



Background briefing The 11th revision of the WHO International Classification of Diseases (ICD-11)

Offered to you by the **SOCIETAL IMPACT OF PAIN (SIP)**

Taking its physical and emotional toll, chronic pain can dominate people's lives, and those of their families, friends and caregivers.

The challenges which health care systems are facing when it comes to managing pain are diverse. One of the most significant challenges is the lack of a 'health system quality indicator' for pain. Health system quality indicators are used to gather data and establish the relative quality of care offered between hospitals or even between countries. Measuring and managing the impact that pain has on the individual, to his/her relatives and social life, as well as on society will support the overall functioning of our health care systems by minimising the chance of pain conditions becoming chronic, and reducing long-term expenditures.

Without adequate quality indicators it is difficult to allocate budget and resources for pain management. The issue of whether chronic pain can be considered a diagnostic entity, or even a condition "in its own right", can lead to consternation. The first step in getting clarity on this issue is to define common ground regarding the documentation of chronic pain for clinical, budget and policy purposes.

With the inclusion of chronic pain in the new ICD-11 a giant step has been taken. The inclusion of chronic pain conditions in the ICD-11 will increase the recognition of chronic pain as a health problem in its own right and contribute to improved access to adequate pain treatment for patients with chronic pain worldwide.

The story of



Ms. P

(Nicholas et al. 2019)

A 45-year-old woman reports persisting pain in her lower right leg and foot since an ankle sprain 6 years ago. Initial examination by an orthopaedic surgeon indicated that a conservative rehabilitation approach was recommended.

After immobilizing the foot with a cast, she started to use crutches and avoided touching the ground with her right foot. Soon she noticed swelling and discoloration in her foot and reported it often felt hot and sweaty. Her husband also noticed the swelling and temperature changes. When sitting, she places her leg horizontally to prevent swelling.

A combination of severe pain, inability to wear socks/shoes on the affected foot due to heightened sensitivity to pressure, and difficulties in walking and standing made it impossible to keep her job in a grocery store. She has been unable to work for over 5 years.

What is the ICD?

The International Classification of Diseases (ICD) 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. The ICD allows for:

- Recording individual health conditions at desired level of detail. This is why it is used in many countries' health systems to diagnose conditions and determine which treatment is received
- Generating of health care statistics and reimbursement information
- Sharing and comparing health information between hospitals, regions, settings and countries
- Comparing data in the same country across different time periods.

Uses include monitoring of the incidence and prevalence of diseases, observing reimbursements and resource allocation trends, and keeping track of safety and quality guidelines. They also include the counting of deaths as well as diseases, injuries, symptoms, reasons for the encounter with the health system, factors that influence health status, and external causes of disease. Thus the ICD offers the framework for all our health care information and statistics.

The data captured through ICD codes is of enormous importance for national health care systems. ICD provides the basis for key indicators of a population's health and its social determinants, it guides policies such as the allocation of resources, informs research agendas and determines the treatments available to each person.



The ICD-11 in clinical practice

Case presentation

The ICD-11 enables a standardized way of case presentation

Documentation in medical records

Documentation of diseases in a patient-centred and comprehensive manner using a common language transcending healthcare disciplines, sectors and country borders.

The ICD-11 comes with:

- Improved clinical utility - more clinical detail with less training time
- Updated scientific content
- Enables coding of all clinical detail from primary care to specialist settings
- Made eHealth ready for use in electronic environments
- Linked to relevant other classifications and terminologies
- Full multilingual support (translations and outputs)

HOW CAN THE CASE OF MS. P BE DOCUMENTED USING THE ICD-11?

Similarly to Ms P., for many patients with chronic pain, frequently the documented diagnosis does not reflect the nature of their complaints adequately.

Under the ICD-10, Ms P.'s pain complaints would be described as M89.0 Algoneurodystrophy resp. G90.51 CRPS I of the lower limb (ICD-10-GM) or as G56.4 Causalgia resp. G90.61 CRPS II of the lower limb (ICD-10-GM), if a nerve lesion was present, or F45.4 persistent somatoform pain disorder. In addition to the unclear definition of the different entities, these five diagnoses are in three different chapters of the ICD-10 (Diseases of the musculoskeletal system and connective tissue, Diseases of the nervous system, Mental and behavioural disorders) linking to three different medical specialties (orthopaedics, neurology, psychiatry / psychotherapy), but not to pain specialists. Some codes are available only in certain adaptations of the ICD-10, for example the German modification.

Using the ICD-11 helps to document Ms P.'s persisting pain in her lower right leg and foot causing restrictions in work participation (through linkage with ICF). The specific diagnosis also helps Ms. P as well as her physicians to direct her to adequate multimodal management

Furthermore, the diagnosis can be used for data collection, making Ms P.'s diagnosis visible in epidemiological studies as part of the broader range of chronic pain conditions with similar therapeutic needs.

