



World in Pain



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*A “passport” to a better
understanding of pain
across the globe*

Pain – a worldwide experience



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The experience of pain is an almost universal phenomenon and relief from pain ranks among the most fundamental bases for the practice of medicine. Despite this, there has been – until now – little information about the global prevalence, impact and consequences of chronic, long-term pain. This is partly because pain is frequently a symptom or a legacy of an underlying disease or injury, but the pain itself is generally not recorded in national statistics.

The exception to this is pain arising from malignancy: the number of cancer pain articles in the principal medical journals has increased ten-fold in the last thirty years compared with a meagre increase in the number of articles on non-cancer pain – despite the fact that non-malignant conditions vastly outnumber cases of malignancy. According to the World Health Organization (WHO), “Freedom from pain should be seen as a right of every cancer patient and access to pain therapy as a measure of respect for this right”. Importantly this right should not be simply for cancer patients alone but for all those who suffer chronic pain. This was recognised at governmental level in the US where January 2001 saw the beginning of the congressionally declared Decade of Pain Control and Research.

Since chronic pain has exceptionally far-reaching implications, not only for the individual concerned but also for their family, healthcare organisations, employers and the economy, it is an issue that desperately needs greater insights. We need to know how many cases of chronic pain there are across the globe; assess the effect on day to day living, social functioning and ability to work; gain a sense of discrepancies between different nations; highlight instances where greater efforts to manage pain optimally are called for and pinpoint areas where further analysis is needed.

World in Pain represents a significant milestone in this voyage of discovery. Comprising a distillation of several high profile pain studies and surveys carried out in different parts of the world (both published and unpublished) it opens a new chapter in our appreciation of this important topic from an international perspective. While similar levels of research and information are unfortunately not available from all parts of the world – for example the true extent of pain in Africa due to HIV/AIDS is unknown – it is likely that the high levels of chronic pain and inadequate treatment revealed are reflected in other regions. In essence, by collating data from a wide cross-section of countries, *World in Pain* provides a “passport” to a global understanding of chronic pain and its terrible toll.

Definition of chronic pain

The definitions of chronic pain varied slightly among the studies but were broadly in line with participants having suffered pain for 6 months, having experienced pain in the last month and several times during the last week, and rating their pain intensity as 5 on a 10-point scale

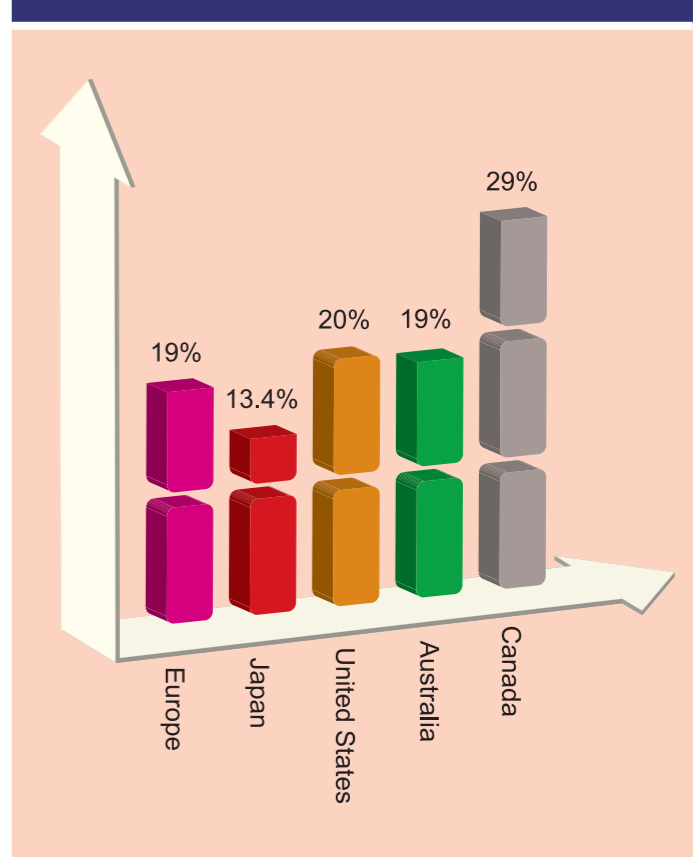
How widespread is chronic pain?

