



SPECIAL ARTICLE

EUROPEAN EFFORT FOR THE SYSTEM-WIDE IMPLEMENTATION
OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY
AND HEALTH (ICF) IN PHYSICAL AND REHABILITATION MEDICINEPractice, science and governance in interaction:
European effort for the system-wide implementation
of the International Classification of Functioning,
Disability and Health (ICF) in Physical
and Rehabilitation MedicineGerold STUCKI^{1, 2, 3 *}, Mauro ZAMPOLINI⁴, Alvydas JUOCEVICIUS⁵,
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ABSTRACT

Since its launch in 2001, relevant international, regional and national PRM bodies have aimed to implement the International Classification of Functioning, Disability and Health (ICF) in Physical and Rehabilitation Medicine (PRM), whereby contributing to the development of suitable practical tools. These tools are available for implementing the ICF in day-to-day clinical practice, standardized reporting of functioning outcomes in quality management and research, and guiding evidence-informed policy. Educational efforts have reinforced PRM physicians' and other rehabilitation professionals' ICF knowledge, and numerous implementation projects have explored how the ICF is applied in clinical practice, research and policy. Largely lacking though is the system-wide implementation of ICF in day-to-day practice across all rehabilitation services of national health systems. In Europe, system-wide implementation of ICF requires the interaction between practice, science and governance. Considering its mandate, the UEMS PRM Section and Board have decided to lead a European effort towards system-wide ICF implementation in PRM, rehabilitation and health care at large, in interaction with governments, non-governmental actors and the private sector, and aligned with ISPRM's collaboration plan with WHO. In this paper we present the current PRM internal and external policy agenda towards system-wide ICF implementation and the corresponding implementation action plan, while highlighting priority action steps – promotion of ICF-based standardized reporting in national quality management and assurance programs, development of unambiguous rehabilitation service descriptions using the International Classification System for Service Organization in Health-related Rehabilitation, development of Clinical Assessment Schedules, qualitative linkage and quantitative mapping of data to the ICF, and the cultural adaptation of the ICF Clinical Data Collection Tool in European languages.

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In 2001, the World Health Assembly (WHA) endorsed the International Classification of Functioning, Disability and Health (ICF).¹ The launch of the ICF was a landmark event for rehabilitation.^{2, 3} This is because for rehabilitation “the ICF serves as a practical lens through which we can observe the lived experience of health in a way that is meaningful and useful to practitioners who aim to optimize functioning of individual patients, policy makers who aim to shape the health system in response to persons’ functioning needs, and researchers who aim to explain and influence functioning”.³

Consequently, since the launch of ICF, relevant Physical and Rehabilitation Medicine (PRM) bodies at the international, regional and national level have aimed to implement the ICF in PRM. First and foremost is the application of the ICF in the definition of the PRM specialty. Thus, in 2011 the umbrella organization of PRM physicians worldwide, the International Society of Physical and Rehabilitation Medicine (ISPRM), endorsed an ICF-based conceptual description of PRM, understood as the “Medicine of Functioning”,⁴ as well as an ICF-based conceptual description of rehabilitation, understood as a health strategy in conjunction with prevention and cure.⁵ Both conceptual descriptions were developed based on the responses to two discussion papers published in 2007 on behalf of the Professional Practice Committee of the European Union of Medical Specialists (UEMS) PRM Section.^{6, 7} The conceptual descriptions endorsed by ISPRM have served as the basis for other conceptual descriptions *e.g.* for specific applications like vocational rehabilitation.⁸ Based on these ICF-based conceptual descriptions, rehabilitation aims to optimize peoples’ functioning and to minimize the experience of disability.

