

University of Dundee

## The IASP classification of chronic pain for ICD-11

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## Abstract

The International Classification of Diseases, 11<sup>th</sup> Revision (ICD-11) proposes, for the first time, a coding system for chronic pain. This system contains one code for 'chronic primary pain', where chronic pain is the disease, and six codes for secondary chronic pain syndromes, where pain developed in the context of another disease. This provides the opportunity for routine, standardised coding of chronic pain throughout all healthcare systems. In primary care, this will confer many important, novel advantages over current or absent coding systems. Chronic pain will be recognized as a centrally important condition in primary care. The capacity to measure incidence, prevalence and impact will help identification of human, financial, and educational needs required to address chronic pain in primary care. Finally, opportunities to match evidence-based treatment pathways to distinct chronic pain subtypes will be enhanced.

Keywords: Primary Care; Chronic Pain; ICD-11; ICPC; General Practice; Family Doctor; General Practitioner

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## 1. Introduction

For the first time, the International Classification of Diseases, 11<sup>th</sup> Revision (ICD-11) contains a coding system for chronic pain. Recognizing chronic pain in a systematic classification represents an opportunity to improve pain coding and treatment throughout all healthcare systems and treatment tiers. Since the large majority of patients with chronic pain are managed in primary care, adopting the main structure of the new classification may have substantial benefits. In this paper, we will provide a brief introduction to primary care and its goals. The treatment of people with chronic pain will emerge as an important task of primary care. Currently, this central task is impeded by the way chronic pain is classified and coded. We explain the main aspects of the new classification of chronic pain for ICD-11 and argue that adopting it in the context of primary care may help overcome many of the challenges.

### 1.1 Definition and goals of primary care

The World Health Organization (WHO) defines primary care as 'first-contact, accessible, continued, comprehensive and coordinated care'.<sup>36</sup> It is generally characterised by numerous, brief appointments between patients and multi-disciplinary healthcare professionals led by GPs or equivalent generalists. In 1978, in the Declaration of Alma-Ata, the International Conference on Primary Health Care enshrined the rights of every human to primary care, and called on all Governments and non-governmental agencies to deliver this.<sup>35</sup> The ultimate goal of primary health care is better health for all, and the World Health Organization has identified five key elements to achieving that goal:<sup>36</sup>

- reducing exclusion and social disparities in health (universal coverage reforms);

- organizing health services around people's needs and expectations (service delivery reforms);
- integrating health into all sectors (public policy reforms);
- pursuing collaborative models of policy dialogue (leadership reforms); and
- increasing stakeholder participation

## 1.2 Chronic pain and its management in primary care

Chronic pain affects between one fifth and one half of the general population,{ ADDIN EN.CITE

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of disability worldwide.<sup>23</sup> Primary care is often the first point of contact for a person with chronic pain. Patients with chronic pain are 1.5 times more likely to visit their primary care physician than those without chronic pain,<sup>1</sup> and 22% to 50% of General Practitioner (GP) consultations are related to pain.<sup>11,17,28</sup> A Swedish study showed that, of those presenting to primary care with pain, this was chronic in 37%, chronic and intermittent in 11% (predominantly migraine), and intermediate, with a duration of 1 to 3 months, in 13%.<sup>13</sup> A one-day cross-sectional study from primary care in Paris observed that, of all patients seen, 43% presented with pain.<sup>28</sup> In 20% of those with pain, it was chronic (for musculoskeletal

