

A Societal Impact of Pain (SIP) Platform Position Paper on the International Classification of Diseases 11th Revision (ICD-11)

2023

Key Recommendations

SIP calls upon EU and national policy makers to:

1. Ensure effective implementation of ICD-11, which facilitates the recording and reporting of pain diagnoses and allows international agreement on the use of standardised tools. 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.
2. Ensure semantic interoperability is considered in ICD-11 and health information systems to enable seamless health data exchange and standardised coding of symptoms and diagnosis.
3. Recognise the burden and impact of pain on societies and patients, and increase its priority within healthcare systems, funding, and policymaking.
4. Pain as a quality indicator: Develop instruments to assess the impact of pain.
5. Pain research: Increase investment in research on the societal impact of pain.
6. Pain in employment: Initiate policies addressing the impact of pain on employment and work productivity and include pain in relevant existing initiatives.
7. Pain education: Prioritise pain education for healthcare professionals, patients, policymakers, and the general public.

Background

In Europe¹ there are approximately 740 million people², most of whom experience an episode of severe pain at some point in their life. For approximately 20 percent, that pain is chronic pain. This means that, at present, 150 million people are experiencing pain across Europe, approximately equal to the population of France and Germany combined. This situation is exacerbated by the inconsistent approach in classifying symptoms of chronic pain that would allow more accurate data to be collected.

In 2018, the Societal Impact of Pain (SIP) Platform, published its Joint Statement³ which includes recommendations for action and collaboration by the European Commission, Member States, and civil society to reduce the societal impact of pain. These recommendations form the over-arching and guiding principles for SIP, and are divided into four categories: health indicators, research, employment, and education.

SIP's Joint Statement calls to explore opportunities to build on existing instruments which are available to define, establish and / or use pain as an indicator in the assessment of healthcare systems' quality, as this will contribute to assessing and filling the data gap on the societal impact of pain³.

The inclusion of pain as a disease under the World Health Organization (WHO) 11th revision of the International Classification of Diseases (ICD-11)⁴ is a key development, which came into effect in 2022. It will facilitate the recording and reporting of pain diagnoses in a standardised format. In its response to the European Commission's Health Data Space Roadmap⁵, SIP called for the implementation of the ICD-11 definition of pain throughout healthcare systems, to improve analysis of health systems performance, and to 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. According to experts in the field, ICD-11, the International Classification of Functioning, Disability and Health (ICF) and the International Classification of Health Interventions (ICHI), will contribute the transformation of healthcare in the context of the Digital Single Market⁶.

ICD-11 defines chronic pain (MG30) as follows: Pain is an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage. Chronic pain is pain that persists or recurs for longer than 3 months. Chronic pain is multifactorial: biological, psychological and social factors contribute to the pain syndrome.

Additionally, Chronic Pain (MG30) has the following subsections with their own classification codes, which in turn will likely support pain management and treatment:

- 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

1. Digital Recording and Assessment of Pain

The World Health Organization (WHO) - International Classification of Diseases (ICD)

ICD is an international standard diagnostic tool for epidemiology, health management, research and clinical purposes, as well as the international standard for reporting of diseases and health problems, developed by the WHO. ICD can be used to record individual health conditions, and to generate and share data on these conditions for a variety of purposes, including research, reimbursement and policy planning.

What is Pain?

Pain is an “unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage⁷”. SIP views pain through the holistic ‘biopsychosocial’ model of pain, comprised of biological, psychological, and social factors. The model represents a change of focus from traditional approaches to pain (i.e., those focusing solely on the biological aspects of diseases and treatment). It ensures the full spectrum of factors

affecting diseases and treatment are acknowledged along the illness pathway (biological, psychological, and social), and emphasises the importance of acknowledging different approaches to reduce or prevent disabilities⁸.

Acute and Chronic Pain

Acute pain is pain with a duration of less than three months⁹, while pain which persists for longer than three months is generally classified as chronic pain¹⁰. The transition process is known as 'chronification'. Chronic pain is also associated with significant emotional distress, such as anger or depressed mood, and/or significant functional disability, such as negatively affecting daily activities, hobbies and participation in social roles¹¹.

