a scientific mandate to address the obstacles to realizing the right to health (1).

Until now ISPRM has focused on the fulfilment of its professional and scientific mandate. Its current organizational structure was sufficient and well suited to serving these specific aims. However, in the process of achieving its goals (2) a set of challenges has arisen. They include the limits of volunteer commitment, economic resources, resources available to the

central office, membership growth, and questions surrounding the regional representation and the congress bidding system (2). These challenges, seen from an internal perspective (1), imply that their solution might be found in a review of ISPRM's organizational procedures and structures.

From an external perspective, ISPRM is expected to live up to the civil-societal mandate it has been granted by WHO. As an international NGO in official relation with WHO, ISPRM has a set of rights and responsibilities (3) that directly translate to a range of challenges to its organizational procedures and structures (1). ISPRM could review these with respect to legitimacy, accountability and effectiveness of policy processes. The organizational structures may then be aligned with good governance principles of WHO as well as ISPRM's evolving role, as described elsewhere (4). Procedures must, in any case, be clearly defined and self-explanatory to avoid their perpetual iteration, which can only reduce the time available for content discussions. Yet, there is no perfect solution to every challenge – arguments in favour and against can always be found.

The objective of this paper is to analyse how ISPRM can develop its organizational structures and procedures suited to enhance ISPRM's legitimacy, downward accountability, and policy process effectiveness.

The specific aims of this paper are to review the current structures, procedures and challenges of accountability in light of ISPRM's civil-societal mandate and of legitimacy management. Furthermore, this paper aims to present suggested modifications and possible new scenarios of ISPRM's organizational structures. Moreover, the current external liaison structures of ISPRM and respective challenges will be outlined, and future perspectives of ISPRM's external policy relations and suggested adaptations, drawn from current findings, will be presented.

ISPRM'S ORGANIZATIONAL STRUCTURE: CURRENT SITUATION, CHALLENGES, FUTURE PERSPECTIVES AND SUGGESTED ORGANIZATIONAL SCENARIOS

ISPRM's achievements rest on an organizational and procedural structure not unknown in the realm of international professional health societies (5, 6). In fact, ISPRM, as is the case for every NGO in official relation with the WHO, is required to have a form of constitution clearly stating the organization's structures and procedures (3).

Current internal organizational and governance structure

ISPRM defines its internal organizational structures and procedures as stated in the By-Laws and Policy and Procedures Document (7, 8). These laws and regulations state the rights and responsibilities of elected officials and bodies.

The organizational structure of ISPRM (Fig. 1) includes the President's Cabinet, the Executive Committee, the Board of Governors and Regional Vice Presidents. Other committees are assigned to special fields of expertise or operational tasks, such as the Nominating Committee or the By-Laws Committee.

The *President's Cabinet* recommends nominees to the Nominating Committee. It has the authority to act on issues that need immediate attention and can pass this *ad hoc* authority to the President. He is to act as determined by the Cabinet, until the next meeting of the Executive Committee and/or Board of Governors.

The members of the President's Cabinet are also automatically represented on the *Executive Committee*. They are joined by the Executive Director (ex-officio), the Regional Vice Presidents, one representative at large for the individual members and one representative at large for the national societies. The Executive Director is responsible for the overall operations of ISPRM, whilst the Secretary and Treasurer have special duties.

ISPRM's *Board of Governors* is the main legislative body of the society. It consists of the Executive Committee, one representative for each member nation nominated by the national societies and the same number of representatives of the individual members.

The Board of Governors elects candidates to ISPRM's governing bodies. It decides on suggested amendments to the By-Laws, i.e. the constitutional framework of the organization which is binding for its members, with a simple majority of its quorum.

Challenges to ISPRM's internal organizational and governance structure

ISPRM's organizational structure and dependant procedures are deliberate, but complex, and arguably unclear in parts.

An international NGO's organizational structure needs to be rooted in 2 underlying themes of designated good governance – legitimacy and accountability. Legitimacy refers to the authority to speak for a constituency based on equity in elections and some form of expertise, or practical legitimacy to advise or help others (9). Downward accountability (10) is an intra-organizational trait resulting from good governance. In addition, accountability is a managerial prerequisite of a professional organization in terms of capacity, efficiency, standards and anti-corruption (11).

ISPRM's past experience has shown that further organizational development must be centred on the enhancement of sustainable capacities in terms of personnel, funds, bureaucracy, and membership representation (2). Volunteer leadership and engagement can only carry an organization as far as the leadership reaches. The focus of control resting on few can pioneer rapid growth. Yet, this leadership has to be able to pass its legacy down to accountable others, who are willing to implement and live ISPRM's decisions, not just in zones of indifference (12), but as a matter of conviction. Sustainable

growth needs economic resources as much as these are needed to uphold a legitimate and accountable organizational structure for a growing global membership and the organization's mandates. The challenge lies in bolstering internal participatory structures, when higher degrees of professionalization, centralization, and bureaucratization – elementary for the survival of a voluntary, non-profit NGO – seem to pull in other directions (13).

*The organizational challenge of individual member representation and suggested solutions.* The electoral process to the Board of Governors and consequently its proportionate composition could be revised to better define the roles and constituencies of its members.

To start, the term Governor in the name Board of Governors could be seen as inappropriate. The current Board is so large and

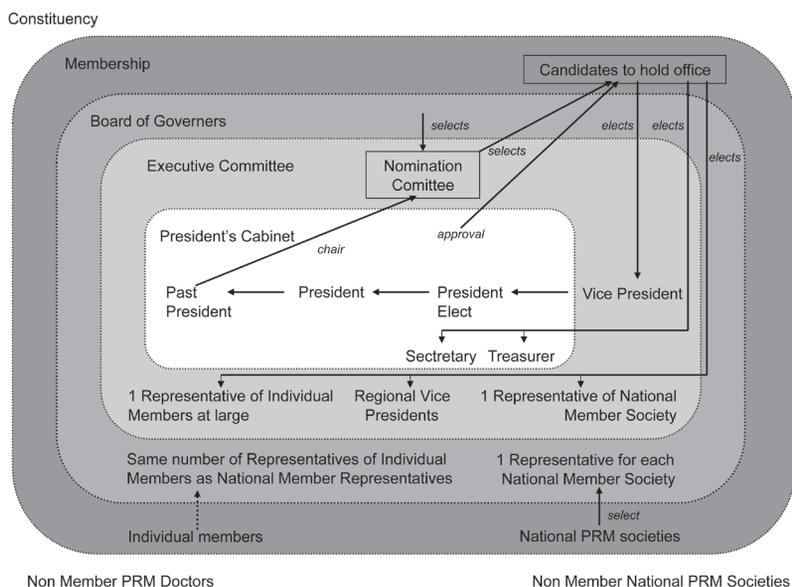


Fig. 1. Internal organizational and governance structure of the International Society of Physical and Rehabilitation Medicine (ISPRM) (7).

meets so infrequently that it does not serve the roles usually assumed by a Board of Governors. An orientation towards WHO's terminology seems better, i.e. the Assembly of Delegates.

The National Societies are to individually nominate candidates to be elected later to the Board to represent them. Although the procedures in Appendix III of the Policies and Procedures (8) outline a process for the open nomination of individual members, nominating committees have, at times, not communicated clearly to the members how they might exercise these rights. However, the membership in the past has submitted very few nominations for any of the ISPRM positions even when asked explicitly to do so in the News and Views. Thus, they have been nominated out of the overall membership by a Nomination Committee comprised of already elected members. This can lead to a limited selection and exclusion of lesser known individuals.

Also, national societies that pay a lump sum for all their members may have additional leverage when it comes to voting through influencing their individual members.

Possible organizational solutions are presented in Table I. All members of the Council of Presidents could be assigned to the Nomination Committee, thus limiting the number of Executive Committee members with approval and disapproval rights of nominations. The Council of Presidents could itself elect a chair and co-chair to co-ordinate and guide toward the new duties. The Nomination Committee would only review and approve or disapprove nominations. The Board of Governors would then nominate candidates directly itself, rather than having its representatives on the Nomination Committee suggest nominees. Also, all other members willing to hold office should be able to be candidates if approved of by the Nomination Committee.

In terms of recognition of all member votes, a web-based absentee balloting solution could be discussed. Not all members are able to participate in all meetings and congresses to vote. It should, however, be mentioned that these digital voting systems have been proven to be problematic in some elections (14). Also, a postal vote system needs to be reviewed in light of resource limitations in many parts of the otherwise under-represented developing world.

This, perhaps initially daunting, task could be handled professionally and efficiently by an enlarged central office.