In the case of Ms P. the following ICD-11 codes should be used:

- MG30.0 - Chronic primary pain:
8D8A.00 - Complex Regional Pain Syndrome (CRPS) type I.
- Her severity code is 323, with pain intensity estimated at 7/10 (code 3, severe); pain-related distress at 6/10 (code 2, moderate); and pain-related disability at 8/10 (code 3, severe).



Why do we need a classification of chronic pain in the ICD-11?

Before the ICD-11, chronic pain diagnoses were not represented systematically in the ICD. This meant for individual persons suffering from chronic pain that it was often difficult to provide a conclusive diagnosis within the classification system. This sometimes had far-reaching consequences for the person affecting their treatment, their life and social participation. The classification is important for questions as:

- What diagnosis do I have?
- What treatments are on offer for me? Which should I choose and which to avoid?
- What can I do myself to contribute to a good outcome?
- Will treatment costs be compensated?
- What is on offer for me to ensure my participation in all areas of life?

The absence of a systematic classification also made it very difficult to collect accurate epidemiological data on a world-wide level. As a result, decisions on health policies could not take chronic pain into account appropriately. This included important decisions such as:

- What treatments should be financed?
- Which research programs should be pursued?

Examples of who will use the ICD-11 include:

- Health politicians: to receive the necessary information about costs, treatments, societal impact etc. of pain conditions
- Insurers: to decide which conditions result in treatments to be financially compensated
- Legal issues: to decide about consequences of accidents
- Health care providers: to communicate clinical conditions, and to decide about treatment options
- And finally patients and patient organizations: to inform themselves and others about clinical conditions such as chronic pain, to choose from different treatment options, and to advocate or raise awareness of the challenges related to such clinical conditions

How is the ICD updated?

The ICD is updated in regular intervals to reflect the current state of health knowledge. Experts, international societies for the medical areas and professions, patients and their organizations are brought together by the World Health Organization (WHO) to revise the ICD. The current version is the 10th edition. However, on 25 May 2019, the World Health Assembly (WHA) has adopted the ICD-11, the latest revision. The ICD-11 is the first classification system to include a systematic representation of chronic pain and is publicly available via the WHO website. The ICD-11 will come into effect on 1 January 2022.



What is new for chronic pain in the ICD-11?

In cooperation with the WHO, the International Association for the Study of Pain (IASP) has developed a classification that is based on the latest scientific evidence. The IASP is an international professional organization representing an interdisciplinary mix of pain experts, including scientists, doctors, psychologists, physiotherapists and others. So, for the first time, the ICD-11 will include systematic diagnostic codes for chronic pain.

Recognizing chronic pain in a systematic classification affords a unique opportunity to improve pain diagnoses and treatment throughout health care systems worldwide. Through the hierarchic structure of the ICD-11, doctors can use the diagnoses at different levels (from very broad to rather specific). This is an advantage because the diagnoses can be implemented through all tiers of each healthcare system from primary care to specialist contexts such as tertiary centres for pain.

Chronic pain in the ICD-11 at a glance:

- Chronic pain recurs or persists 3 months or more
- Chronic primary pain: the pain is the disease in itself
- Chronic secondary pain syndromes: chronic pain in the context of another disease
- Several additional diagnostic levels are available for a specialist use

What does the documentation of chronic pain in the ICD-11 look like?

Chronic primary pain represents chronic pain as a disease in itself. Chronic secondary pain is chronic pain where the pain is a symptom of an underlying condition. Chronic primary pain is characterized by significant functional disability or emotional distress and not better accounted for by another diagnosis of chronic pain. Here, you will find chronic widespread pain, chronic primary musculoskeletal pain previously termed “non specific” as well as the primary headaches and conditions such as chronic pelvic pain and irritable bowel syndrome. They are recognized as a group of chronic pain syndromes for the first time in ICD-11.

MG30		Chronic pain			
MG30	0	Chronic primary pain	MG30	4	Chronic secondary visceral pain
MG30	1	Chronic cancer related pain	MG30	5	Chronic neuropathic pain
MG30	2	Chronic postsurgical or post traumatic pain	MG30	6	Chronic secondary headache or orofacial pain
MG30	3	Chronic secondary musculoskeletal pain			
MG30	Y	Other specified chronic pain	MG30	Z	Chronic pain, unspecified



BASIC CODES:

A complete documentation of chronic pain according to the new classification should contain the basic diagnoses plus the respective codes.