ISPRM has also been instrumental in the development of practical tools necessary for the application of the ICF in rehabilitation practice, research and policy. Based on a decision taken by the ISPRM Assembly of Delegates during its first congress in 2001 in Amsterdam⁹ ISPRM spearheaded the application of the ICF by leading the effort to develop ICF Core Sets, standards for the application of the ICF in rehabilitation and health care at large.¹⁰⁻¹³ Collaborating with the World Health Organization (WHO), ISPRM also contributed to the development of the so-called ‘func-

tioning properties’ that will be introduced into the 11th revision of the International Classification of Diseases (ICD-11) to describe the potential impact of a specific disease/disorder on a person’s functioning, and hence will allow for the coding of functioning *e.g.* in the context of diagnosis-related groups (DRGs).¹⁴⁻¹⁶ Responding to an initiative by the Chinese Association for PRM (CARM)¹⁷ to develop a simple ICF Clinical Data Collection Tool as a “default assessment tool” for rehabilitation and health care at large, ISPRM, supported by the Italian Society of PRM (SIMFER), is now collaborating with the Asian-Oceanian Society of PRM, the UEMS PRM Section and Board, and national PRM societies in its cultural adaptation worldwide. These practical tools allow for the implementation of the ICF in day-to-day clinical practice, the standardized reporting of functioning outcomes in both quality management and research, and for guiding evidence-informed policy.

Parallel to the developments of practical tools major educational initiatives¹⁸⁻²¹ have reinforced the ICF knowledge of PRM physicians and other rehabilitation professionals, and numerous implementation projects have explored how to apply the ICF in clinical practice, research and policy.^{22, 23} What is still largely lacking, however, is the full and systematic integration of the ICF in day-to-day practice across all rehabilitation services of national health systems, that is, its system-wide implementation.

In Europe, the system-wide implementation of the ICF in day-to-day rehabilitation practice requires a concerted effort and interaction between practice, science and governance. Considering its mandate in the field of competence of PRM specialists, the UEMS PRM Section and Board has decided to lead a European effort towards the system-wide implementation of the ICF in PRM, rehabilitation and health care at large in interaction with governments, non-governmental actors and the private sector. The effort is aligned with ISPRM’s work plan with WHO.

In this paper we present the leadership role of the UEMS PRM Section and Board, the emerging internal and external policy agenda and the implementation action plan towards the system-wide implementation of the ICF in PRM, rehabilitation and health care at large.

The leadership role of the UEMS PRM Section and Board

Recognizing the opportunities and overcoming the challenges arising from the system-wide implementation of the ICF is primarily a matter of governance. Governance in this context relates to the role of a non-governmental actor such as the UEMS PRM Section and Board in the specification of norms within its field of competence and in cooperation with other medical specialties, governments, other non-governmental actors, and the private sector.

Figure 1 shows how the UEMS with its Sections, including the PRM Section, provides advice to the European Commission for primary legislation and participates in committees for the implementation of directives. It is in contact with members of the European Parliament, and through its national member associations, UEMS cooperates with national governments and provides advice to the European Council. Through these policy channels the UEMS PRM Section and Board has the capacity to advocate for the system-wide implementation of the ICF not only in PRM, but also in other areas of rehabilitation and health care at large. Thus, the UEMS PRM Section and Board is ideally positioned to lead the

efforts in the system-wide implementation of the ICF in PRM, rehabilitation and health care at large in interaction with governments, non-governmental actors and the private sector.

Against this backdrop, the assembly of the UEMS PRM Section and Board decided at its meeting in St. Petersburg (3-5 September 2015) to initiate a European effort with the goal of the “system wide implementation of the ICF in PRM, envisioning its implementation in rehabilitation and health care at large”. The effort is being led by the Presidents of the UEMS Section and Board (NC, AJ) and coordinated by its Secretary General (MZ) and its Expert for the ICF (GS), and involves the Clinical Affairs and the Professional Practice Committee as well as the entire UEMS PRM Board. To develop an implementation action plan a workshop was held in Nottwil, Switzerland, from 22-23 January 2016, and hosted by the Swiss Society of PRM (SGPMR) and the Swiss Paraplegic Foundation. The implementation action plan was presented, reviewed and updated in the meeting of the UEMS PRM Section and Board in Athens from 25-27 February 2016.