*Organizational challenges regarding the Presidency and suggested modification.* The electoral process to the presidency could be discussed and potentially revised. The Vice President, elected by the Board of Governors, succeeds the President Elect after a 2-year term to become ISPRM's President for the following 2 years. This accession process over 2 legislative periods means the Board of Governors elects a President that will not serve during its term, thus reducing its direct influence on the President. Also, because of the selection process of the individual members on the Board, the process of choosing a President may lack the input of less well-known or active members. The Vice President's role is not clearly defined in the By-Laws, although his or her term in office as Vice President serves as a learning period for the future President to gain familiarity with the governance of the organization through participating in key committees. Also, the election of ISPRM's Regional Vice Presidents by the Board of Governors is challengeable. Persons with limited influence in the regions they are to represent may be elected to the Executive Committee.

To meet these challenges the post of Vice President could be faded out of the present system in favour of shorter, more directly accountable terms of the Presidency. The constitution does not state what role the Vice President has. His post can also be confused with the Regional Vice Presidents, who in future are to play a more prominent role (1, 4). The electorate would thus vote on the President to first become President elect for 2 years. Those favouring this approach believe the term would allow the President Elect to prepare his Presidency in full and assist the President at the same time. The enlarged Central Office (4), when implemented, could compensate for the loss of institutional memory by this reduction in personnel.

Also, the ISPRM Regional Vice Presidents need to be selected or elected by the Regional Societies (4), to be then approved by Board of Governors. It would then not be the other way around as in the present system.

*Future perspectives – suggested organizational scenarios*

ISPRM's internal policy structures and procedures, as stated above, could be more democratic in terms of representation and decision-making. On the one hand, to demand a complete, democratic regime (15) to be put in place would exaggerate the point. On the other hand, an NGO reaching out to the world

Table I. The International Society of Physical and Rehabilitation Medicine (ISPRM)'s internal organizational challenges and suggested solutions

Challenge	Suggested solution	Pro/Contra
Representation of individual members	Election of representatives of individual members to the Assembly of Delegates	Plus in legitimacy and downward accountability Technical/resource challenges
Composition of the Nomination Committee	All members of the Council of Presidents alone assigned to Nomination Committee Nominations to be placed directly by Assembly of Delegates Review of nominations by Nominations Committee	Prevents self-selection Plus in legitimacy and downward accountability
Election of the ISPRM President and the role of the ISPRM Vice President	Election of President Elect by Assembly of Delegates or General Assembly President Elect serves a 2-year term to become ISPRM President for 2 years The post of ISPRM Vice President is to be faded out	Presidential post is more directly accountable Technical challenge Quicker turnaround of terms is more flexible and appropriately fit to new agenda Less confusion about Vice Presidencies

should strive to be as inclusive as possible (13). In order for ISPRM to be seen as a legitimate representative of regional, national and individual PRM voices, the organization may consider modifying its structures and procedures to hear the whole choir and facilitate more participation (16, 17).

The current political organizational system has many concepts well suited to the time in which it was designed. It was especially beneficial in realizing ISPRM's achievements, as described in an accompanying paper (2). However, no system is immune to changes in demands set by time and a dynamic world societal agenda (1). Organizations must evolve over time just to survive – a fact ISPRM's leadership has acknowledged by appointing an Organizational Structure Task Force. The scenarios outlined below are aimed at differing stages of ISPRM's perceived future position in world health polity to accommodate this gradual evolution over time.

The underlying structural principles of the following possible scenarios are already incorporated in the current system. These are in particular: (i) the integration of all world levels through Regional Vice Presidents, (ii) parity in occupancy of governing bodies between representatives of individual and national members; (iii) the accession process in the presidency to allow the accumulation of institutional memory (18); and (iv) the democratic foundation to all structures.

Many elements presented below are well known from the present system, for instance the Executive Committee, the Board of Governors and the Nomination Committee. The 2 suggested scenarios incorporate these elements with alterations to their election, composition and responsibilities.

The proposed changes within the present system apply mainly to the relations *between* the elements. Furthermore, innovative ideas are introduced (Figs. 2 and 3).

The reward of organizational change to ISPRM will be an increase in structural and procedural legitimacy. In other words, ISPRM will be perceived as the appropriate society to do the job from an internal and external perspective (9). The challenge will

be to gain these perceptions and yet develop a structure that is effective and efficient within the resources, human and monetary, available to ISPRM at any given moment in time.

For clarity, from here on we refer to the Board of Governors as the Assembly of Delegates and to the By-Laws and Policy and Procedures document as the Constitution. Furthermore, when mentioning the regions and ISPRM Regional Vice Presidents we are referring to the current and the envisioned ISPRM regions as outlined in an accompanying chapter of this special issue (4).

The following 2 scenarios incorporate the above-suggested modifications to the present system. The composition of the Executive Committee and the President's Cabinet is only changed in relation to the expiring Vice Presidency. The duties of the Treasurer, the Secretary and the Executive Director, as well as those of standing committees, special committees or task forces, are not discussed here. Their role, like that of the Membership Committee, could be discussed after agreement on the general organizational structures.

*Two-level transitional scenario*

This first scenario is designed to serve ISPRM in a transition phase between the present and the three-level, best case, scenario described below. It has a two-level structure now of interest to us (Fig. 2). The lower level is composed of the Assembly of Delegates; the upper level is represented by the Executive Committee.

National and regional societies are automatically represented in the Assembly of Delegates and eligible to vote. Each national society can send one representative to the Assembly of Delegates and each regional society can send 2 representatives. This is to ensure that the few regional societies gain more leverage in terms of voting in relation to a potentially large number of national societies. Whoever is present at the Assembly can vote.

The individual members, however, vote on representatives to the Assembly of Delegates then eligible to vote. Their number is not to exceed those of the national and regional representatives. No more than 5 individual representatives are to be from 1 single country. Their eligibility to hold office should by then have been reviewed in the membership application process by the Secretary as in the old system. The dotted line in Fig. 2 indicates that the individual members form a kind of virtual assembly. This is a first reference to the lowest level of the three-level scenarios, to be described next.

The Assembly of Delegates nominates and elects all candidates to hold office, be they the presidential candidate, the Treasurer or other Executive Committee or President's Cabinet members. The legitimacy and accountability of the elected is thus assured. The nominees are reviewed and approved by the Nomination Committee. The ISPRM Regional Vice Presidents appointed by the regional societies ascend to the Executive Committee after approval by the Assembly of

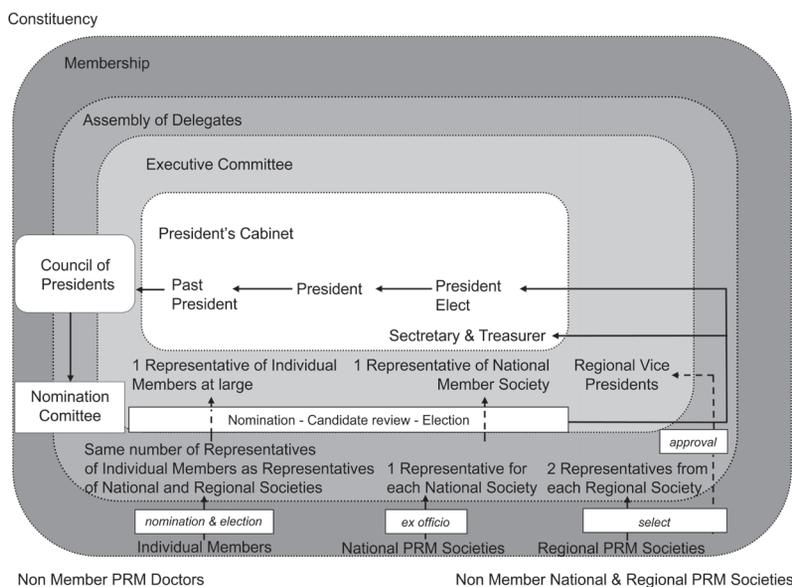


Fig. 2. Two-level scenario.

Delegates. This approval process replaces the electoral process of the Regional Vice Presidents to the current Board of Governors, because the Regional Vice Presidents are already elected officials of their regional societies. This mechanism allows ISPRM to adhere to the WHO's requirements of the integration of regional organizational structures.

*Three-level best case scenario*

The two-level scenario is complemented in this case by a third and lowest level (Fig. 3), best designed to incorporate all requirements derived from ISPRM world societal mandate (1) and an envisioned membership growth. This lowest level is to ensure a more legitimate and organizationally manageable transmission of membership rights to their representatives' powers to govern ISPRM. Also, an adjusted and more appropriate electoral process from a managerial perspective at the same time enhances downward accountability (10) and democratic legitimacy towards the member and non-member constituency.