From a global perspective, the prevalence of chronic pain in adults is as much as 1 in 5. This increases still further to up to 1 in 3 amongst elderly people. Even in children pain occurs in between 20–30%

Breaking this down, it is estimated that across Europe there exists a total chronic pain prevalence of 19% of the population (highest in Norway, Poland and Italy; lowest in Spain, UK and Ireland),¹ while in Japan prevalence was judged to be a lower but still substantial 13.4%² amounting to 17 million people. In Australia chronic pain prevalence has been estimated at 17.1% for males and 20% for females, affecting more people than other common chronic conditions such as diabetes, hypertension and asthma.³ According to recent US and Canadian studies, the prevalence of chronic pain in these countries is around 20%⁴ and 29%⁵ respectively (see Figure 1). Another study shows that up to half of Americans live with chronic or recurrent pain.⁶

Female gender, increasing age, low education and heavy physical work are considered the most common risk factors for chronic pain.⁷

Fig 1: Chronic pain prevalence



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As a pain sufferer myself, and as the president of the European Pain Network, which is the united voice of people in pain across Europe, I have first hand experience of what it is like to live with pain every day and also the challenges faced when trying to access adequate pain relief. Chronic pain is a constant struggle, and can take over everything else that you would otherwise enjoy and value in life, if you don't have effective treatment. It is difficult to understand why chronic pain is so neglected by governments when compared with other disease areas. Hopefully, as the knowledge and understanding about the number of people affected by pain around the world – and the real impact on those in pain and their loved ones – increases, the situation will continue to improve.

**Mandy Leighton, President, European Pain Network;
President, The Society for Fighting Pain, Israel**”

Types of pain

- Back pain is the most common pain cited, with arthritis/osteoarthritis being the most common underlying cause
- For both men and women, visceral pain (pain from internal organs) is the most common reason for out-patient doctor visits⁸

Across Europe, as in most other regions, pain most commonly originates in the back, with osteoarthritis and disc problems being the most likely underlying causes.¹ Forty six percent in Europe,¹ 58% in Japan,² 35% in Australia⁷ and 40% in New Zealand⁷ described their pain as constant rather than intermittent. Pain intensity was ranked as severe (≥ 8 on a scale of 1–10) by 13% of Japanese² and 33% of European respondents.¹ In the US, 22% of interviewees rated their pain as “severe”.⁴ Finally, in Europe 31%¹ – and 23% in Australia and New Zealand⁷ – said they could not imagine being able to tolerate any more severe pain. Clearly, for many people, the experience of pain is extreme.

Effects on daily activities

Impact of pain on patients’ lives

- Chronic pain is universally detrimental on quality of life aspects: exercise, sleep, work and employment, energy level, walking, relationships, independence, psychological wellbeing...

“My wife has lived with pain for 35 years, and it has had a major impact on her and our family and friends. I know many other sufferers who have had traumatic experiences with chronic pain. It can be an incredibly debilitating and depressing condition to live with. Unfortunately it is often more difficult than it should be to get access to treatments that alleviate this pain. I have found that there is an incredible support network amongst people with chronic pain and their families, but what we are all asking for is greater recognition and access to better relief.

Raymond Berggren, EPN board member and Chairman of the Swedish Pain Society”

In Europe, the main activities affected by pain were exercising, sleeping, lifting, walking, carrying out chores, having sexual relations and working outside the home.¹ These findings were broadly echoed in the Australia and New Zealand survey and by US studies. What is more, 50% of European¹ and 44% of Japanese respondents² said they feel tired all the time while 30% of European¹ and 20% of Japanese² respondents said they feel socially isolated as a result of their pain. Over a quarter of the European sample felt their independence and ability to maintain family relationships was impaired,¹ while in Japan nearly 50% felt that no-one believes how much pain they are in,² underlining the loneliness of the condition.