Chronic pain, along with several other types of pain, is included in the 11th revision of the International Classification of Diseases (ICD-11), as revised in June 2018. A major inclusion is the diagnosis of Chronic Primary Pain. ICD-11 describes chronic primary pain as multifactorial, capturing its persistence and disruptive nature, without making assumptions about aetiology. Therefore, its implementation in all Member States is of vital importance in order for chronic pain data to become available in standardised manner, as we move forward to more digitalised healthcare systems³.

ICD-11 is more independent from language and culture than any of its predecessors, as well as clinically relevant and scientifically updated, bringing greater detail to ICD-10. Terminology and classification have been integrated into one structure. ICD-11 allows the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or regions at different times¹². Additionally, it ensures the semantic interoperability and reusability of recorded data for the different use cases, such as decision support, resource allocation, reimbursement, and guidelines among others.

ICD-11, if used combined with the International Classification of Health Interventions (ICHI) and the International Classification of Functioning, Disability and Health (ICF), will widen 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. The terminology extension codes, allows for a greater detail of patient symptoms and data recording.

In terms of ICD-11 implementation, Member States should carry out a Health Information System ecosystem analysis and review, in order to highlight challenges and opportunities when implementing ICD-11 in their countries, as well as to specify and carry out a step-wise transition process.

2. Why Do We Need to Implement ICD-11?

Not recording and reporting diagnoses in a standardised format has significant consequences for people living with chronic pain. It affects their treatments, their life and their social participation on an individual level¹³. In research, the lack of a systematic classification has also made it impossible to collect accurate epidemiological data at the global level, which impacts on the ability of policy makers and health services to design appropriate policy, services and interventions for those requiring them. In public health policy, receiving accurate and timely information and data on costs, treatments and

the societal impact of painful conditions is of paramount importance in order to dictate public health policy and campaigns¹³.

Additionally, ICD-11 integrates the coding process into electronic health records in a much more efficient manner, if compared to previous versions. The current version of ICD-11 contains more than 16, 000 unique codes for disease, injuries and causes of death, more than 120, 000 codable terms, and for the first time, it's entirely electronic¹³.

Chronic primary pain (CPP) is a term that has been implemented in the latest revision of the International Classification of Diseases (ICD-11). It is defined as pain in one or more anatomical regions that is characterised by significant emotional distress (anxiety, anger/frustration or depressed mood) or functional disability (interference in daily life activities and reduced participation in social roles), unless another diagnosis would better account for the presenting symptom.

Therefore, the chronic pain is the dominant clinical problem and is considered a condition in its own right. Before a diagnosis of chronic primary pain can be made, diagnoses that could explain this pain need be ruled out through a proper assessment. If the pain can be accounted for by another diagnosis, it will be categorised as a form of chronic secondary pain which includes chronic cancer pain, chronic postsurgical or posttraumatic pain, chronic neuropathic pain, chronic secondary headache or orofacial pain, chronic secondary visceral pain, and chronic secondary musculoskeletal pain.

Moreover, extension codes will improve pain management as it will then be part of the diagnostic code, which in turn 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.

Furthermore, patients often do not know what ICD-11 is or what its direct benefits are, therefore, education becomes a key priority with regards to ICD-11 implementation. Benefits for patients include reduced stigma and anxiety for patients, as conditions are officially recognised, as well as guaranteed referral and treatment options, and guaranteed payments for treatments by health insurance companies, among others.

Therefore, overall, by acknowledging the role of emotional distress and function in the definition of primary pain, the ICD-11 recognises that various factors affect pain - and so a promote a biopsychosocial assessment.

Evolving Evidence

ICD-11 pain coding is in infancy and it is expected to evolve to reflect the evolving pain evidence, and feedback on barriers and enablers to implementing the model across various settings. For example, some scientists argue that the term nociplastic pain overlaps with functional pain. They state that separating functional neurological and gastrointestinal disorders, from chronic primary pain, may undermine the biopsychosocial model of pain, as neurological and gastrointestinal, are part of chronic primary pain¹⁴. Others argue that more evidence is needed on the fact that nociplastic pain has a specific mechanism that can be targeted by a clinical intervention, for the betterment of patient care. Therefore, ensuring that the definitions of primary pain and nociplastic pain, serve the many

patients who have severe, limiting conditions, is key to guarantee that they do not feel invalidated by such codes¹⁵.