One representative of every national and 2 of every regional society jointly form the Assembly of National and Regional societies. On the same level all individual members form the Assembly of Individual Members. Both chambers would be chaired by members of the Council of Presidents. These bodies are virtual assemblies in so far as they only meet on special occasions. Elections could be administered by the central office by means of an electronic and postal ballot system. A scheduled meeting, however, could be devised in order for individual members to put questions to the President's Cabinet and discuss policies and procedures. Such a meeting could be convened at a scientific Physical and Rehabilitation Medicine (PRM) congress (4).

In this scenario both chambers together form a General Assembly, which jointly elects the President Elect. The chambers each elect 15 representatives to the Assembly of Delegates, one level above. On the one hand, the limit to 15 candidates for each chamber is to ensure that the governing Assembly of Delegates

is still manageable when ISPRM's membership grows. Imagine 60 member countries and, respectively, 60 individual member representatives voting on a policy item – one on an agenda of 20! On the other hand, a certain number of delegates is needed to fully reflect ISPRM's global diversity in membership (19). The special representation of the regional societies by means of 2 representatives sent to the Assembly of Delegates is not incorporated in the three-level scenario. However, the Regional Vice Presidents are still sent to the Executive Committee after approval of the Assembly of Delegates. As do their colleagues on the Nomination Committee, the Assembly chairs screen and approve nominations to the Assembly of Delegates one level above outside of the executive structure.

Such a more inclusive three-level system toward the incorporation of a broad-based and global membership, equipped with the power to vote on issues and people, enhances the stability of ISPRM's internal and external policy. On the one hand, the more veto players are in place the less likely it is that radical shifts in the direction of ISPRM's policies occur (20). On the other hand, a less accountable leadership can be pioneers in erecting structures not yet in place (21). This is especially needed in countries where there are no PRM societies. In the long run, however, policy structures need to incorporate pluralism and democratic parity to uphold sustainable policies. The success of external activities lies in dependable policies born out of accountable organizational structures and procedures.

EXTERNAL RELATIONS AND LIAISON STRUCTURES: CURRENT SITUATION, CHALLENGES, AND FUTURE PERSPECTIVES

ISPRM's external relations and liaison structures are equally important to ISPRM's further development. They are, in fact, primarily responsible for ISPRM's organizational structures and procedures (1). To be able to respond to external impulses directed at organizational change and adaptation are favourable attributes of a flexible and capable international NGO (1, 22).

*Current external relations*

ISPRM has official working relations with WHO's Disability and Rehabilitation (DAR) team in Geneva. A collaboration plan is in place and regular formal meetings are held (23). ISPRM is also part of a group with the other professional rehabilitation organizations, including the World Federation of Occupational Therapists (WFOT) and the World Confederation of Physical Therapists (WCPT) that meets for consultations with WHO (24).

*Challenges within ISPRM's external relations*

The challenges within the collaboration with WHO (23) involve: (i) the development of a systematic representation of ISPRM during the World Health Assembly (WHA) in

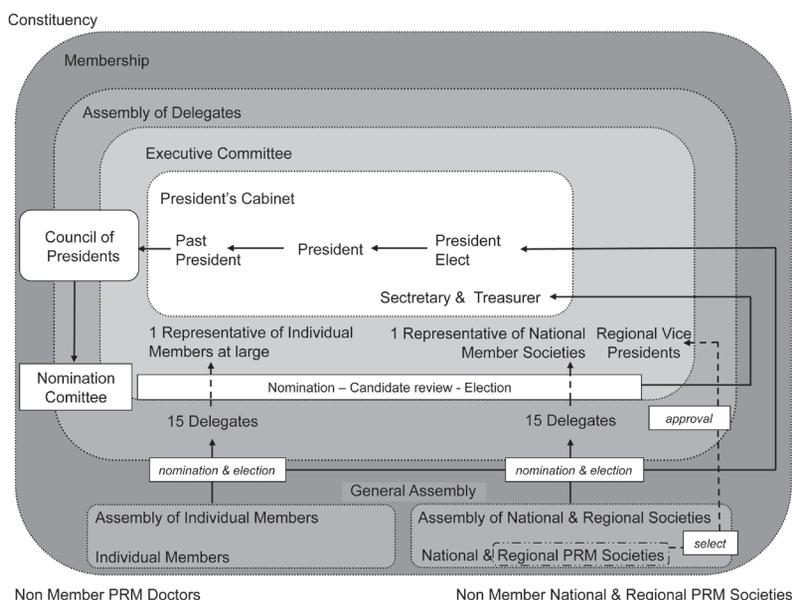


Fig. 3. Three-level scenario.

May every year (3); (ii) the assemblies of the WHO regional meetings; and (iii) the systematic input by ISPRM delegates with respect to activities across WHO secretariats relevant to rehabilitation and PRM. Obviously, meeting these challenges creates new coordinative challenges, which may be beyond the powers of an organization run by individual members. As outlined in an accompanying paper, it is of utmost importance that ISPRM expands its Central Office (4). This expansion may include the employment of an officer responsible for coordinating the activities with WHO and United Nations (UN) systems.

Since WHO is emphasizing the work within the WHO regions and since much relevant action is taking place in the regions, ISPRM may want to further systematically develop its presence with the regional WHO offices, e.g. by holding ISPRM sessions at regional conferences (4) and by monitoring and contributing to the development of policies relevant for rehabilitation on the regional level. The current WHO/ISPRM collaboration plan provides the “names of the Regional Vice Presidents of ISPRM who can serve as regional advisors to DAR” (23). The role of these regional points of contact with WHO offices and collaboration centres and the inclusion of lower, national and local levels could be discussed (1, 22).

ISPRM currently has no formal mechanism to work with regional societies with which it shares its constituency, and it is thus challenged to define its position in relation to them (2). The WHO principles governing relations with NGOs explicitly states that an NGO in official relation with WHO “shall represent a substantial proportion of the persons globally organized for the purpose of participating in the particular field of interest in which it operates.” (3). Thus it seems that regional societies must be able to become ISPRM members representing their whole region. Since the interests of a whole region may collide with the particular interests of all national societies within that region, it makes sense, as described above, to have representatives for whole regions as well.

Furthermore, negotiating the relationship terms, such as the principle of subsidiarity, between allies and partners, is necessary to avoid future conflict (25). In turn, this dialogue can be used to incorporate regional societies’ experience into ISPRM’s policy agenda (22), which can lead to influence legitimacy more by addressing then common goals (9). It would thus seem important to invite regional societies to ISPRM venues in a call to openly discuss interests and expectations of possible future membership relations.

#### *Challenges to ISPRM’s organizational structures regarding external relations*

ISPRM’s official relation status to WHO implies a set of rights and responsibilities (3) that entail managerial and organizational consistency with WHO governing principles. Most importantly, the membership of such an NGO in official relation must be able to vote on Policies and Procedures. WHO’s scrutiny of all official relations is not only directed at reviewing organizational efficiency and fiscal accountability. The bodies of the UN system and its partners are more crucially questioning the legitimacy of an organization to act on its behalf (1, 22).

This suggests that international NGOs affiliated with the WHO should strive to represent their membership as accurately as possible. The outlined organizational scenarios aim to take these arguments into consideration.

Similarly, a non-profit NGO’s role in advising the provision of publicly funded services once delivered by states to its own citizens could be subject to some controversy (13). This holds especially true in light of the fact that an NGO may pursue activities in states with non-democratic regimes. The NGO may soon itself become a political space (26), preferably cultivating democratic values, procedures and skills. Its potential to act as a bridge between allies and partners of varying resources and interests requires maintaining its legitimacy, including representation of its vision through the process of participatory governance (13).

Other external organizations (1) are themselves bound by codes of conduct and, in most cases, international law. This holds true for nation states and international governmental organizations in or outside the UN system as well as other international NGOs. These possible partners and allies are thus very sensitive to ISPRM’s legitimacy. Private companies approached to become possible sources of funds are equally interested in a partner’s practical and moral legitimacy (9, 27), even more so in view of shareholder interests. In light of increasing activities in potentially culturally sensitive contexts (28) ISPRM must be aware of other professional watchdog NGOs. A good public image is an extremely valuable asset in times of global mass media (1, 22).

#### *Future perspectives of ISPRM’s external relations*

The future development of the field of PRM and worldwide implementation of programmes and initiatives to meet “health-for-all” goals, as set out by WHO (29, 30) gives exceptional opportunities to ISPRM. The implementation process of the UN Convention on the Rights of Persons with Disabilities gives guidance on what challenges need to be addressed where.

Collaborative initiatives in the form of global public-private partnerships are only one of many policy tools the organization can utilize to help meet those challenges (22, 27, 31). The other professional rehabilitation organizations are hereby valuable allies to ISPRM.

