



Supporting the Integration of ICD-11 within the European Health Data Space

Brussels, 2 July 2025

Dear Commissioner Várhelyi,

We, the Societal Impact of Pain (SIP) Platform, are writing to reiterate our support for the integration of the International Classification of Diseases, 11th Revision (ICD-11), within the framework of the European Health Data Space (EHDS).

The SIP Platform is a multi-stakeholder platform led by the European Pain Federation EFIC and Pain Alliance Europe (PAE). Its aim is to raise awareness about the impact of pain and to influence policies that address this issue. EFIC oversees the scientific framework of SIP, while the strategic direction is jointly guided by both EFIC and PAE.

This letter follows previous engagement by the SIP Platform on the topic and aims to reaffirm the relevance of ICD-11 for the successful implementation of the EHDS. We are pleased to note that MEP Tomislav Sokol has expressed his support for this position and has agreed to co-sign this letter.

ICD-11 is the international standard diagnostic tool for epidemiology, health management, research, and clinical purposes, as well as the international standard for reporting diseases and health conditions. ICD-11 allows the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or regions and at different times and ensures semantic interoperability and reusability of recorded data for the different use cases.¹

Chronic pain, defined as pain persisting for more than three months,² is the most prevalent health condition in Europe and one of the leading causes of global disability.³ It affects approximately 20% of the adult population in Europe, making it one of the most common and disabling long-term conditions.⁴

For these individuals, the condition often becomes a daily barrier to independence, mobility, and active participation in society. Chronic pain can lead to persistent disability, limiting opportunities for employment and engagement in community life, and undermining independence and quality of life. Everyday tasks, such as working, contributing to society, or taking part in family and community activities, can become difficult or impossible.

We believe that a harmonised and interoperable adoption of ICD-11 is essential to ensuring that health systems use the most up-to-date and valid terminology. The transition of ICD-11 also aligns



with ongoing digitalisation efforts, particularly in the content of the European Health Data Space (EHDS), which aims to improve healthcare delivery across Member States.⁵

Beyond its technical and structural improvements, ICD-11 holds particular significance for people living with chronic pain. Currently, only a few patients are aware of the existence and relevance of ICD classification systems, and finding and understanding this information requires a very high level of health literacy. This highlights the need for education and the promotion of health literacy as part of implementation efforts. The clarity and consistency provided by ICD-11 allows for more accurate diagnosis, tailored treatment plans, and better access to referrals, specialised care, and insurance-covered services.

Therefore, we appreciate the ongoing efforts of the European Commission in advancing the EHDS and ensuring that health data serves the needs of both systems and citizens. As the implementation process continues, we simply wish to underline the significant potential of ICD-11 to support more consistent, inclusive, and interoperable healthcare across Europe.

We thank you for your attention and remain available should further dialogue be helpful.

Yours sincerely,

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