3. 2022 SIP Road Map Monitor

In 2022, SIP revisited the 2019 SIP Road Map Monitor in order 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. The top key findings of the 2022 SIP Road Map Monitor¹⁶ include:

- Development and implementation of specific national pain plans is largely missing and therefore, 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 the adaptation of workplaces and the 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, which are both key areas for improvement.

4. National Case Studies

CASE STUDY – GERMANY

The German Pain Society, in cooperation with the Federal Institution for Drugs and Medical Devices (BfArM), have been organising different actions related to ICD-11 and pain, such as a two-day workshop, translating of ICD-11 coding and description, among others. Experts in the field state that in order to establish ICD-11 in Germany, 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 (i.e. children, bio-psycho-social diseases, etc.).

CASE STUDY – NORWAY

Some pain clinics in Norway have introduced ICD-11 into their practice, even though the coding is not yet implemented in the country. However, the need to classify pain in a correct and reliable way, was imperative. In such cases, ICD-11 is integrated within the electronic patient register. Healthcare professionals then choose an ICD-11 code and extension code, which results in a suggested list of ICD-10 diagnosis, however, it's ultimately based on ICD-11.

CASE STUDY – SPAIN

Spain recently adopted ICD-10, however, while it may take at least 5 years for Spain to fully implement ICD-11, studies are being conducted, such as 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. Spanish experts highlight that ICD-11 provides a great opportunity to standardise coding for chronic pain across healthcare systems.

Conclusion

Implementing ICD-11 is crucial to achieving a systematic coding of health terminology across Europe, and appears particularly useful in the context pain. Its implementation will contribute to the digitalisation of healthcare services, which are complementary and can support each other, and will ensure patients' needs and rights are rightly covered. Additionally, highlighting the fact that ICD-11 incorporates the biopsychosocial dimension of pain is crucial when discussing ICD-11 implementation. As seen in the case studies, both a top-down and a bottom-up approach to ICD-11 implementation would have successful outcomes.

Regarding policy, the inclusion of chronic painful conditions in ICD-11 will increase the recognition of chronic pain as a health problem and contribute to better access to adequate pain treatment. Further, it is to be hoped that the improvement in both recognition and classification, will lead to enhanced and focused research funding from a wider selection of funding bodies, when considering the widespread impact of chronic pain¹³.

Moreover, society as a whole will benefit from more appropriate and standardised diagnostics through the implementation of ICD-11 and, in particular, those either at risk of developing, or having already developed, chronic pain¹³.

Finally, societal aspects have an impact on political priorities and political research agendas. Identifying research priorities facilitates advancements in knowledge and data collection, which, in turn, can have a positive societal impact. That is why implementing accurate coding helps the science and practice of pain while adhering to policies¹³.

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SIP remains available for further discussions with the European Commission, the Members of the European Parliament, the Council, digital health technology developers, and civil society stakeholders for future cooperation to ensure our recommendations are implemented in the area of digital health and pain.

About SIP

The 'Societal Impact of Pain' (SIP) platform is a multi-stakeholder partnership led by the [European Pain Federation EFIC](#) and [Pain Alliance Europe \(PAE\)](#), which aims to **raise awareness of pain and change pain policies**.

The platform provides opportunities for discussion for health care professionals, pain advocacy groups, politicians, healthcare insurance providers, representatives of health authorities, regulators, and budget holders.

The scientific framework of the SIP platform is under the responsibility of EFIC and the strategic direction of the project is defined by both partners. The pharmaceutical companies [Grünenthal GmbH](#) and [GSK](#) are the main sponsors of the Societal Impact of Pain (SIP) platform.

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Sources

¹ Note: data taken from 37 countries, absent in Andorra, Armenia, Azerbaijan, Belarus, Georgia, Iceland, Liechtenstein, Luxembourg, Malta, Monaco, and the Vatican City.

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