A good example of a collaborative WHO effort involving a governmental agency, a consumer organization, a trust, a university and a professional organization is the WHO publication Guidelines on the provision of manual wheelchairs in less resourced settings (32). ISPRM has also proven its capability to consult WHO both on technical guidelines (2) and other publications (33). The society could now focus on bringing such partners together and on *initiating, leading and helping implement* guidelines and standards in its field of competence (31).

Toward an organizational development and enlargement, ISPRM could consider using so called bridging groups, which may be developed into strategic alliances (22). These would be comprised of members of existing ISPRM national or regional societies and of other members from relevant organizations, such as development agencies. They would first serve as a basis



*WHO meeting schedule*

The WHO Executive Board meets in January to revise the WHO's Medium-term Strategic Plan and the proposed Program Budget. The revised documents are handed to the Director General (DG), who then incorporates suggested amendments by member state governments. The DG recommends the revisions to the documents at the World Health Assembly (WHA), as may be necessary. After the WHA the Executive Board meets for its second session of the year. The Executive Board gives effect to decisions and policies of the WHA. During the later part of the year the Medium-term Strategic Plan is implemented and continually revised at the WHO's Regional Committee meetings. The draft Strategic Plan is then again passed to the Executive Committee for revision at its first session of the following year. The specific functions of the WHA and the Executive Board are stated in Table II.

This consultation cycle is open for contributions by external allies and partners, such as ISPRM. The agenda of the WHA,

the Medium-term Strategic plan and the Program Budget are published in advance of sessions and revised throughout the year. ISPRM can thus easily recognize points of interest and adjust its own strategies accordingly.

*ISPRM's meeting schedule*

As shown in Fig. 4, it is suggested to hold an additional ISPRM Executive Committee meeting in February of each year. This way, last minute changes to the WHA agenda or network constellations could be acknowledged. Memoranda that the Assembly of Delegates has voted upon the year before could thus be amended appropriately. Also, activities to form coalitions with member states and other international NGOs at the WHA could be coordinated and ISPRM representatives briefed.

It is further suggested to coordinate ISPRM regional and national working groups or task forces to participate in WHO regional consultations. These working groups could be chaired

Table II. *Functions of the World Health Assembly (WHA) and the World Health Organization (WHO) Executive Board (40)*

Functions of the WHA	Functions of the WHO Executive Board
Article 18 The functions of the Health Assembly shall be:	Article 28 The functions of the Board shall be:
(a) to determine the policies of the Organization;	(a) to give effect to the decisions and policies of the Health Assembly;
(b) to name the Members entitled to designate a person to serve on the Board;	(b) to act as the executive organ of the Health Assembly;
(c) to appoint the Director-General;	(c) to perform any other functions entrusted to it by the Health Assembly;
(d) to review and approve reports and activities of the Board and of the Director-General and to instruct the Board in regard to matters upon which action, study, investigation or report may be considered desirable;	(d) to advise the Health Assembly on questions referred to it by that body and on matters assigned to the Organization by conventions, agreements and regulations;
(e) to establish such committees as may be considered necessary for the work of the Organization;	(e) to submit advice or proposals to the Health Assembly on its own initiative;
(f) to supervise the financial policies of the Organization and to review and approve the budget;	(f) to prepare the agenda of meetings of the Health Assembly;
(g) to instruct the Board and the Director-General to bring to the attention of Members and of international organizations, governmental or nongovernmental, any matter with regard to health which the Health Assembly may consider appropriate;	(g) to submit to the Health Assembly for consideration and approval a general programme of work covering a specific period;
(h) to invite any organization, international or national, governmental or non-governmental, which has responsibilities related to those of the Organization, to appoint representatives to participate, without right of vote, in its meetings or in those of the committees and conferences convened under its authority, on conditions prescribed by the Health Assembly; but in the case of national organizations, invitations shall be issued only with the consent of the Government concerned;	(h) to study all questions within its competence;
(i) to consider recommendations bearing on health made by the General Assembly, the Economic and Social Council, the Security Council or Trusteeship Council of the United Nations, and to report to them on the steps taken by the Organization to give effect to such recommendations;	(i) to take emergency measures within the functions and financial resources of the Organization to deal with events requiring immediate action. In particular it may authorize the Director-General to take the necessary steps to combat epidemics, to participate in the organization of health relief to victims of a calamity and to undertake studies and research the urgency of which has been drawn to the attention of the Board by any Member or by the Director-General.
(j) to report to the Economic and Social Council in accordance with any agreement between the Organization and the United Nations;	
(k) to promote and conduct research in the field of health by the personnel of the Organization, by the establishment of its own institutions or by co-operation with official or non-official institutions of any Member with the consent of its Government;	
(l) to establish such other institutions as it may consider desirable;	
(m) to take any other appropriate action to further the objective of the Organization.	

by the Regional Vice Presidents. The working groups would send reports to the Executive Committee in preparation of the WHA in May and of the ISPRM congress in June. The task forces and working groups could reconvene a day or so before the ISPRM congress to evaluate progress. If necessary, they should then recommend amendments to their own mandate and plan of action to be voted on by the Assembly of Delegates.

The biennial electoral process to the Assembly of Delegates and the Presidency could be held in June to correlate with ISPRM scientific meetings.

## CONCLUSION

The above outline serves to show that ISPRM is in a unique position to be the leading international, non-governmental PRM actor. Its official relation status to WHO empowers ISPRM to actively participate together with many possible allies and partners in the fulfilment of “health-for-all” goals as envisioned by the world health policy agenda (1, 3).

However, the current internal structural situation seems to be inefficient and not well suited to this task. Moreover, ISPRM may be inadequately equipped to utilize its full potential. In light of major future challenges, modifications to its current policy structures may become increasingly relevant. These even seem mandatory against the background of: (i) an envisioned growth of membership and the implications for manageability, accountability and legitimacy; (ii) the self-imposed vision and mission as outlined in the By-Laws; (iii) and ISPRM’s duties toward the WHO and the global PRM constituency.

Sowing the seeds of change necessarily involves strong regional and national societies willing to take leadership in the implementation of ISPRM policy agenda. They are the cornerstones of sustainable growth and influence – notably in regions where no PRM society exists. Externally, ISPRM must be conscious of the rights and possibilities it already has with WHO and must foster new alliances within the world political system of IGOs and international NGOs.

Additionally, it would be of great advantage to appreciate fully WHO’s schedule of yearly organizational meetings on all world levels. Aligning ISPRM’s own meeting schedule to that of WHO would significantly improve ISPRM’s influence on, and ability to react to, world health policy.

Finally, the possible solutions to ISPRM’s perceived challenges outlined in this paper are not to be misunderstood as being ISPRM’s official position or that of its individual bodies. The main purpose of this paper is to stimulate discussion of the introduced arguments and suggested scenarios in the appropriate ISPRM bodies.

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## ISPRM DISCUSSION PAPER

### CHAPTER 6: THE POLICY AGENDA OF ISPRM

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#### SUMMARY

*This paper suggests a comprehensive policy agenda and first steps to be undertaken by the International Society of Physical and Rehabilitation Medicine (ISPRM) in order to realize its humanitarian, professional and scientific mandates. The general aims of ISPRM, as formulated in its guiding documents, the relations with the World Health Organization (WHO) and the United Nations system, and demands of ISPRM's constituency herein form the basis of this policy agenda. Agenda items encompass contributions to the establishment of rehabilitation services worldwide and the development of rapid rehabilitation disaster response, the enhancement of research capacity in Physical and Rehabilitation Medicine (PRM), and the development of PRM societies. ISPRM's possible input in general curricula in disability and rehabilitation, and in fighting discrimination against people experiencing disability are discussed. Moreover, the implementation of the International Classification of Functioning, Disability and Health (ICF) in medicine, contributions to WHO guidelines relevant to disability and rehabilitation, the provision of a conceptual description of the rehabilitation strategy and the outline of a rehabilitation services matrix are seen as important agenda items of ISPRM's external policy. With regard to its constituency and internal policy, a definition of the field of competence and a conceptual description of PRM, as well as the development of a consistent and comprehensive congress topic list and congress structure appear to be crucial items. The proposed agenda items serve as a basis for future discussions.*

#### INTRODUCTION

The basis for the International Society of Physical and Rehabilitation Medicine's (ISPRM) international role in Physical and Rehabilitation Medicine (PRM) and rehabilitation is a comprehensive internal policy agenda in relation to its constituency, and an external policy agenda in relation to international institutions including the World Health Organization (WHO),

the United Nations (UN) and other non-governmental organizations (NGOs) in official relation with WHO (1–3). Both sets of policies may be influenced from the outside as well as from the inside of the organization (1). They differ analytically, but in practice are often intertwined.

