Event Summary & Recommendations
Pain in the International Classification of Diseases (ICD-11): A SIP Event

Recommendations

The inclusion of pain as a disease under the World Health Organization (WHO) 11th revision of the International Classification of Diseases (ICD-11), is a key development. In its response to the European Commission's Health Data Space Roadmap, SIP called for the implementation of the ICD-11 definition of pain throughout healthcare systems to improve analysis of health systems performance. This will also provide the research community with data to facilitate further clinical research. The creation of a European Health Data Space will ensure the appropriate use, access, and sharing of health data for healthcare delivery purposes, and will allow the use of data for research, innovation, and policymaking. It is with these factors in mind, as well as with the above recollection of the ICD-11 SIP Event, that SIP outlines below several policy recommendations for European Institutions and National Governments in the area of digital health and pain.

SIP calls upon EU Institutions & National Governments to:

1. Recognise the burden and impact of pain in societies and people, and increase its priority within healthcare systems, funding, and policymaking
2. Pain as a quality indicator: Develop instruments to assess the impact of pain
3. Pain research: Increase investment in research on the societal impact of pain
4. Pain in employment: Initiate policies addressing the impact of pain on employment and include pain in relevant existing initiatives
5. Pain education: Prioritise pain education for healthcare professionals, patients, policymakers, and the general public
6. Ensure effective implementation of ICD-11, ICHI and ICF at national level, as their combined use widens the use of recording patient data, and allows for greater detail when recording symptoms. This will contribute to the development and digitalisation of healthcare services, which are complementary and can support each other, and will ensure patients' needs and rights are rightly covered
7. Ensure the semantic layer of health data is appropriately taken into consideration in ICD-11 and Health Information Systems implementation

1. Introduction

On 29th November 2022, the Societal Impact of Pain (SIP) Platform, hosted a virtual event with over 150 registrants entitled "Pain in the International Classification of Diseases (ICD-11)".

This event covered a broad and engaging discussion of the benefits and the challenges of implementing ICD-11. Alongside speakers from the World Health Organization (WHO) Europe, national representatives gave insight into their countries or regions progress and findings. The event also presented the SIP Road Map Monitor 2022, launched the same day and available to read online.

2. World Health Organization (WHO) Perspective on ICD-11

Robert Jakob (RJ), Team Leader Classifications and Terminologies at WHO-Headquarters, explained that ICD-11 is a legally mandated health data standard since January 2022 for reporting mortality and morbidity information. ICD-11 is both independent of language and culture and clinically relevant and scientifically updated, bringing greater detail to ICD-10. Terminology and classification have been integrated into one structure. RJ explained the multiple uses of ICD-11, which include causes of death, clinical terms, records and surveillance, functioning assessment, primary care, prevention research, patient, drug, and device safety, casemix, costing resources and DRG and cancer registration. **RJ stated that ICD-11 is not alone, if used combined with the ICHI and ICF, it widens the use of recording patient data. Additionally, stem codes for the classification go beyond diagnosis, and allows external reasons or causes to be recorded and recognised, and the terminology extension codes, allows for a greater detail of patient symptoms and data recording.** RJ showcased an example of chronic cancer pain in ICD-11. The structure allows for adding information such as severity of pain, alternative severity, temporal pattern and onset. In terms of implementation, an application programme interface replacing software is available, and can be provided by WHO services. This can be used online like a Cloud system, however, it can also be downloaded and used locally and offline.

Nenad Friedrich Ivan Kostanjsek (NK), Technical Officer at WHO-Headquarters, used national examples of ICD-11 implementation to demonstrate ICD-11's tooling infrastructure, which ranges from implementation tools to software integration tools, amongst others. This is a key additional feature of ICD-11, which builds upon ICD-10. **Some key considerations for ICD-11 implementation would be to carry out a Health Information System ecosystem analysis and review, to specify the value proposition of ICD-11 from the country perspective, to specify opportunities and challenges for ICD-11 implementation in the country and to specify and carry out a step-wise transition process**. NK stated that ICD training also needs to be rethought, some principles to consider when training personnel would be to leverage technology, use different media (i.e. YouTube), to build more competencies around the core by gradually adding increasing levels of complexity and to include problem based learning through stories and practical cases.