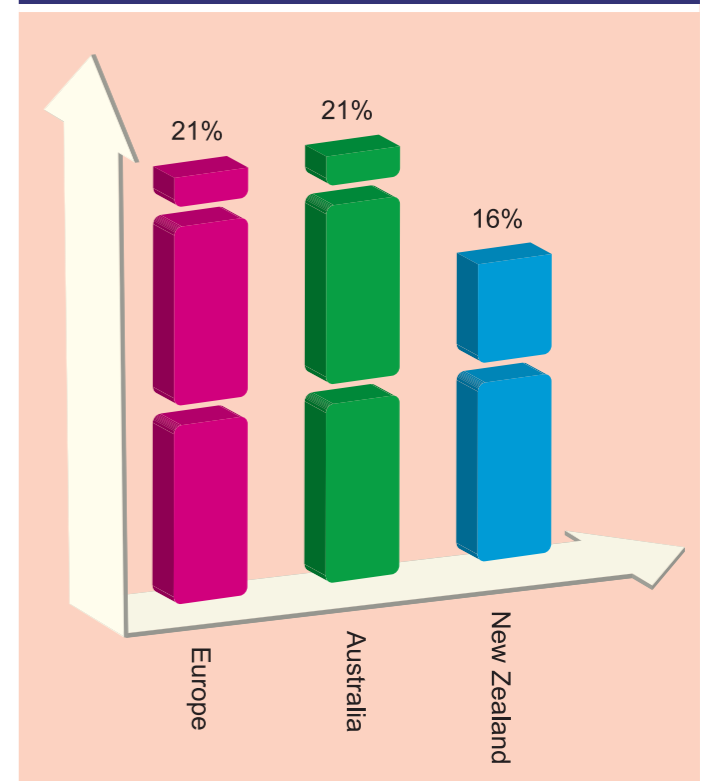
Impact on working life

Pain means people are actually unable to work, or causes them to lose their jobs, in turn placing an extra burden on families and society to support them. In Europe 19% of respondents lost their job, 13% changed jobs and 16% changed their responsibilities as a result of their pain, with unemployment in this group more than double national levels.¹ Job loss occurred in 15% and 7% of Australian and New Zealand respondents respectively⁷ while responsibilities were changed in 25% and 38% respectively.⁷ In the US, 48% of sufferers were currently employed and 19% of those said their employment status was affected by their pain.⁴

Psychological effects

The prevalence of diagnosed clinical depression associated with pain is high – 21% in Europe,¹ 21% in Australia⁷ and 16% in New Zealand⁷ (see Figure 2). While prevalence of depression was not specifically assessed in Japan, 33% of Japanese respondents said they feel much older than their age, 19% are gripped by fear that they will lose their jobs and 50% said that their pain is unconquerable and something they just have to endure.² In the US, this last figure rises to 80%.⁴ These findings underline the serious psychological consequences of unrelieved chronic pain. In Europe up to half of chronic pain sufferers reported feelings of helplessness and a third said they could not remember what it was like not to be in pain.¹ Most significant of all, 17% of European,¹ 14% of Japanese² and 31% of US⁴ respondents claimed their pain is sometimes so bad that they wanted to die.

Fig 2: Diagnosed clinical depression associated with pain



Seeking treatment for pain

- Pain patients quite often do not have access to a specialist physician
- Chronic pain equals long-term pain in many cases
- Globally, the burden on patients and the system is high with numerous consultations taking place

“It took me years to get effective treatment for my chronic pain. During that time I was a different person. The pain was so bad, it made me confused and dazed, unable to think clearly – it was like torture. My doctors were unsure of which medicine to prescribe and seemed afraid to prescribe the opioids which finally relieved my pain.

Joan, patient, UK”

With regard to healthcare practitioners consulted, a sizeable majority of respondents (70% in Europe,¹ 57% in Japan,² 51% in the US,⁴ 66% in Australia⁷ and 76% in New Zealand⁷) reported that their pain was being treated by their primary care physician rather than by a pain specialist (see Figure 3). In Europe 24% had consulted three to six different doctors about their pain,¹ 70% had seen a doctor one to six times in the last six months¹ and 11% had seen a doctor a staggering 10 or more times over this period.¹