ISPRM's guiding documents, the By-laws (4), the Policy and Procedures (5) and the WHO/ISPRM collaboration plan (6) serve as a framework for the development of the policy agenda. They are aligned with the guiding documents of the Disability and Rehabilitation (DAR) team at WHO and DAR's Action Plan (7) and priorities (8), since ISPRM is an NGO in official relation with WHO (1, 9, 10). Beyond that, the main anchor point for ISPRM's policy agenda is the UN. In other chapters of this special issue on international perspectives in rehabilitation (1, 3, 9, 10) we have described basic features of the world societal environment within which ISPRM operates, policy processes and tools at the disposal of ISPRM, and organizational structures suited to ISPRM's evolving role.

The objective of this chapter is to describe ISPRM's current and emerging internal and external policy agenda. The specific aims are to describe the rationale of each agenda item, to outline the current status of ISPRM activity, and to discuss the next steps ISPRM can take to reach its policy objectives.

#### EXTERNAL POLICY AGENDA

A distinction is made between agenda items set by the UN system or from the outside and agenda items set by ISPRM itself or from the inside.

From the outside ISPRM's external policy agenda is currently driven by 3 developments in the UN and WHO context: (i) the implementation process of the UN Convention on the Rights of Persons with Disabilities (in the following called UN Convention (11)); (ii) the call by the World Health Assembly (WHA) Resolution on Disability and Rehabilitation (in the

following called WHA Resolution) to expand rehabilitation capacity (12); and (iii) the implementation of the International Classification of Functioning, Disability and Health (ICF) (13) into medicine and, more specifically, into rehabilitation (14–17).

From the inside ISPRM's external policy agenda is driven by the need: (i) to conceptualize rehabilitation as a health strategy based on the ICF and relevant to all health professions; and (ii) to develop an internationally shared understanding of the principles of rehabilitation services provision along the continuum of care and within the broader perspective of health services and care delivery.

#### *Supporting the establishment of rehabilitation services worldwide*

*Rationale of agenda item.* The WHA Resolution stresses “that 80% of people with disabilities, particularly in the child population, live in low-income countries and that poverty further limits access to [...] rehabilitation services [...]” (12). The WHA resolution thus requests the Director General of WHO “[...] to provide support to Member States in strengthening national rehabilitation programmes [...]”, and urges member states “[...] to promote [...] full physical, informational, and economic accessibility [...] to health and rehabilitation services [...]”. By the same token, the UN Convention recognizes “[...] the importance of accessibility [...] to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms [...]”, and requests that states parties “shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services” (11). The UN convention also recognizes “the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries [...]” (11). ISPRM, as an NGO in official relation with WHO, is therefore requested to address these issues.

*Status of ISPRM activities.* In the past, ISPRM has contributed to WHO DAR's Community Based Rehabilitation (CBR) guidelines, the WHO Violence and Injury Prevention trauma guidelines, and the World Report on Disability and Rehabilitation (2). Also, ISPRM is contributing to a WHO report on “International Perspectives in Spinal Cord Injury” (IPSCI) (18) which reviews the current situation of spinal cord injury rehabilitation and beyond.

A set of activities is evolving in the context of the newly established network of professional organizations in official relation with WHO's DAR team. In a meeting of the DAR professional organizations network during the 61<sup>st</sup> WHA assembly in 2008, in which ISPRM participated, the need to develop a document outlining the minimum requirements to build a national rehabilitation programme covering all specializations (Physical Therapy, Occupational Therapy, PRM, etc)” was recognized. A “needs assessment for physical rehabilitation services in developing countries” was called upon, as well as

the development of “guidelines for service provision”, and guidelines for people with disabilities “and their role in their own care, in line with CRPD (Convention on the Rights of Persons with Disabilities; the authors (11)) Article 26” (19). A meeting to build consensus on the next steps was envisioned. Furthermore, “educational programs so that services are available in rural districts” are planned and the development of consulting capacity of policy makers in rural areas and outreach support were seen as targets of joint activities (19).

*Next steps.* In addition to the described and ongoing activities in collaboration with DAR and its professional organizations network, ISPRM may commission a discussion paper on the agenda item. The paper could review the current situation of PRM in the provision of rehabilitation services in low resourced settings and discuss how ISPRM can support the work of PRM physicians in these areas. The paper could also explore possible collaborations with other organizations involved in fostering rehabilitation services provision in low resource countries, such as the International Society of Prosthetics and Orthotics (ISPO) and the International Rehabilitation Forum (20). Considering the importance of the issue, ISPRM may consider the formation of a committee.

#### *Developing rapid rehabilitation response to natural and man-made disasters*

*Rationale for agenda item.* War, terrorism, civil unrest, epidemics, earthquakes, flooding and storms may result in a sudden onslaught of huge numbers of catastrophic and disabling injuries. National governments, NGOs, and the UN develop sophisticated plans to respond to disasters. Rapid rehabilitation response and specific strategies to protect and evacuate people with disabilities are important elements of complete disaster response programmes. Governmental plans seldom recognize the acuity of medical rehabilitation. The responses to recent disasters ranging from the Indonesian tsunami (21, 22) to the wars in Iraq and Afghanistan (23–25) involved limited efforts to provide acute medical rehabilitation for the local populations. Conversely, in the earthquake in China in May 2008 the rehabilitation perspective was considered from the first day, and PRM physicians including members of ISPRM were involved in the planning and execution of the rescue effort.

*Status of ISPRM activities.* In the WHO DAR professional organizations meeting this agenda item has been identified as an important issue. The World Federation of Occupational Therapists reported on ongoing activities (19).

*Next steps.* In addition to the ongoing activities in collaboration with DAR and its professional organizations network ISPRM may commission a discussion paper on the agenda item. The paper could review PRM's role in rehabilitation service provision in recent disasters, discuss lessons learned and outline how the rehabilitation perspective can be enhanced in organizations involved in disaster response. Such a paper could serve as input from PRM's perspective for the respective ongoing DAR activity.

*Enhancement of research capacity*

*Rationale for agenda item.* The WHA resolution urges member states to “develop their knowledge base” and particularly highlights the “importance of reliable information on various aspects of disability prevention, rehabilitation and care” (12). In this it is clearly recognized that “today’s investments in rehabilitation research are investments in improved rehabilitation care in the future” (26).

The challenges to build research capacity have been summarized in 2 recent initiatives, the Rehabilitation Summit in the USA (27) and an initiative by the *Journal of Rehabilitation Medicine* (JRM) to conceptualize, organize and develop human functioning and rehabilitation research based on the ICF as a unifying model (28, 29). The latter is in line with the notion by WHO’s DAR team that the “ICF should be used to put order into research” (19).

*Status of ISPRM activities.* ISPRM is currently addressing this agenda item through its contribution to the DAR professional organizations network where this agenda item is being explored.

*Next steps.* In addition to the ongoing activities in collaboration with DAR and its professional organizations network, ISPRM may commission a discussion paper on how to develop rehabilitation research capacity from the perspective of PRM. This paper could build on the 2 mentioned initiatives. Beyond the issues discussed in these initiatives it should explore how an NGO such as ISPRM can contribute to building research capacity internationally and particularly in low resourced countries (1). For this, one could draw on relevant experiences including the European School Marseilles, France, the Euro-Mediterranean Rehabilitation PRM School in Syracuse, Italy and the work by the American Austrian Foundation (AAF). The paper could serve as input from PRM’s perspective for the ongoing DAR activity.

ISPRM may also explore how it could contribute to a more widespread use of the ICF to enhance the relevance and comparability of disability statistics worldwide and the consideration of disability in addition to mortality in international health policy.

*Development of PRM societies for low resource settings*

*Rationale for agenda item.* The development of PRM societies in low resourced settings is an important means to achieve the goals of the UN Convention and WHA Resolution. It is a highly desirable condition for building sustainable medical rehabilitation service provision. There are regions where no PRM societies, and even no PRM, exist. It has, for instance, been reported that in Sub-Saharan Africa, only 6 PRM doctors serve 750 million Africans (30).

*Status of ISPRM activities.* Based on a list of PRM societies, ISPRM has identified the countries that currently do not have a PRM society (1).

*Next steps.* It is envisioned that ISPRM commissions a discussion paper on how to facilitate the development of PRM

societies. The paper could review the state of rehabilitation and PRM within the countries that do not have a PRM society (1, 30). The latter task will, in part, be covered by the WHO’s World Report on Disability and Rehabilitation (31), to which individual ISPRM members as well as the organization as a whole are providing input. The paper could also discuss how to involve PRM physicians from developing regions, such as Sub-Saharan Africa (30) in ISPRM’s policy processes, e.g. through an observer status in the Board of Governors.

*General curricula in disability and rehabilitation*

*Rationale for agenda item.* All medical doctors and allied health professions are confronted with issues related to functioning and disability. Besides the education of PRM doctors and academic researchers in PRM, all medical students, health professionals and medical researchers should therefore receive basic training in disability and rehabilitation. Unfortunately, many respective curricula currently do not include appropriate modules in functioning, disability and PRM.

