

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/) (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/) (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 58th 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 58th 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/). 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), 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.

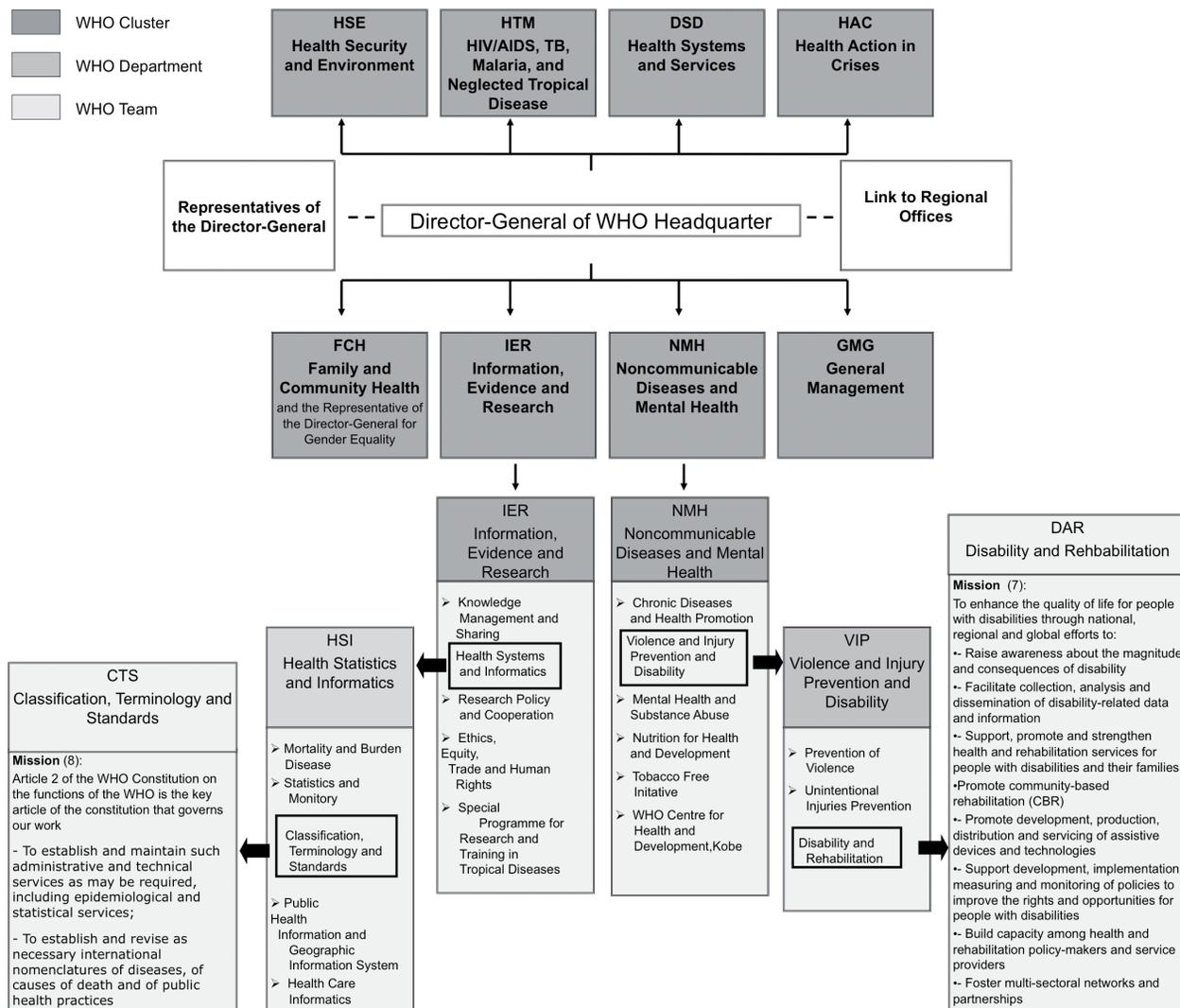


Fig. 1. Structure of the World Health Organization (WHO).

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). | http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0438 |
| II | WHO/ISPRM collaboration plan for the years 2008–10 (pdf file). | http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0439 |
| III | Extract from the report “neurological disorders” describing the rehabilitation strategy in the context of other public health strategies (pdf file). | http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0440 |