To strengthen its effort, the UEMS PRM also collaborates with its national member organizations and ISPRM according to their mutual recognition agree-

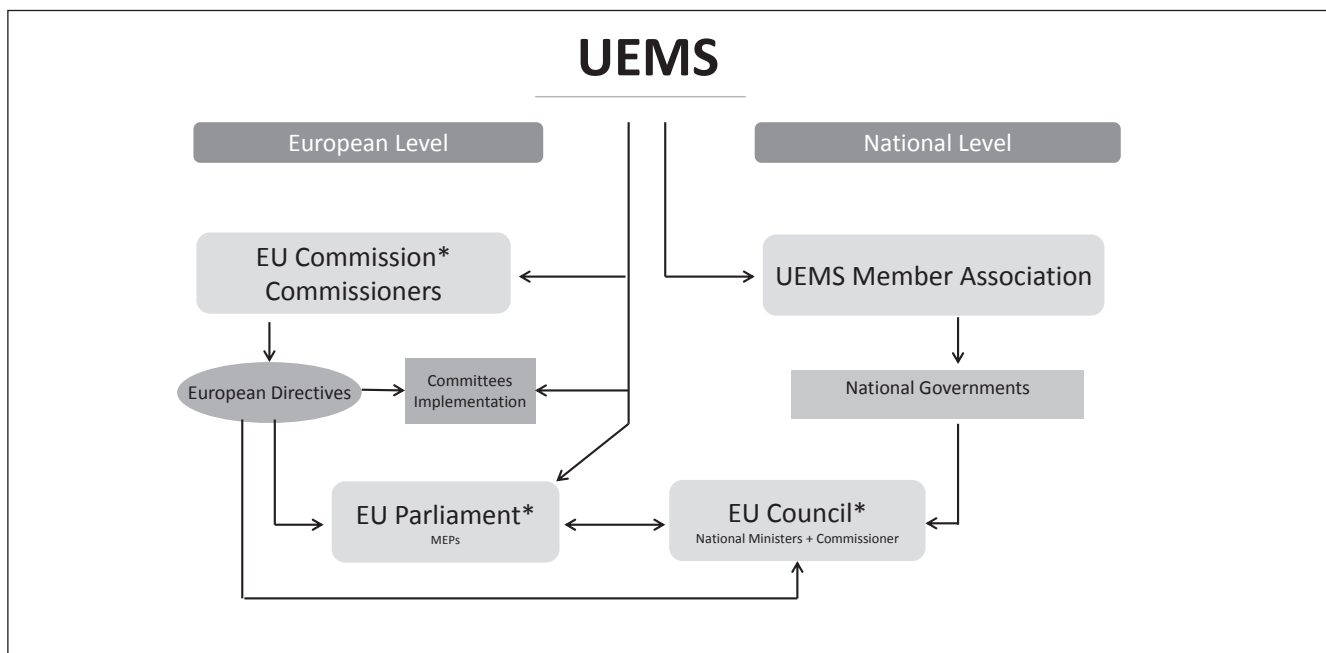


Figure 1.—Organogram UEMS.

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ment.²⁴ The basis for the current collaboration is the ISPRM-WHO collaboration plan 2015-2017²⁵ with a focus on the implementation of WHO's Global Disability Action Plan 2014-2021.^{26, 27} Item 3 of the ISPRM-WHO collaboration plan calls for national models for ICF-based routine data collection and national rehabilitation quality management programs that aim to strengthen the disability component in national health information systems.²⁶ These two concrete goals provide the concrete reference point for the European effort towards the system-wide implementation of the ICF.

Internal policy agenda within the field of competence of PRM specialists

Promoting the use of ICF by PRM specialists

Two related barriers towards the system-wide implementation of ICF in daily PRM practice are misconceptions and its perceived complexity. One misconception to be corrected is the view that the ICF is just another outcome measure. What needs to be promoted is the understanding and use of the ICF as a health information reference. The ICF is not a measure but a reference classification and standard.³ To overcome the perception that the ICF is too complex to implement in day-to-day practice, we need to foster the view that the ICF is a powerful lens through which we can observe, understand and influence people's lived experience. In turn it can guide clinical decision-making and outcome evaluation and most importantly, its use, facilitated by the now available range of suitable tools, such as the ICF Core Sets, is fundamental for rehabilitation practice and not an additional time-consuming activity. For example, the ICF is ideally suited for the standardized reporting of rehabilitation goals. With respect to assessment, the Chinese slogan "simple is best" may provide an important lesson – the ICF Clinical Data Collection Tool developed by CARM and tested for the European cultural context by the SIMFER may be the most promising tool for assessing functioning across rehabilitation and health services of the health care system.²⁸

Entrenching the ICF in the field of competence of PRM specialists

The most important document in defining the field of competence of PRM specialists is the *White book*

on Physical and Rehabilitation Medicine in Europe developed in a collaborative effort of the UEMS PRM Section and Board with the European Society of PRM and the European Academy of PRM.²⁹ The currently planned revision of the White book provides the unique opportunity to embed information about the ICF implementation in the White book chapters where appropriate, thus entrenching ICF implementation in the field of competence of PRM specialists.