For chronic primary pain, the respective chronic pain code is sufficient by itself:

- *Chronic widespread pain syndrome (MG30.01), e.g. fibromyalgia*
- *Complex regional pain syndrome (8D8A.0), e.g. the case of Ms. P above*
- *Chronic primary headache or orofacial pain (MG30.03), e.g. chronic migraine or temporomandibular disorder*
- *Chronic primary visceral pain (MG30.00), e.g. irritable bowel syndrome*
- *Chronic primary musculoskeletal pain (MG30.02), e.g. nonspecific low back pain*

For chronic secondary pain, the diagnosis of the associated disease has to be added to the code for chronic pain.

- *Example: Chronic musculoskeletal pain from persistent inflammation (MG30.30) and rheumatoid arthritis (FA20.Z)*

EXTENSION CODES:

For all chronic pain diagnoses, “extension codes” will be available to document important characteristics of the chronic pain. These are:

1. How severe was the pain in the last week?

Pain severity is a compound measure. It records the patient’s ratings of the average pain intensity in the last week, the average pain-related interference and the average pain-related distress. These can be graded individually as ‘none’ – ‘mild’ – ‘moderate’ – ‘severe’. This gives a clearer view how the patient perceives the pain and how much it affects his or her life. (see case study)

2. What is the temporal course of the pain?

This describes whether the pain is continuous or manifests itself in pain attacks.

3. Are any additional psychosocial factors present?

This code allows recording any psychosocial aspects associated with the pain. They can be emotional (e.g. depressed mood, anger), cognitive (e.g. worry), behavioural (e.g. withdrawal) or social (e.g. work problems) factors. The code can be used to indicate treatment need in relation to these factors.

In most cases, extension codes 1-3 are optional, but their use is strongly encouraged, because high severity may necessitate multimodal management while low severity may be self-managed.

Since the ICD is a growing body of knowledge, there are some more codes describing pain in other chapters. These are integrated and cross-referenced to provide a coherent whole. You find these in the online ICD-11 web browser.

Is there an interface with other coding systems?

The ICD-11 will for the first time provide direct links to electronic health records. It is also linked to the ICF (see above). It aims at being consistent with other information products, such as the *Standardized Nomenclature of Medicine – Clinical Terms*, or SNOMED-CT.

The ICD-11 offers guidance for its use with different cultures as well as translations into 43 different languages. In this way, the revised system provides a common coding language that can be used by healthcare professionals and researchers worldwide. This will result in an international standardization of usage and aid international comparisons and advances of knowledge and management.



Does the ICD-11 link in with function and participation assessment?

Physical, mental, and social well-being are part of the concept of health according to the WHO, in addition to the absence of disease and infirmity. In 2001, the WHO therefore launched the *International Classification of Functioning, Disability and Health (ICF)*. The ICD and ICF constitute the core classifications in the WHO Family of International Classifications (WHO-FIC).

Like the ICD the ICF is maintained by the WHO. The ICF complements WHO's International Classification of Diseases (ICD), which contains information on diagnosis and health condition, but not on functional status. Therefore the two classification systems can be used in concert and synergistically.

The IASP and the *International Society of Physical and Rehabilitation Medicine (ISPRM)* have proposed a specific set of functioning properties of chronic pain. The combined use of ICD-11 and ICF is expected to improve research reports on chronic pain by a more precise and adequate coding, as well as patient management through better diagnostic classification.

Making the switch

Member States will start reporting using ICD-11 on 1 January 2022. However, given the vast technical and technological adaptation and training required to move to a new system - thousands of coders from small primary health care clinics to large hospitals will need retraining - the switch to using the ICD-11 is unlikely to happen overnight.

In some countries extensive testing of the entire ICD-11 has taken place while the IASP Task Force conducted field tests in several pain centres. Some pain centres already use ICD-11 in their daily routine (Japan, Norway, and Thailand).

Not all countries are likely to adopt the ICD-11 at the same speed. Much will depend on the support by the local medical community, so there is a need for action, if you want to benefit from ICD-11 in your country.

Who will benefit?

Society as a whole will benefit from more appropriate and standardized diagnoses from the implementation of ICD-11. Advances in knowledge, and data collection will also inform better allocation of resources where they can make the largest difference.

Given the current prevalence of chronic pain, one in five persons, anyone, anywhere, may develop chronic pain (Eccleston et al 2017). Those one in five persons currently living with chronic pain will especially benefit

directly from more accurate, coded diagnoses and the expected improvements in treatment and care.

In addition, implementing accurate coding helps Member States prepare for an ageing society as the likelihood of chronic pain increases with age.

Therefore, everyone will potentially benefit from the use of the ICD-11.





Do you want to know more about the ICD-11?

You find the ICD-11 at the official ICD-11 website of the World Health Organization (WHO)
<https://icd.who.int>

The IASP website contains a lot of links to work done by the IASP Task Force for the Classification of Chronic Pain in ICD-11
<https://www.iasp-pain.org>

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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 Pfizer are the main sponsors of the Societal Impact of Pain (SIP) platform.