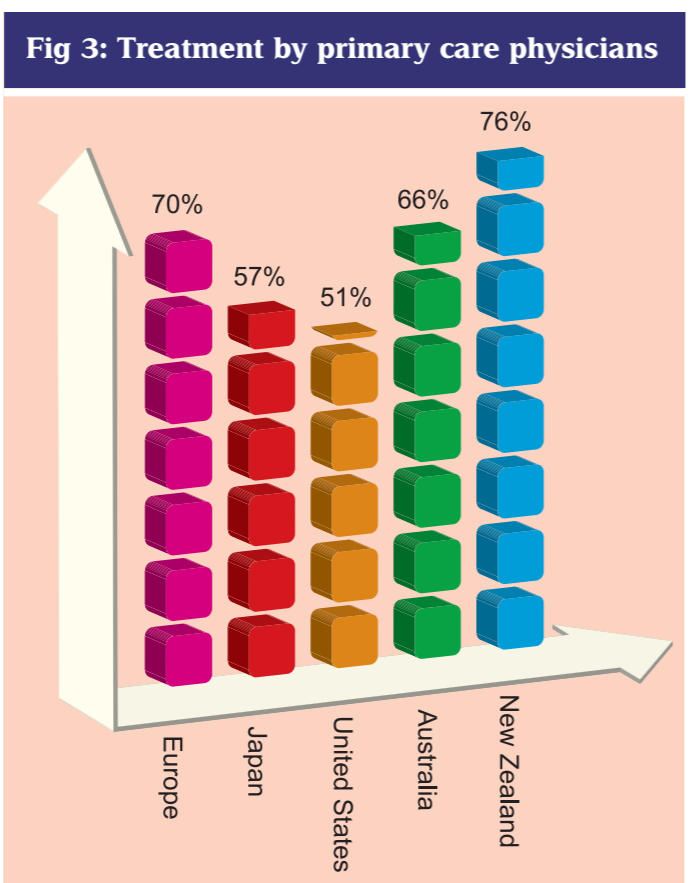
Chronic pain is a long-term problem. In the US, 61% of respondents had been suffering for over five years⁴ while the average length of time in both Europe and Japan was seven years,^{1,2} and nearly 11 years in Canada.⁵ What is more, nearly a quarter of the European sample had been in pain for over 20 years.¹

Despite the fact that two-thirds of respondents in Europe said they felt satisfied with the doctor who treats their pain,¹ more detailed questioning revealed that only 2% had ever been seen by a pain management specialist,¹ only one in 10 had ever been evaluated using pain scales (a validated method for tracking changes in pain intensity),¹ more than one-quarter believed their doctor doesn't know how to control their pain¹ and over one-quarter claimed their doctor only rarely evaluates their pain symptoms.¹

With regard to treatment, 43% of the European respondents said their doctor would rather treat their underlying condition than provide pain relief,¹ a view shared by over 50% of Japanese respondents.²

Pain management

A high proportion of patients around the world say that their pain is inadequately treated



When asked if their pain was adequately controlled, 77% of Japanese respondents said no² – a startlingly high figure, which was somewhat lower but still very significant in Europe (40%),¹ Australia (64%)⁷ and New Zealand (60%),⁷ and in the US the majority of sufferers do not consider either their current prescription or over-the-counter (OTC) medication effective enough,⁴ highlighting substantial room for improvement in medical care (see Figure 4).

When those not receiving therapies were asked why not, 35% of Australian,⁷ 38% of New Zealand,⁷ 13% of Japanese² and 12% of European respondents¹ claimed that nothing more could be done for them – a demonstration of the negative attitude which many patients have been forced to adopt.

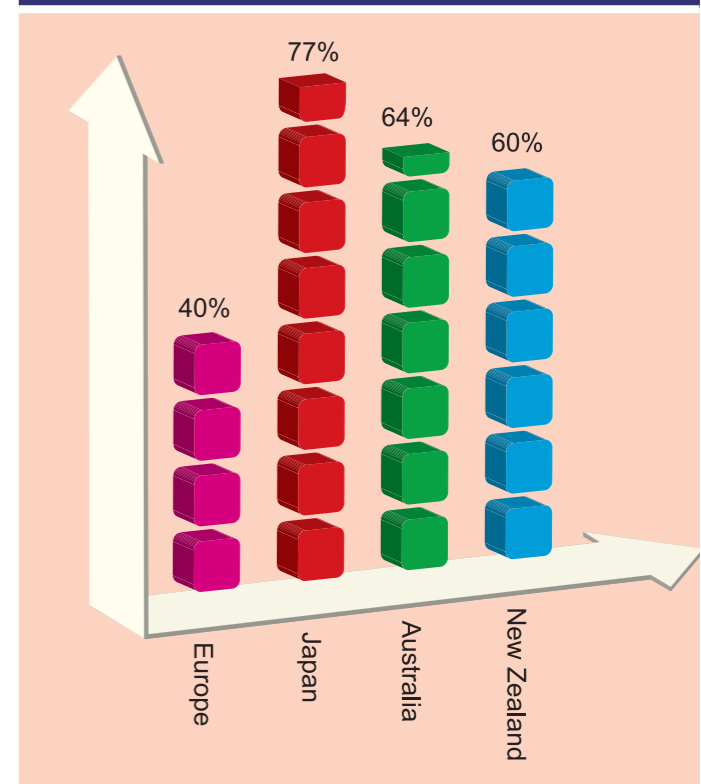
The majority of chronic pain sufferers report taking at least one prescription medication (67% in Europe,¹ 65% in Australia and New Zealand⁷), although they frequently take OTC remedies as well. Prescription medications are generally perceived as more effective than either non-prescription medications or non-drug treatments such as massage and acupuncture.¹