ICF-based outcome evaluation in quality management and accreditation of rehabilitation services

In the future the application of the ICF in rehabilitation service provision may become an essential aspect of rehabilitation service accreditation. More concretely, the accreditation process may examine whether and how an ICF-based measurement-for-improvement system has been integrated in rehabilitation quality management of a service is used for clinical decision-making, and has contributed to continuous improvement of service outcome.

The concrete steps necessary to integrate the ICF in rehabilitation service provision are discussed further in the section "Implementation governance challenges at the level of service and care provision" since this is as much an external as well as a PRM internal policy agenda item.

Beyond PRM: external policy agenda in interaction with the health care system

Implementation governance challenges at the European and national policy level

The first implementation governance challenge faced is at the macro-level of European and national policy. Here the goal is to advocate for the inclusion of the ICF and ICF-based standards for data collection and reporting in the six components of national health systems including health information, service delivery, financing and work force.³⁰

To reach this goal the UEMS PRM Section and Board could elicit the support of other UEMS Sections representing medical specialties with an interest in functioning and rehabilitation. This is highly relevant since the success of system-wide ICF implementation not only depends on the leadership of PRM, but ultimately relies on the support of other medical specialties and health professions involved in rehabilitation and disability

management. One may even argue that the successful implementation of the ICF in PRM can only be achieved with the successful implementation of the ICF in national health systems at large. This insight is reflected in the European effort goal that explicitly extends ICF implementation beyond PRM, envisioning its implementation in rehabilitation and health care at large.

Implementation governance challenges at the National Quality Management level

The second implementation governance challenge is at the meso-level of national rehabilitation quality management against the backdrop of macro-level policies. To address this challenge we first have to develop an approach on how to design and implement a national rehabilitation quality management system in alignment with the micro-level ICF-based rehabilitation quality management approach described below. Moreover, strategies for aligning ICF-based national rehabilitation quality management systems with existing quality management and quality assurance systems in the rehabilitation sector and health care at large must be developed.

In the context of the European effort toward system-wide implementation of the ICF first steps to develop a model for a national rehabilitation quality management, including a data collection architecture, criteria for IT solutions and solutions for data protection, have been taken. In this effort, the UEMS PRM Section and Board has initiated a collaboration with the Japanese Association of PRM (JARM), who has embarked on a project to develop a national rehabilitation quality management system based on an existing registry.³¹

Implementation Governance Challenges at the care provision level

The third implementation governance challenge is at the level of care provision. Clinical leaders are faced with the challenge of implementing the ICF in day-to-day clinical practice at the micro-level, while also ensuring continuous quality improvement at the meso-level of rehabilitation services and adhering to the requirements at the national level. The construction of an ICF-based clinical quality management program that is useful for both the management of individual patients as well as improvement of rehabilitation service quality, is driven by several action steps.

First, it requires the unambiguous description of a service. To ensure recognition by patients, payers and policy makers, a description of a service should include a short narrative description in lay language. To minimize ambiguity and ensure comparability of rehabilitation services a description should include a systematic, classification-based description e.g. by applying the International Classification System for Service Organization in Health-related Rehabilitation (ICSO-R).³² Methods for developing such narrative and classification-based descriptions were explored in the aforementioned Nottwil workshop for 6 exemplary rehabilitation services and are reported in Kiekens *et al.*³³ Based on the deliberations at the Feb. 2016 Athens meeting, developing descriptions for at least 10 rehabilitation services that represent the innovative spectrum of rehabilitation services throughout Europe is envisioned.

The second action step is the specification of a so-called Clinical Assessment Schedule. A Clinical Assessment Schedule specifies what ICF domains to document (compulsory and optional). Methods for developing a clinical assessment schedule was also explored in the Nottwil workshop using the aforementioned 6 rehabilitation services. The results are presented in Prodingler *et al.*³⁴ As with the rehabilitation services descriptions, there is a plan to develop clinical assessment schedules for at least 10 reference rehabilitation services throughout Europe.