pain, this figure was higher with 50%). The great majority of chronic pain is managed in community or primary care settings, with approximately 0.3% to 2% of those with chronic pain referred to specialist pain clinics,<sup>4,28</sup> while 7% to 35% are referred to other secondary care specialists, e.g. an orthopaedic surgeon or a rheumatologist, and 26% to a physiotherapist.<sup>13,28</sup> De facto, chronic pain recognition and treatment is of central importance in primary care. However, the lack of a unified coding system means that chronic pain cannot be coded as the problem of interest. Thus, for the individual patient it may go unrecognized as a clinical entity requiring a unified approach to management,<sup>[ref Mansfield]</sup> and for planning and resource allocation, it is considered only as a disparate group of less prevalent conditions. In addition, many people who consult with common diseases may also suffer from chronic pain, which cannot be coded separately and therefore may remain statistically invisible as a condition that requires treatment, management and resources. Until now, we have lacked a standardised means of recording patient-centred pain parameters, such as pain intensity, pain-related interference and distress. For the individual patient, this hinders continuous monitoring of central parameters of chronic pain; on the level of the healthcare system, it impedes pain-related audits and quality control.

It is clear that addressing chronic pain in primary care is consistent with WHO priorities. Chronic pain affects all ages and socio-demographic groups, but is more common in older and more deprived populations,<sup>4</sup> and successful management will therefore target these populations in particular. It is multi-dimensional in its impact<sup>4</sup> and its management therefore needs to be multi-disciplinary and patient-centred.<sup>6</sup> To achieve this successfully requires imaginative collaboration between healthcare, social and policy sectors, crucially also including service users (people with chronic pain) and an agreed approach to training and resource allocation.<sup>23</sup> A unified use of non-stigmatizing diagnostic terms to describe chronic

pain conditions offers the basis to improve communication about clinically relevant conditions between primary care physicians, specialists, and patients and shape appropriate treatment pathways.

## 2. Coding chronic pain in ICD-11

In ICD-11, chronic pain is defined as pain that recurs or persists longer than 3 months.(REF topical review) It is coded by seven main (=‘parent’) codes for chronic pain diagnoses, including one code for ‘chronic primary pain’, where chronic pain is the disease, and six codes for secondary chronic pain syndromes, where pain developed in the context of another disease (Table 1). These codes are available in the June 18, 2018, version of ICD-11 that is intended for implementation by member states (Website ref).

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Insert Table 1 about here  
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‘Chronic primary pain’ is ‘...chronic pain in one or more anatomical regions that is characterized by significant emotional distress ... or functional disability .... The diagnosis is appropriate independently of identified biological or psychological contributors unless another diagnosis would better account for the presenting symptoms’.<sup>20,34</sup> This is roughly equivalent to that which may previously have been called chronic idiopathic pain. The six categories for chronic secondary pain are: (1) Chronic cancer-related pain, i.e. all chronic pain that arises in the context of cancer or its treatment, (2) chronic postsurgical and posttraumatic pain, i.e. all chronic pain from surgery or accidental trauma, (3) chronic neuropathic pain, (4) chronic secondary headache and orofacial pain, (5) chronic secondary visceral pain, i.e. chronic pain arising from causes such as persistent visceral inflammation or vascular or mechanic causes, (6) chronic secondary musculoskeletal pain, i.e. rheumatoid arthritis etc.

The WHO automatically includes additional codes: one for ‘other specified chronic pain’ which should only be used when a new set of diseases is recognized to cause chronic pain that is not covered by any of the six chronic secondary pain parent categories; the other for ‘chronic pain, unspecified’, which may be useful in primary care when chronic pain is recognized to merit medical attention but it remains unclear whether it is primary (as a disease) or secondary (as a symptom).

### 3. Application to primary care

The numerous, brief consultations that characterize primary care require that ICD-11 coding must be straightforward to apply. It is therefore likely that these seven ‘parent’ codes will be those most useful in this setting, though each also includes four or five subcodes (‘child codes’) should more detail be available and appropriate. However, for primary care to fulfill its central role, a specific biological diagnosis may often be unnecessary.