In Europe the predominant prescribed treatments were NSAIDs (44%), weak opioids (23%) and paracetamol (18%).¹ Strong opioids (also known as narcotics, the strongest of all painkillers) were prescribed in only 5% of cases (with greatest use in Ireland (13%), UK (12%) and Denmark (11%) and least in Italy and Spain).¹ Over 10% of respondents in Europe had taken four to six different prescription medications to try to get their pain under control.¹ In Japan NSAIDs were by far the most common medications used (83%) with negligible use of anything else.² NSAIDs again dominated the picture in Canada, where strong opioids were given in only 7% of cases.⁵

“Chronic pain has considerable impact on the patient, affecting their quality of life and their ability to work. Not only does this result in continued, unnecessary suffering for the patient, but untreated chronic pain can cause a significant economic cost. Undertreatment of chronic pain is apparent, and it is evident that the full range of analgesic medications are not being utilised. Chronic pain should be recognised as an important disease-entity – a healthcare problem in its own right, not only a symptom – and treated with the same priority as any underlying disease.

Professor Harald Breivik, Professor of Anaesthesiology, Rikshospitalet University Hospital, Oslo, Norway; Founding Member and WHO liaison, IASP”

Fig 4: Patients who didn't think their pain was adequately controlled



Given the high numbers of respondents who report that their pain is inadequately controlled, the negligible level of use of strong opioids, which outperform other classes of analgesic, is a cause for concern, especially in light of growing evidence for the efficacy and safety of these agents in chronic non-cancer pain.^{9,10} The reasons for this under-utilisation are numerous and include exaggerated concern about the potential for addiction (40% in Europe,¹ 42% in the US,⁴ 50% in Japan² and almost 70% in Canada⁵) and worry about side effects (67% in Europe,¹ same in Japan²). In the US 16% said they were reluctant to take strong opioids “because of what other people might think”⁴ – an example of the sort of stigma that some chronic pain sufferers perceive. Despite these concerns, the need for effective painkillers remains acute: 40% of European¹ and 24% of Japanese respondents² said they would spend all their money on pain treatment if its effectiveness was guaranteed.

When asked about the reason for switching medications, 33% in Europe said they needed stronger or more effective medication,¹ compared with 47% in the US,⁴ 71% in Australia⁷ and 85% in New Zealand.⁷ Worsening pain was mentioned as a reason for switching medication in 21% of European respondents,¹ 66% in Australia⁷ and 55% in New Zealand.⁷

Barriers to pain management

There appears to be a number of barriers to the alleviation of pain facing both patients and physicians.

The International Narcotics Control Board (INCB) has declared that the global use of essential narcotic medicines to treat pain was inadequate and gives three main reasons for this:¹¹

1. Unnecessarily strict rules and regulations have created an impediment to providing adequate access of populations to certain controlled medicines
2. The negative perception about controlled drugs among medical professionals and patients in many countries has limited their rational use
3. Lack of economic means and insufficient resources have resulted in inadequate medical treatment, including the use of narcotic drugs.

A report compiled by OPEN Minds, a group of leading experts from across Europe specialising in research and the management of persistent pain, revealed that in some countries outdated rules and regulations, based on an outdated fear of opioids, still remain (www.openmindsonline.org).¹²

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It is a tragic irony that the most useful medications for severe pain are also the most feared; despite their undisputed medical value, opioid analgesics are regulated so strictly that most patients in the world, including those with cancer and HIV/AIDS, cannot obtain them. Fortunately, we now have guidelines for evaluating national drug control policies for “balance”. These, coupled with collaboration between national drug regulators and leaders in pain and palliative care are improving the regulatory environment for pain relief in some countries.