The third action step is the ICF-based standardized documentation of functioning with data collected in clinical routine. This entails the qualitative linking and quantitative mapping of data collected with the a range of currently available data collection tools to the ICF. Qualitative linking involves linking concepts contained in the data collected to the ICF following established linking rules.³⁵ To determine the metric equivalence of items or sub-scales of the data collection tools, the items/sub-scales that cover the domain defined by the linked ICF categories are then quantitatively mapped using the Rasch methodology. The resulting Rasch scores can then be compared on a common metric. This methodology was presented at the Nottwil workshop as well.^{36, 37}

A universal alternative to the use of current data collection tools is the use of the newly developed ICF Clinical Data Collection Tool which is based on simple intuitive descriptions and uses a Numerical Rating Scale.³⁸ This tool has been developed in an international coop-

TABLE I.—*ICF Implementation Action Plan.*

Topic	Activity	Deliverable	Comment
ICF in Data Collection			
ICF Clinical Data Collection Tool	National consensus conferences to develop language-specific versions following a protocol established by SIMFER in collaboration with the ICF Research Branch ²⁸ Cooperation across national societies for the development of a language-specific versions spoken in several European countries (<i>e.g.</i> French, Dutch)	Publication of the language-specific versions in a joint publication	Hosting of the language versions of the ICF Clinical Data Collection Tool on the webpages of the relevant national societies, the UEMS PRM Section and Board (www.euro-prm.org) and the ICF Research Branch (www.icf-research-branch.org)
	Development of scoring algorithms using Rasch analysis based on a European-wide data collection effort applying the language-specific versions of the ICF Clinical Data Collection Tool	Scoring algorithms for the ICF components body functions & structures and activity & participation	
ICF in Rehabilitation Services			
Existing data collection tools	Development of unambiguous narrative and classification-based descriptions of specific rehabilitation services by applying ICSO-R ^{32, 33}	List of descriptions of specific rehabilitation services in Europe	The list of data collection tools will grow with the number of Clinical Assessment Schedules This list will enrich the list of data collection tools that cover the Clinical Assessment Schedule domains
	Identification of comparable rehabilitation services across Europe	List of similar rehabilitation services that are used across Europe along the continuum of care (acute, post-acute, long-term)	
	Specification of Clinical Assessment Schedules for specific rehabilitation services using a protocol currently in development ³⁴	Implemented Clinical Assessment Schedules for specific rehabilitation services	
	Development of measurement-for-improvement systems for clinical decision-making in individual patients (micro-level) and continuous improvement of a rehabilitation service (meso-level)	Implementation of measurement-for-improvement systems in rehabilitation services across Europe	
ICF in Data Reporting			
Existing data collection tools	Identification of data collection tools that cover the ICF domains included in the Clinical Assessment Schedules of specific rehabilitation services	List of data collection tools that cover the ICF domains included in the Clinical Assessment Schedule of specific rehabilitation services	The list of data collection tools will grow with the number of Clinical Assessment Schedules This list will enrich the list of data collection tools that cover the Clinical Assessment Schedule domains
	Review of data collection tools identified in a European-wide project called “European Standardization of Outcome Measurement in Rehabilitation” (Pro-ESOR) ^{42, 43}	List of data collection tools described in Pro-ESOR that are well-known, considered valid and are currently used in clinical practice	

(To be continued)

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TABLE I.—*ICF Implementation Action Plan (continues).*