#### 3.1 Gaps in current classification approaches

None of the major international diagnostic coding systems (International Classification of Diseases (ICD); Current Procedural Terminology (CPT); Diagnostic and Statistical Manual of Mental Disorders (DSM)) includes specific codes for chronic pain. This means that chronic painful conditions, if coded at all, are coded inconsistently and without mutual exclusivity. This coding requires creativity on behalf of the coder and might use ill-defined symptom-based codes (e.g. ‘chronic intractable pain’ – R52.1, or ‘persistent somatoform pain disorder’ – F45.4 in ICD-10), diagnostic labels that are difficult to pin down (e.g. ‘dorsalgia’ – M54, ‘sciatica’ – M54.3, ‘lumbago’ – M54.5 in ICD-10) or treatment-based codes (e.g. ‘opioids and related analgesics’ – Y54.0 in ICD-10).

In addition to the uncertainties about the classification of chronic pain in the current ICD-10 system, the global diversity of coding systems in primary care is challenging. The International Classification of Primary Care (ICPC)<sup>33</sup> is the most widely used international classification in primary care.<sup>2</sup> It is developed and formally recognized by the World Organization of Family Doctors' (WONCA) International Classification Committee (WICC), and linked to the International Classification of Diseases (ICD). The most recent version (ICPC-2) was revised in 2015, and ICPC-3 is now in development. ICPC-2 has been carefully mapped to ICD-10 so that conversion systems can be used,<sup>33</sup> and a similar process is currently underway between ICD-11 and ICPC-3 (K van Boyen, personal communication). Extensive use and testing of ICPC has confirmed that it and ICD are complementary rather than in competition, though not wholly compatible.<sup>32</sup> The ICPC philosophy is to encode a diagnosis as a 'manifestation', rather than an 'aetiology', as in the ICD system. However, it would be challenging, for clinical practice and research, to keep both approaches, as this would produce two identical 'clinical labels' expressing the same concept but with different codes. This is an important issue. WHO plans a 'primary care linearization' of ICD-11, which is expected to further facilitate the applicability of ICD-11 in primary care.<sup>37</sup>

A survey including responses from 109 of the 193 countries found that ICPC was used in primary care in only 27 countries worldwide (24%) and as a mandatory standard in only 6 (6%), i.e. Norway, Finland, Denmark, Bulgaria, Portugal and the Netherlands. Nineteen countries (17%) used the ICD-10 (e.g. Poland, Iceland, Slovakia among others), 3 (3%) used other classifications (e.g. the Read Code in UK), and 2 (2%) used no classifications, i.e. Austria and Pakistan. Sweden uses a short-version of ICD.<sup>2</sup>

Disadvantages of such a haphazard approach in primary care are numerous:

- Poor understanding of the local, national and global burden of chronic pain in primary care. For example the Global Burden of Diseases Study 2013 undertook detailed study of the incidence and prevalence of many conditions, but could only examine sub-headings of chronic pain, such as back pain and headache.<sup>12</sup>
- A consequent inability to acknowledge the resources and education required to address chronic pain, particularly in comparison with better defined long-term illnesses, such as diabetes and hypertension.<sup>23</sup>
- Being unable to quantify and map chronic pain at regional or patient level, it is impossible to evaluate any service improvement efforts. With the previous two points, this makes it very difficult to make the service improvement case to health service providers and policy makers.

### 3.2 Establishing a unified classificatory language

The introduction of a primary health care linearization of ICD-11 (ICD-11-PHC) will simplify the application of ICD-11 in primary care<sup>37</sup> Such a linearization is defined as a subset of diagnostic entities from the ICD-11 foundation that are mutually exclusive and jointly exhaustive. The foundation is the complete ICD-11 universe, where every disorder, disease and other diagnostic entity is listed. Different linearizations provide different selections from this foundation at different levels of granularity. In this context, the primary healthcare linearization will show a lesser level of detail, (i.e. fewer subcategories) than a linearization with intended use in tertiary care, and it will contain only those entities relevant for primary healthcare.<sup>37</sup> This will make the coding process straightforward and time-efficient, with GPs selecting from a list of seven well-defined chronic pain codes.