*Status of ISPRM activities.* ISPRM is contributing to the plan of WHO’s DAR team to design curricula “on disability and rehabilitation for schools of public health, medical schools, and other institutions training personnel for work in broader public services” (7). In this context ISPRM has contributed to a review of curricula on violence and injury prevention and disability called TEACH VIP.

*Next steps.* As the only physician organization in official relation with DAR, ISPRM could facilitate the work of WHO’s DAR team by commissioning a discussion paper that specifically addresses how functioning and disability could best be included in curricula for medical doctors.

*Fighting discrimination and promoting comprehensive views of disability*

*Rationale for agenda item.* According to the UN Convention, discrimination against people with disabilities is a worldwide major political issue. This discrimination may be a product of the medical model of disability in conjunction with cultural ideas about personal guilt and punishment (32). Also, the view that disabled people are of no value to, and need to be cared for by, society because they are no longer productive in economic terms, still prevails in some countries.

*Status of ISPRM activities.* ISPRM may contribute to changing underlying attitudes towards the recognition “that people with disabilities are important contributors to society and that allocating resources to their rehabilitation is an investment [...]” (12). Towards this goal ISPRM has an important role in promoting and disseminating the comprehensive ICF model of disability which is reconciling the social and the medical model. In particular, the social aspects need to be highlighted, i.e. that it may be the environment that causes the disability and not only impairments. Indeed, blaming the environment including health and social services is a strategy of keeping the person from being discriminated against.

*Next steps.* The strategic pathway regarding ISPRM's contribution to fighting the global discrimination against people with disabilities may entail the publication of a discussion paper elaborating, for example, the anti-discriminative potential of the ICF.

#### *Implementation of the icf in medicine*

*Rationale for agenda item.* The ICF is becoming the unifying and universal model for rehabilitation practice (15, 16, 33–35) and research (28, 29). In addition, the ICF is instrumental for comparable and meaningful disability statistics and the fighting of discrimination and the promotion of comprehensive views on disability, as outlined in previous sections of this paper. While the ICF is now widely accepted as the unifying and universal conceptual model for rehabilitation and PRM, it is not yet widely implemented in clinical practice (34).

*Status of ISPRM activities.* To facilitate the implementation of the ICF in medicine and rehabilitation in particular, practical tools such as the ICF Checklist and the ICF Core Sets have been developed (34). ISPRM is spearheading the development of the ICF Core Sets in close collaboration with other international organizations, WHO and the ICF Research Branch of the German WHO Family of International Classification (DIMDI) ([www.icf-research-branch.org](http://www.icf-research-branch.org)). ICF Core Sets have been developed along the continuum of care and across a wide spectrum of health conditions (34, 36, 37). Currently, a Generic ICF Core Set which serves as general reference is underway (38).

While the development of the ICF Core Sets has been conducted under the auspice of WHO's Classification, Terminology and Standards (CTS) team, the implementation of the ICF and ICF Core Sets in rehabilitation is under the auspice of WHO's DAR team, with which ISPRM is in official relation.

*Next steps.* The first 2 steps along the strategic pathway towards implementing the ICF in PRM are the adoption of the ICF and the endorsement of the WHO ICF Core Sets by the ISPRM board. The third step is the ratification through the national societies in a process outlined in another article in this special issue (9).

To facilitate the implementation based on the scientific literature (15, 16, 34, 35) ISPRM may consider the development of manuals on using the ICF in clinical practice and on translating values obtained with specific measurement instruments such as the Functional Independence Measure (FIM) into the ICF and vice versa (34).

In addition, ISPRM may consider the development of web-based training tools, or facilitate the link to existing training tools, such as the ICF Case Studies ([www.icf-casestudies.org](http://www.icf-casestudies.org)).

A special issue featuring studies on the implementation of the ICF in concrete clinical settings inviting authors from different world regions and implementing the ICF along the continuum of care could enhance the implementation process.

Finally, and most importantly, ISPRM may want to collaborate with WHO's DAR team, which is leading the implementation of the ICF within WHO and worldwide in the development

of a WHO Technical Guideline for the Implementation of the ICF in Rehabilitation Practice. In this case, and considering both the importance of the ICF agenda item and the wide range of activities, the formation of an ICF Implementation Committee seems advisable.

#### *WHO guidelines and glossary on terminology relevant to disability and rehabilitation*

*Rationale for agenda item.* It is almost a normative expectation that an international medical society such as ISPRM is involved in the production and publication of guidelines on health intervention standards and procedures. Guidelines are of utmost value to clinical practice, since they provide the basis for the development of more or less flexible routines (39) that are informed by the current state of evidence and expert opinion. A guideline can be understood as a document containing recommendations about health interventions, whether they are clinical, public health or policy. One may, for example, differentiate between emergency, standard, and management guidelines. Prerequisite for guidelines that can be applied globally is a unified terminology in disability and rehabilitation.

According to the WHO DAR Action Plan 2006–2011 (7), a number of guidelines relevant to PRM have recently been published, are currently being compiled or are planned.

In collaboration with the Measurements and Health Information Systems (MHI), the UN Statistics Division and the Washington Group on Disability Statistics, guidelines on appropriate data collection methods addressing the need for disaggregated gender-specific disability statistics at the country level are envisioned. Likewise, guidelines on strengthening medical rehabilitation services are currently being developed. Furthermore, guidelines on the provision of manual wheelchairs in less-resourced settings (40) have been published. Guidelines for training personnel in developing countries for prosthetics and orthotics services (41), as well as guidelines for CBR are in preparation (18). Another important item of the WHO DAR Action Plan is a glossary on terminology relevant to disability and rehabilitation.

*Status of ISPRM activities.* ISPRM has already contributed to the review of, and as advisors for, a WHO guideline on CBR, which will be published in 2009. Collaboration in the compilation of a position paper for medical rehabilitation is provided according to ISPRM's work plan with WHO: "ISPRM will continue to be actively involved and to contribute to the revised position paper on strengthening medical rehabilitation and any other activities in relation to this; by attending informal and formal meetings and the submission of written reports and by commenting on revised versions. The new position paper on strengthening medical rehabilitation will include and comprehensively cover aspects brought in by the expertise from ISPRM" (6). ISPRM's collaboration with regard to the glossary that is going to be included in the WHO World Report on Disability and Rehabilitation (31) encompasses reviews by ISPRM representatives and ISPRM's representation on the advisory committee.

*Next steps.* ISPRM may review already published guidelines and, if applicable, adopt them by a vote of ISPRM's Board of Governors or Assembly of Delegates. Beyond adoption, ISPRM may develop a ratification process for guidelines by ISPRM member countries following the procedures outlined in another chapter of this special issue (9).

As far as the guidelines currently under development are concerned, ISPRM may consider enhancing its input and could, accordingly, evolve its activities in the next work plan with WHO's DAR team.

#### *Conceptual description of the rehabilitation strategy*

*Rationale for agenda item.* As outlined in another article in this special issue, conceptual descriptions and definitions are powerful tools influencing the perception of real world problems by internal and external players (9). A conceptual description and derived definitions of rehabilitation are thus instrumental in achieving the goals outlined in the UN Convention (11) and the WHA resolution (12). More specifically, they facilitate the development of a common understanding within the rehabilitation professions in order to act in concert to enhance rehabilitation capacity worldwide. By the same token, they are essential for the successful development of the professional discipline of PRM (42).

When describing and defining rehabilitation, it is useful and necessary to distinguish between different understandings or applications. From a public health perspective, rehabilitation can be understood and described as a strategy in healthcare. Other strategies include prevention, cure and support. From the perspective of care provision, the rehabilitation strategy is instrumental for the understanding and definition of professional disciplines including the medical specialty PRM (42). From a primarily scientific perspective, the rehabilitation strategy serves as a basis for the understanding and description of distinct scientific fields, including integrative rehabilitation sciences or biomedical rehabilitation sciences and engineering (43–45).

There is no single appropriate definition of rehabilitation understood as a health strategy. For example, a legal definition may differ from definitions suitable for the perspective of service providers and payers, policy-makers, advocacy groups or scientists. In addition, depending on the purpose, one may, for example, wish to use a comprehensive or a brief definition.

To facilitate purpose-tailored, but consistent, definitions of rehabilitation, the development of a conceptual description that can serve as reference seems most useful. Considering the ICF as an emerging unifying model for functioning and rehabilitation a conceptual description should be based on the ICF and use its taxonomy.