Topic	Activity	Deliverable	Comment
ICF-based reporting of data	Qualitative linking and quantitative mapping of data collected with the tools identified above to the ICF using the methodology developed in the ICF INFO project ^{37, 44}	Tables displaying ICF domains resulting from the qualitative linking of data collection tools Transformation tables using a 0-100 interval reference scale that resulted from the quantitative mapping of data collected with the data collection tools to the ICF	Only data collection tools that fulfill three criteria should be considered for quantitative mapping: 1) extensively used in daily practice; 2) well-known and considered valid by experts; 3) available and validated in various European languages Hosting of the qualitatively linked and quantitatively mapped data collection tools on the webpages of the relevant national societies, the UEMS PRM Section and Board (www.euro-prm.org) and the ICF Research Branch (www.icf-research-branch.org)
ICF in National Rehabilitation Quality Management			
	Promotion of ICF-based standardized reporting of functioning outcomes to national quality agencies responsible for quality management in rehabilitation and health care at large	Implementation of ICF-based standardized reporting of functioning outcomes within national quality management agency programs	This is an opportunity for PRM to promote the ICF as a health information reference in national health systems
	Cooperation with the International Society of Physical and Rehabilitation Medicine (ISPRM) and the Japanese Association of PRM (JARM) in the development of a model data architecture for national rehabilitation registries	Availability of a model data architecture for the development of national rehabilitation registries	
	Development of IT and data protection solutions	Exemplary IT and data protection solutions	
ICF in the Accreditation of Rehabilitation Services			
	Development of criteria for the accreditation of ICF-based measurement-for-improvement systems that complement the current UEMS criteria for quality assurance	Document outlining the criteria for ICF-based measurement-for-improvement systems	The development of criteria for ICF-based measurement-for-improvement systems may lead to an update of the UEMS Section criteria for rehabilitation services
ICF in the Health Care System at Large			
	Cooperation between the UEMS PRM Section and Board with the whole UEMS in using the policy channels described in Figure 1	The UEMS supports the UEMS PRM Section and Board in its effort to implement the ICF and ICF based standards, specifically the health information component, in medicine and the health care system at large	In implementing the ICF in health systems throughout Europe the leadership of the UEMS PRM Section and Board may inspire other medical specialties to use the ICF as a health information reference for the standardized reporting of health outcomes

eration under the auspices of ISPRM and in cooperation with the ICF Research Branch, a cooperation partner within the WHO Collaborating Center for Family of International Classifications in Germany. The first version was developed by CARM.^{17, 39} A second version, including its process for the cultural adaptation of the tool in European languages, was developed by SIMFER in collaboration with the ICF Research Branch.^{40, 41} As part of the European effort for the system-wide implementation of the ICF, European language-specific versions will be developed and published. At the Nottwil workshop there was also agreement to develop scoring

algorithms for the ICF Clinical Data Collection Tool that would allow the use of scores for clinical follow-up and outcome evaluation.

ICF implementation action plan

The ICF implementation action plan that resulted from discussions of the internal and external policy agenda items clearly shows that the system-wide implementation of the ICF in PRM requires a multi-faceted effort. Currently envisioned activities and deliverables are summarized in Table I.^{28, 32-34, 37, 42-44} They are not

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set in stone but must be adjusted along the way as we learn what works and what does not work. At this stage the number of services ultimately needed to adequately describe the innovative spectrum of rehabilitation services across Europe still needs to be determined. Similarly, the data collection tools that are currently used and considered both useful and valid will only be identified once the action plan has progressed. The action plan will have important consequences with respect to the human and time resources needed for qualitative and quantitative cross-mappings.

Conclusions

At its core the system-wide implementation of the ICF in PRM, rehabilitation and the health care system at large requires the introduction of ICF-based standardized reporting of data collected with various data collection tools and the integrative use of these data for clinical practice, clinical and national quality management as well as outcomes and epidemiological research. This represents important changes to current practice at all levels.

Thus, for system-wide implementation of the ICF to be successful an unprecedented interaction between practice, science and governance is crucial. From the so-called “theory of change”⁴⁵⁻⁴⁸ we can learn that to succeed we need “champions” and “knowledge brokers”. Champions are highly credible and convincing advocates of the cause at the European, national and local level. Champions we find in delegates of national PRM societies, their network of PRM specialists and patient advocates. Knowledge brokers are those who have unique expertise that they are willing to share. The knowledge brokers in our European effort are the colleagues who spearheaded the work on developing the conceptual description of rehabilitation services, including the specification of a Clinical Assessment Schedule and the construction and application of a measurement-for-improvement system for continuous quality improvement.

Finally, the UEMS PRM Section and Board’s endeavor to bring together practice, science and governance would be empowered if other European PRM organizations, including the European Society of PRM and the European Academy of PRM, would join the effort. Indeed, the European effort towards the system-

wide implementation of the ICF in PRM, rehabilitation and the health care system at large provides the three European organizations with a unique opportunity to collectively strengthen rehabilitation and the specialty of PRM in national health systems.

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