Introducing the new ICD-11 coding, and/or mapping this to other coding systems for chronic pain routinely in primary care would confer several key advantages over current practice (Box 1). Evaluation of these potential effects will be an important activity following the introduction and linearization of the ICD-11 coding in primary care.

### 3.3 Further benefits

#### 3.3.1 Chronic primary pain

The option to code a diagnosis of ‘chronic primary pain’, may confer several advantages to patients and professionals. These potentially include:

- minimising unnecessary diagnostic procedures and treatments (saving resources and avoiding iatrogenic problems);
- shifting focus early in the patient journey from finding a cause to managing the impact of chronic pain, including multimodal treatments;
- avoiding unhelpful labels such as ‘psychosomatic’ or ‘functional’ illnesses;
- greater potential for a patient-centred approach, with shared decision-making in achieving a mutually acceptable management plan.

#### 3.3.2 Red Flags

The remaining six chronic secondary pain syndrome codes will allow early flagging of patients at risk of complex chronic pain (after cancer treatment, surgery or trauma), and may help to pre-define possible referral to the appropriate specialists. Initial coding of ‘chronic primary pain’ may progress to a chronic secondary pain code when further information becomes available from assessment (Table 1). Pilot field testing in Norway suggested that primary care physicians can distinguish between chronic primary and

secondary pain syndromes with reasonable accuracy. With a moderate amount of training and practice, this accuracy can likely be further improved.

### 3.3.3 Additional assessment and coding options

For additional assessment needs with regard of chronic pain, the ICD-11 also provides so-called 'extension codes' endorsed by the WHO that allow coding of pain severity, its temporal course and psychosocial aspects. The severity of chronic pain is determined by pain intensity, pain-related distress and interference of the pain with daily activities and participation. At each assessment, the patient should rate (separately) the average intensity, the distress and the interference in the previous week on a numerical rating scale from ranging from 0 'no pain/distress/interference' to 10 'worst pain/distress/interference imaginable'. These ratings can be translated into extension codes to be used with the underlying pain code. This will provide a rapid method of recording the most important pain parameters as rated by the patients and will improve the standardization of pain assessment in primary care.

### 3.3.4 Treatment pathways

The large Pain in Europe Study found that only 40% of community-based people with chronic pain considered themselves to be adequately managed.<sup>4</sup>

In the USA, Fink-Miller and colleagues investigated the differences between patients with chronic pain treated in primary care and those treated in tertiary care and found that the groups were similar across a range of indices.<sup>9</sup> Those presenting at primary care reported greater average pain severity, however those in tertiary care displayed greater pain-related catastrophizing. On average, the tertiary care group were 6 years older than the primary



care group and this greater age may lead to different perceptions about their condition and life in general. However, contrasting findings have also been identified, i.e. that patients with pain problems at the primary care level seem to be older than pain patients attending a specialist pain clinic.<sup>7</sup> According to Fink-Miller and colleagues,<sup>9</sup> both groups were similar with regard to measures of psychological distress as well as the use of opioid medications. However Hasselstrom and colleagues found that only 2% of patients presenting with pain in primary care were defined as neuropathic in contrast to 40% in a specialist pain clinic.<sup>13</sup> In reality, again without a standard coding system that is feasible to apply in the primary care setting, our understanding of the true picture is obscured.

A coding system that categorises chronic pain into diagnoses with distinct management pathways (for example neuropathic pain<sup>26</sup> or chronic widespread pain<sup>16</sup>) is likely to lead to better differentiated and targeted management approaches. It is a strength of the new classification that it allows for such categorization. Especially useful is its biopsychosocial framework that recognizes the benefits of early multimodal treatment for chronic pain. Important goals for the treatment of chronic pain include the improvement and maintenance of functioning, the improvement of quality of life and the reduction of pain-related distress. It has been widely recognized that these goals are best achieved by an integrated treatment approach that includes timely contact with physiotherapists, rehabilitative measures, and appropriate psychological and behavioural interventions in addition to targeted pharmacological interventions.