David E. Joranson, Senior Scientist, Director, Pain & Policy Studies Group, World Health Organization Collaborating Center for Policy and Communications, University of Wisconsin Comprehensive Cancer Center”

Their research identified inequalities in government policies towards opioids that contribute to the inadequate treatment of pain, that need to be reviewed and replaced with policies that will support doctors and patients in their efforts to relieve pain. For example: in every country in Europe prescription forms for strong opioids must be filled in differently from those for other medicines; reimbursement for chronic pain is inconsistent and in some cases minimal.

Stigma is also a major problem. In a survey conducted amongst a sample of the general population across five European countries, one in five people said they had experienced a negative reaction when they told someone they were taking a strong painkiller.¹³ Thirty percent reported having a different opinion of opioids compared to other strong painkillers, with 45% explaining they would feel worried if one of their family were to be prescribed an opioid.¹³

In India, opioid treatment is often not even available to the one million and more cancer patients that need it, due to excessive regulations on supply.¹⁴

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The situation is similar in Latin America, where a preliminary survey showed that there are a number of barriers to the optimal management of cancer pain, such as inadequate staff knowledge of pain management practices, patients’ inability to pay for services or analgesics and excessive state/legal regulations for prescribing opiates.¹⁵

Liliana De Lima, Executive Director, International Association for Hospice and Palliative Care (IAHPC)”

Goals for the future

Although modern medicine has made pain a treatable condition, the under-treatment of chronic pain has been recognised as a serious health concern by the WHO, which last year co-sponsored the first Global Day Against Pain with IASP (the International Association for the Study of Pain) and EFIC (the European Federation of IASP Chapters).

EFIC states in its current “Europe Against Pain” initiative that chronic pain isn’t just a symptom but a condition in its own right and should be given the same priority as the disease or injury that causes it. All those involved in the management of pain – healthcare professionals, regulatory decision makers and patients themselves – need the support required to “raise their game” so that evaluation and control of pain begin to match its prevalence and impact.

This goal is echoed by advocacy and patient groups around the world, such as the European Pain Network and the American Chronic Pain Association, which are calling for greater awareness of the issues of living with chronic pain.

World in Pain aims to go some way towards meeting this important objective, by highlighting the effects of chronic pain and its management on lives across the globe.

For a better future for people suffering from pain around the world

- 🌐 Acknowledgement of pain as a disease in its own right
- 🌐 Putting into practice the principle of relief from pain as a human right – pain is inevitable, suffering is optional
- 🌐 Concerted effort by physicians, patients, governments and the media to de-stigmatise pain and its treatments through improved communication and education

“The recognition that chronic pain is a serious illness in its own right may be among the most important clinical insights of the past 50 years. As more is learned about the epidemiology of chronic pain, the extraordinary magnitude of the public health problem it poses has become apparent. For the individual patient, unremitting pain compromises physical health, undermines function, drives psychosocial disturbances, and causes financial stress. For society overall, both the prevalence of pain and its impact in these multiple domains create a high burden for the healthcare system and for the economy overall. The need for an informed response to the enormous problem of chronic pain is now abundantly clear.

Dr Russell Portenoy, Chairman of the Department of Pain Medicine and Palliative Care, Beth Israel Medical Center, New York; Secretary of IASP”

Resources and links

- 🌐 EAPC: European Association for Palliative Care, www.eapcnet.org
- 🌐 EFIC: European Federation of IASP Chapters, www.efic.org
- 🌐 EPN: European Pain Network, www.europeanpainnetwork.com
- 🌐 IAHPC: International Association for Hospice & Palliative Care, www.hospicecare.com
- 🌐 IASP: International Association for the Study of Pain, www.iasp-pain.org
- 🌐 OPEN Minds: Opioids and Pain European Network of Minds, www.openmindsonline.org
- 🌐 paineurope: Online archive of the quarterly publication for health professionals, www.paineurope.com
- 🌐 People With Arthritis/Rheumatism in Europe (PARE) Manifesto, www.paremanifesto.org
- 🌐 PPSG: Pain Policy Studies Group, www.medsch.wisc.edu/painpolicy
- 🌐 WHO: World Health Organization, www.who.int

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For more information on chronic pain and treatment needs from the patients' point of view, please refer to the European Pain Network



For more information on the role of opioids in the management of pain, please refer to OPENMinds