Karapet Daytyan (KD), Data and Digital Health Unit, Division of Country Health Policies and Systems, WHO Regional Office for Europe, presented opportunities and efforts for ICD-11 implementation within the WHO European Region (EURO). **KD stated that WHO is supporting different actions for ICD-11 promotion, such as guiding documents for ICD-11 implementation and attending/organising workshops and events.** KD explained that in September 2022, during the 72nd Session of WHO Regional Committee for Europe, member states approved a Digital Health Action Plan, which demonstrates that the topic is becoming a high priority on the Agenda. **KD stated that ongoing or implemented ICD-11 support in EURO includes 14 WHO collaborating centres for the WHO-FIC (Family of International Classifications), across 9 countries, the introduction and implementation preparation training, in which 25 countries participated, translation to 29 languages and/or preparation for translation in WHO Europe and guidance development of digitalisation of Health Information Systems.**

3. A Patient's Perspective on Digital Health and ICD-11 Implementation

Martina Phelan (MP), Chairperson, Chronic Pain Ireland, shared the patient perspective on how patients view ICD-11 and how they can benefit from ICD-11. MP stated that most patients didn't know what ICD-11 is, therefore, education and training patients on what ICD-11 is and its direct benefits, is key to support patients and to move forward with realistic implementation of ICD-11. **Benefits for patients include reduced stigma and anxiety for patients as conditions are officially recognised, recognised condition across health care providers and personnel,**

guaranteed referral and treatment options, and guaranteed payments for treatments by health insurance companies, among others.

4. Impact of ICD-11 on Pain Management

Prof. Dr. Antonia Barke (AB), University of Essen, discussed the impact of ICD-11 on pain management, and stated that ICD-11 classification of chronic pain has been adapted to the current internationally recognised definition:

Chronic Pain (MG30) – Pain is an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissues damage. (Raja 2020). Chronic pain is a pain that persists or recurs for longer than 3 months. Chronic pain is multifactorial: biological, psychological, and social factors contribute to the pain syndrome.

AB explained that pain management will be improved, due to the fact that dualism between mind and body is replaced by the unified biopsychosocial model. Additionally, a multidisciplinary treatment would be the logical consequence and is recommended in the ICD-11, among others. Moreover, Chronic Pain (MG30) has the following subsections with their own classification codes, which in turn will improve pain management:

- MG30.0 – Chronic primary pain
- MG30.1 – Chronic cancer-related pain (new to ICD-11)
- MG30.2 – Chronic postsurgical and post traumatic pain (new to ICD-11)
- MG30.3 – Chronic secondary musculoskeletal pain
- MG30.4 – Chronic secondary visceral pain
- MG30.5 – Chronic neuropathic pain (new to ICD-11)
- MG30.6 – Chronic secondary headache or orofacial pain

AB additionally indicated that the extension codes will altogether improve pain management, as it will then be part of the diagnostic code, it will inform other treatment providers, it will allow monitoring of the pain over time and treatments, it will stimulate discussions between the healthcare provider and the patient, as the healthcare professional providing the treatment will have to ask the patient about their pain.

5. Presentation of the 2022 SIP Road Map Monitor

Rolf-Detlef Treede (RDT), Medical Faculty Mannheim of Heidelberg University, presented the SIP Road Map Monitor from 2022, which revisited the previous version in 2019, to understand how national guidelines, action plans and the status of policies supporting the updated priorities of SIP have evolved in the last few years, especially in the post-pandemic context. Top key findings are:

- Development and implementation of specific national pain plans is largely missing European governments should learn from each other
- There is a lack of prioritisation of pain in Europe. Action is needed to reach the standard of the WHO directive and classification in these areas
- The establishment of pain registries, collection of broad socioeconomic data and patient involvement within pain research projects are key areas for improvement
- More needs to be done to ensure a holistic patient-centred approach is established for adaptation of workplaces and reintegration into the workplace
- There are large discrepancies across Europe in pain education at both undergraduate and postgraduate level and major gaps in patient involvement in the development of

educational tools for pain management; both are key areas for improvement

5. Perspectives from National Government: Portugal

Filipe Mealha (FM), Coordinator for Planning, Architecture, Compliance and Engineering, introduced himself as working for the Shared Services of the Portuguese Ministry of Health (SPMS). **FM focused on the four layers to extract value from health data (legal, organisational, semantic and technical) and discussed in more detail the semantic layer, which is the layer that ensures that information is registered and received in the same manner across the whole ecosystem.** Additionally, FM linked his presentation to the European Health Data Space, and stated that such regulation discusses the primary and secondary use of data. In both cases the SPMS have created working groups to involve the private and public sector, in order to agree on and normalise interfaces. FM then explained that the SPMS will bridge the gap between Portugal and the other MS. Finally, FM explained the data strategy to establish a standardised data chain management:

- Standardise values and definitions used in reporting systems to allow uniform understanding of data stored in the NHS information systems
- Publish an integrated, accurate and consistent set of master data for use by other applications
- Create metadata standards for Health Information Systems
- Enforce compliance with metadata quality requirements in national Health Information Systems
- Builds a standard data repository and distribution system where standardization occurs at the source

6. Interventions from Key National Experts: Case Studies

Audun Stubhaug (AS), Professor at University of Oslo and Head of Department of Pain Management and Research at Oslo University Hospital and Institute of Clinical Medicine, University of Oslo, presented the Norway case study and **explained that the main reason for his clinic to introduce the use of ICD-11, even though the coding is not yet implemented in the country, was the need of classifying pain in a correct and reliable way, since pain was not classified in ICD-10.** AS stated that ICD-11 is integrated within their electronic patient register and explained that the clinician has to choose an ICD-11 code from the pull-down menu at the first consultation and then choose a second code, which is a more detailed one, which results in a suggested list of ICD-10 diagnosis (but based on the ICD-11).

Victor Mayoral Rojals (VMR), Instituto Aliaga; Centro Médico Teknon, Spain, provided the Spanish case study and **stated that ICD-11 provides a great opportunity to standardise coding for chronic pain across health care systems**, however, he notes it will take at least 5 years to get fully implemented in Spain. VMR explained he conducted a study entitled 'Community Prevalence of Different Types of Pain and Validation of a Unified Screening Questionnaire'. The study aims to identify the prevalence of the 7 types of pain in the community of patients attending a single primary care health service and design and validate a unified screening questionnaire that allows differentiating between nociceptive, neuropathic and nociplastic pain, and stated there will be a focus on chronic primary pain as it is perceived as the most important new code.

Esther Pogatzki-Zahn (EPZ), Anaesthesiologist, and pain specialist, in the Council of IASP and Councillor from the German Pain Society, provided the German case study and stated that in Germany, the Federal Institution for Drugs and Medical Devices (BfArM) is responsible for all

ICD-11 issues. **EPZ stated that several activities related to ICD-11 and pain have been organised within the German Pain Society in cooperation with the BfArM such as a two-day workshop on ICD-11 and Pain, translation of ICD-11 coding and description, among others. EPZ explained that in order to implement ICD-11 in Germany, projects with double coding are required, user-friendliness in connection with coding must be checked to ensure it is practical to use in all clinics and ensure all areas are appropriately represented (children, bio-psycho-social, diseases specific, etc,.) is needed.**

7. Q&A Discussion and Closure

The event concluded with an engaging discussion, where attendees and speakers debated about the European Health Data Space, the implementation of data sharing and the integration of information for a health or research purpose. Attendees also exchanged best practices of how different countries (i.e. Denmark and Sweden) were working on care guidelines for pain patients, as well as debating on the importance of GP's understanding the biopsychosocial aspects of chronic pain and the fact that screening tools are needed in primary care.

Patrice Forget (PF), Chair of SIP, offered a summary of the importance of implementing ICD-11 and the fact that harmonised terminology needs to be at the centre of all debates, as it will ensure a common language is spoken across Europe. PF stated that there can be both a top-down or a bottom-up approach to implementation, both successful. PF placed a special focus on the fact that ICD-11 integrates the biopsychosocial model, as well as the need to improve and inform treatment into national plans.

Deirdre Ryan (DR), Co-Chair of SIP and President of Pain Alliance Europe (PAE), stated that next steps should now be aimed at placing the focus at national level and on how patient can be best supported with ICD-11. DR stated that SIP is preparing a series of advocacy materials for next year, including an ICD-11 Position Paper and the translation of those materials into national languages to ensure it is accessible for all.