### 3.3.5 Terminological continuity across the health care service tiers

A standardised coding system utilised throughout primary, secondary and tertiary services will highlight anomalies in the recognition of different pain diagnoses. We also need to

recognize and quantify the resources required – educational, personnel and financial – to address this major primary healthcare issue. This requires an adequate coding system for chronic pain, and the new ICD-11 coding can provide this,<sup>30</sup> if adopted or adapted in primary care.

### 3.3.6 Educational aspects

Clinicians, including (but not limited to) those working in primary care, may lack sufficient teaching and training in relation to the treatment and management of chronic pain.<sup>18,19,21</sup> This lack of sufficient teaching and training can result in poor treatment choices,<sup>25</sup> which in turn leads to inadequate outcomes for patients with chronic pain. This deficiency may stem from inadequate undergraduate training. A survey of pain curricula in 242 medical schools across Europe between 2012 to 13 revealed a median of only 12 hours' teaching on pain (range 4-56h; IQR 12h).<sup>5</sup> In the above study in Paris, 43% of the GPs thought they were not sufficiently trained in pain and only 6% used pain assessment scales.<sup>28</sup> In a US survey, 54% of participating primary care physicians indicated that their chronic pain training during residency was insufficient.<sup>31</sup> Even those with sufficient education may struggle to put their knowledge into practice, for a variety of reasons such as lack of validated outcome measures, short consultation times and concerns over the adverse effects of pharmacological treatments.<sup>27</sup> Increased recognition of chronic pain as a central primary care problem, for example through a standardised coding system, is likely to lead to the identification and uptake of associated education needs, including at undergraduate level.<sup>15</sup>

### 3.3.7 Electronic patient documentation

Electronic records can allow clinicians to input and observe systematically patient-level data on pain, emotional functioning and physical functioning (see also the International Classification of Functioning ICF that is cross-referenced from ICD-11), which can then be used to monitor the effectiveness of treatments and allow for auditing of services,<sup>27</sup> as well as facilitating epidemiological research and needs assessments. An internationally agreed and validated coding system that lends itself to electronic implementation will aid in the recognition of chronic pain in primary care, providing measures of prevalence, which can guide treatment provision and reimbursement, service improvement, and comparisons across time and regions.

#### 4. Conclusions

The coding system for chronic pain proposed in ICD-11 is therefore novel, comprehensive yet practical and flexible, and feasible to apply in primary care. It is to be welcomed for its numerous potential benefits in managing chronic pain, in primary care and beyond, and in improving our understanding of chronic pain and its management. It is intended to be compatible with the other coding systems in primary care, described above. Further work will now be needed to determine how this will apply in practice – including whether ICD-11 and ICPC can be used interchangeably, whether one might be adopted as a subset of the other, or even whether ICPC it should be replaced. Meanwhile the ‘chronic primary pain’ code will be particularly advantageous in primary care, and its inclusion along with the six chronic secondary pain syndrome codes into the Primary Care linearization, will allow compatibility with ICPC and other clinical coding systems, and improve the lives of patients and professionals in this complex clinical field.

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### Contributions:

BHS, EAF, BK and AB contributed equally to the manuscript; RDT and WR also contributed equally.

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### Conflict of Interest Disclosures:

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Box 1. Benefits of applying ICD-11 chronic pain coding in primary care practice.

Chronic pain recognized as a centrally important condition in primary care

Capacity to measure incidence, prevalence and impact – locally, nationally and internationally

Identification of human, financial, and educational needs required to address chronic pain in primary care

Enhanced opportunities to match evidence-based treatment pathways to distinct chronic pain sub-types

Greatly improved potential for audit and evaluation, leading to efficient service improvement

For research, the ability to use primary care registers as sampling frames for intervention studies and pragmatic trials that reflect real-world chronic pain.<sup>24</sup>

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