An ICF-based conceptual description can overcome the limitations of past definitions of rehabilitation that have been criticized for their narrow perspective based on the biomedical model. They include the WHO's definition of rehabilitation from 1981 (46) and the UN standard rules from 1993 (47). Whilst the biomedical perspective is essential in enabling people to achieve optimal physical capacity, other approaches are equally important. They include approaches that focus on the

factual performance of individuals in their concrete life situation, which aim at the empowerment of proxies and caregivers of the person, and which create a facilitating environment by, for instance, removing environmental barriers.

*Status of ISPRM activities.* Towards a globally accepted ICF-based conceptual description of the rehabilitation strategy (Table I), JRM has recently published a discussion paper and subsequent letters to the editor (48). A derived short definition describes rehabilitation as the health strategy applied by PRM and professionals in the health sector and across other sectors that aims to enable people with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning in interaction with the environment (48).

*Next steps.* Considering the importance of a conceptual description and derived definitions of the rehabilitation strategy, ISPRM may prioritize this agenda item in its work with WHO's DAR team. As a first step towards a globally accepted and ICF-based conceptual description of the rehabilitation strategy ISPRM thus brought the agenda item to the attention of DAR and its professional organizations network during the meeting held during the 61<sup>st</sup> WHA in 2008. In the envisioned process towards a universally accepted conceptual description, ISPRM may consider the development of a position statement based on the JRM discussion paper.

Table I. ICF-based conceptual description of rehabilitation strategy (48) (ICF terms in the proposed ICF-based conceptual description are marked in bold)

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*Rehabilitation is the health strategy which*  
based on WHO's **integrative model of human functioning and disability**  
applies and integrates

- ⇒ biomedical and engineering approaches to optimize a **person's capacity**
- ⇒ approaches which build on and strengthen the resources of the **person**
- ⇒ approaches which provide a **facilitating environment**
- ⇒ approaches which develop a **person's performance** in the interaction with the **environment** over the course of a **health condition**; along and across the continuum of care,
- ⇒ ranging from the acute hospital to rehabilitation facilities and the community;
- and across sectors
- ⇒ including health, education, labor and social affairs with the goal
- ⇒ to enable people with **health conditions** experiencing or likely to experience **disability** to achieve and maintain optimal **functioning**

*Rehabilitation is*

- ⇒ the core strategy for the medical specialty PRM,
- ⇒ a major strategy for rehabilitation professions,
- ⇒ a relevant strategy for other medical specialties and health professions, service providers and payers in the health sector,
- ⇒ and a relevant strategy for professionals and service providers across sectors caring for or interacting with people with **health conditions** experiencing or likely to experience **disability**.

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ICF: International Classification of Functioning, Disability and Health; PRM: Physical and Rehabilitation Medicine; WHO: World Health Organization.

*Rehabilitation services within health services matrix*

*Rationale for agenda item.* According to the WHO DAR action plan (7), “the number of people with disabilities is increasing due to population growth, ageing, emergence of chronic diseases and medical advances that preserve and prolong life. [...] These trends are creating overwhelming demands for health and rehabilitation services”.

A prerequisite to meet these demands is an internationally shared understanding of the principles of rehabilitation services provision within the broader perspective of health services and care delivery. Recognizing the large international variation in the types of services provided and their financing, basic principles guiding rehabilitation services provision along the continuum of care, for varying health conditions, and involving different levels of care in varying environments may be identified. An envisioned matrix of rehabilitation within the broader context of health services and care provision may facilitate the specification of services tailored to a specific context and hence foster an effective and efficient service provision.

*Status of ISPRM activities.* ISPRM has brought the agenda item to the attention of the DAR meeting with the professional organizations network during the WHA in 2008. During this meeting it was emphasized that the ICF should serve as reference for a matrix with regard to intervention goals. The matrix should further “cover different time frames: acute, post acute, maintenance or habilitation” (19). The matrix should also “be applicable across different care settings (tertiary, secondary, primary – community and family) and highlight the need for a continuum of care” (19). It was decided that “WHO will develop an outline of the objectives of the matrix and process for development for feedback by the professional organizations” (19).

*Next steps.* Next steps on the strategic pathway towards the development of a rehabilitation services matrix include a review and discussion of the draft proposal within ISPRM’s executive board and the publication of a discussion paper in order to prepare for further discussions within DAR’s professional organizations network.

## INTERNAL POLICY AGENDA

ISPRM’s internal policy agenda is driven by activities perceived by its members to be of value to them. The agenda is limited by the resources available to achieve all of interest to the members.

From a policy perspective, a re-emerging current topic is the definition of the “field of competence” of PRM. Examples are an initiative of the professional practice committee of the European Union of Medical Specialists (UEMS), which aims to specify PRM’s “field of competence” (49, 50).

The key difficulty in defining the field of competence of PRM physicians may lie in the fact that PRM is not defined by a disease or organ system, but rather by limitations of functioning associated with health conditions in interaction

with personal and environment factors. As a result of this complexity, PRM is a highly interdisciplinary area in both practice and research.

The discussion regarding the field of competence of PRM is timely since we can now build on the ICF as a unifying model for PRM allowing to conceptualize PRM as the “medicine of functioning” (33, 42, 51, 52) or to identify a comprehensive set of topics relevant for PRM congresses (53).

*Conceptual description of PRM*

*Rationale for agenda item.* An essential element for the definition of the field of competence of PRM is a respective conceptual description. A conceptual description can serve as basis for derived definitions suited for specified purposes and audiences (42). A conceptual description and derived definitions of PRM are likely to foster a common identity of PRM physicians and make the field more attractive for medical students and other physicians.

Both the scientific basis of functioning and the conceptual issues, such as the definition of the field of competence, are of importance to develop a rehabilitation strategy. Thus cooperation both with scientific and professional organizations is important, for instance in Europe these are the European Society of PRM (ESPRM) and UEMS PRM-Section and Board. The Professional Practice Committee has already started a process to define the field of competence of PRM as well as the relations with other health professionals, in a series of statements and position papers.

*Status of ISPRM activities.* A discussion paper providing a first version of an ICF-based conceptual description of PRM has been published in JRM (42). A modified version of the suggested conceptual description of PRM is reprinted in Table II.

*Next steps.* The basis for the development of an ICF-based conceptual description and derived definitions of PRM is the adoption of the ICF as the unifying framework for PRM by ISPRM’s Board of Governors, as mentioned under the respective agenda item.

Next steps could include the review of a proposed conceptual description and definitions and related letters to the editor published in JRM within ISPRM’s governing bodies. A position paper could then be drafted by an author team commissioned by ISPRM’s executive committee. After voting on the draft and possible amendments, an ISPRM position paper could be published.

A brief definition derived from the conceptual description may then be included into an envisioned revised ISPRM constitution (Bylaws and Policy Principles (4)). Finally, a ratification process by national societies along the lines described in another article in this special issue (9) is conceivable.

*Congress topic list and congress structure*

*Rationale for agenda item.* Scientific conferences are instrumental in the development of scientific fields or “fields of competence”. Conferences bring scientists together and

Table II. *ICF-based conceptual description of the medical specialty Physical and Rehabilitation Medicine (PRM) (42) (ICF terms in the proposed description are marked in bold)*

PRM is the medical specialty which based on

- the diagnosis and treatment of **health conditions**,
- WHO's integrative model of human **functioning**,
- and rehabilitation as its core health strategy.
- assesses functioning in relation to health conditions, personal and environmental factors
- performs or applies biomedical and engineering interventions to optimize capacity

suitable to:

- ⇒ stabilize, improve or restore **impaired body functions and structures**,
- ⇒ prevent **impairments**, medical complications and risks
- ⇒ compensate for the absence or loss of **body functions and structures**
- leads and coordinates intervention programmes to optimize performance
  - ⇒ in a multi-disciplinary iterative problem-solving process
  - ⇒ performing, applying and integrating a wide range of biomedical, psychological and social interventions
- provides advice to patients and their immediate **environment**, service providers and payers
  - ⇒ over the course of a **health condition**
  - ⇒ along and across the continuum of care from the acute hospital to rehabilitation facilities and the community
  - ⇒ and across sectors from health, education, labor to social affairs
- manages rehabilitation, health and multi-sectorial services
- informs and advises the public and decision makers about suitable policies and programmes in the health sector and across the other sectors which
  - ⇒ provide a **facilitating** larger **physical and social environment**;
  - ⇒ ensure access to rehabilitation services as a human right;
  - ⇒ and empower practitioners to provide timely and effective PRM care with the goal
- to enable people experiencing or likely to experience **disability** to achieve and maintain optimal **functioning** in the interaction with the **environment**

ICF: International Classification of Functioning, Disability and Health; WHO: World Health Organization.

foster the exchange of ideas as well as the formation of a common identity. Against this background, continuity of topics discussed at scientific conferences in a field of competence is essential to develop both, science and clinical practice. A list of topics to which participants can refer when submitting abstracts and presentations defines the field on the one hand, and encourages researchers interested in these topics to attend a conference on the other.

For scientific societies that are organizing congresses, it is therefore worthwhile to carefully define the topic list for the free submission of abstracts (either for poster sessions or presentations). In the case of conferences in PRM, topics need to be related to PRM practice, but should also be attractive for PhD researchers working in such diverse fields as biology and sociology and focusing on the understanding of human functioning from the cell to society.

Until now topics of international PRM congresses, including the ISPRM world congress (3), have varied widely, leading to

varying coverage of issues relevant to PRM and limited continuity and institutional memory. Appendix II of the ISPRM Policies and Procedures (5) provides only general guidance regarding the topics to be provided at World Congresses.

*Status of ISPRM activities.* To foster a shared understanding of the field of PRM, the ESPRM has initiated the discussion towards the development of a topic list (53) and a minimal structure for international PRM congresses (54).

*Next steps.* ISPRM may consider the development of a topic list (53) and a minimal structure for international PRM congresses (54) in close collaboration with the large regional societies, including Asia-Oceania Society of Physical and Rehabilitation Medicine (AOSPRM), European Society of Physical and Rehabilitation Medicine (ESPRM) and Asociación Médica Latinoamericana de Rehabilitación (AMLAR). This would facilitate envisioned joint congresses of ISPRM in collaboration with regional societies (3). When developing a topic list for abstract submission it should provide orientation, but should also allow flexibility. Topics thus need to be broadly defined, providing leeway for innovation and specific focus.

As a final step ISPRM may endorse a topic list in concert with the regional societies and set a date for revision. The topic list could then become binding for abstract submissions to future congresses.

## DISCUSSION

This paper has described the main current policy agenda items focusing on external policies (see Table III). Some agenda items are quite clearly contoured; others are complex and need long-term development and more extensive discussion within ISPRM's governing bodies, with other rehabilitation professions, disabled persons organizations and so forth. Also, there are a range of additional items that will require attention in the future. These include clinical curricula and clinical guidelines.

While it may be perceived as less tangible than congresses and clinical guidelines, ISPRM's members will probably benefit from the development of ISPRM's external policy agenda. This includes an increased recognition of the specialty by the WHO and the UN, as well as other medical disciplines and health professions, disabled persons organizations and the general public, including people with disabilities. Efforts to increase rehabilitation capacity worldwide will enhance the opportunities of PRM physicians to provide services and care to people in need of rehabilitation. A central challenge hereby is funding, an issue that has been addressed in some detail in another chapter in this volume (3, 9). The authors wish to invite ISPRM members and the wider constituency to participate in an open debate on the suggested policy agenda. It must be emphasized that this paper discusses only selected policy agenda items. A broad discussion will need to introduce new and worthwhile aspects of future political engagement.

Table III. Overview of selected items of ISPRM's policy agenda

Agenda item/strategic goal	Internal/External	Status of ISPRM activity	Type of mandate	Policy process stages*	Next steps	Relation to UN system
Supporting the establishment of rehabilitation services worldwide	External	Envisioned; Ongoing activities of complementary organizations	Humanitarian; Professional; Scientific	Agenda setting	Discussion paper	UN Convention, WHA Resolution, Reduction of Poverty WHO-DAR professional organizations initiative
Developing rapid rehabilitation response to natural and man-made disaster	External	Envisioned	Humanitarian	Agenda setting	Discussion paper	UN Convention, WHA Resolution, WHO-DAR professional organizations initiative WFOT (ongoing activities)
Enhancement of research capacity	External	Envisioned	Scientific	Agenda setting	Discussion paper	WHA Resolution, WHO-DAR professional organizations initiative
Development of PRM societies in low resource settings	External and Internal	Envisioned; Identification of white spots	Professional; Humanitarian	Agenda setting	Discussion paper	Implementation of UN Convention, WHA Resolution
General curricula in disability and rehabilitation	External	Envisioned; Contribution to review	Professional	Agenda setting	Discussion paper	WHO-DAR Action Plan, WHO-DAR professional organizations initiative
Fighting discrimination	External	Envisioned	Humanitarian	Agenda setting	Discussion paper	UN Convention
Implementation of the ICF in Internal and ICF tools	External and Internal	Envisioned ICF Core Sets; ICF tools	Professional; Scientific	Implementation	1. Adoption of ICF 2. Endorsement of the WHO ICF Core Sets 3. Ratification by the national societies 4. Development of manuals on ICF implementation with WHO and other rehabilitation professions including relation of ICF Core Sets and existing functional status measures 5. Development of web-based training tools or facilitate the link to existing training tools	ICF, WHO-FIC, WHO-FDRG, WHO-DAR professional organizations initiative
Contribution to WHO guidelines and glossary on terminology relevant to disability and rehabilitation	External	Work in progress; Envisioned	Professional; Scientific	Goal setting Implementation	1. Review of published guidelines 2. Adoption 3. Input to guidelines and glossary in development stage through DAR professional organizations initiative	WHO-DAR Action Plan WHO-DAR professional organizations initiative
Conceptual description of the rehabilitation strategy	External and Internal	Discussion paper	Professional; Scientific	Agenda setting	Position paper (with WHO-DAR, other rehabilitation professions)	WHO-DAR Action Plan WHO-DAR professional organizations initiative

Table III. *Contd.*

Agenda item/strategic goal	Internal/ External	Status of ISPRM activity	Type of mandate	Policy process stages*	Next steps	Relation to UN system
Rehabilitation services within health services matrix	External and Internal	Envisioned	Professional; Scientific; Humanitarian	Agenda setting	Discussion paper	UN Convention; WHA Resolution WHO-DAR professional organizations initiative
Conceptual description of PRM and the definition of the field of competence	Internal	Discussion paper; UEMS initiative	Professional	Agenda setting Implementation	1. Position paper 2. Integration into ISPRM constitution	
Congress topic list and congress structure	Internal	Discussion papers	Scientific; Professional	Implementation	1. Development of topic list 2. Endorsement of topic list	

\*The policy process stages refer to the policy cycle introduced in an accompanying paper (9). Goal setting is the process of defining and prioritizing goals. Agenda setting means the communication of an issue and related goals to specific audiences. Resource mobilization refers to fundraising and human engagement. Implementation means the realization of goals in real world settings. Evaluation refers to outcomes assessments.

DAR: Disability and Rehabilitation; FDRG: The Functioning and Disability Reference Group; FIC: Family of International Classification; ICF: International Classification of Functioning, Disability and Health; ISPRM: International Society of Physical and Rehabilitation Medicine; PRM: Physical and Rehabilitation Medicine; UEMS: European Union of Medical Specialists; UN: United Nations; WFOT: World Federation of Occupational Therapists; WHA: World Health Assembly; WHO: World Health Organization.

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# Contents

<b>Abstract</b>	788
<b>Foreword</b>	
<i>DeLisa, J.A., Melvin, J.L. &amp; Stucki, G.:</i> Foreword	789
<b>ISPRM Discussion Papers</b>	
<i>Stucki, G., Reinhardt, J.D., DeLisa, J.A., Imamura, M. &amp; Melvin, J.L.:</i> Chapter 1: Achievements and challenges of ISPRM	791
<i>Stucki, G., Reinhardt, J.D., von Groote, P.M., DeLisa, J.A., Imamura, M. &amp; Melvin, J.L.:</i> Chapter 2: ISPRM's way forward	798
<i>Reinhardt, J.D., von Groote, P.M., DeLisa, J.A., Melvin, J.L., Bickenbach, J.E., Li, L.S.W. &amp; Stucki, G.:</i> Chapter 3: International non-governmental organizations in the emerging world society: The example of ISPRM	810
<i>Reinhardt, J.D., von Groote, P.M., DeLisa, J.A., Melvin, J.L., Bickenbach, J.E. &amp; Stucki, G.:</i> Chapter 4: A policy process and tools for international non-governmental organizations in the health sector using ISPRM as a case in point	823
<i>von Groote, P.M., Reinhardt, J.D., Gutenbrunner, C., DeLisa, J.A., Melvin, J.L., Bickenbach, J.E. &amp; Stucki, G.:</i> Chapter 5: Organizational structures suited to ISPRM's evolving role as an international non-governmental organization in official relation with the World Health Organization	833
<i>Stucki, G., von Groote, P.M., DeLisa, J.A., Imamura, M., Melvin, J.L., Haig, A.J., Li, L.S.W. &amp; Reinhardt, J.D.:</i> Chapter 6: The policy agenda of ISPRM	843

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**No. 46, 2008.** Abstract book: Asian Oceania Conference of Physical and Rehabilitation Medicine, May 16–19, 2008, Nanjing, China (176 pp.).

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