



The Burden of Pain

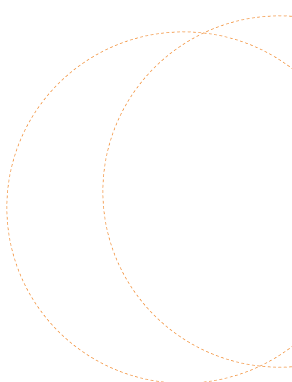
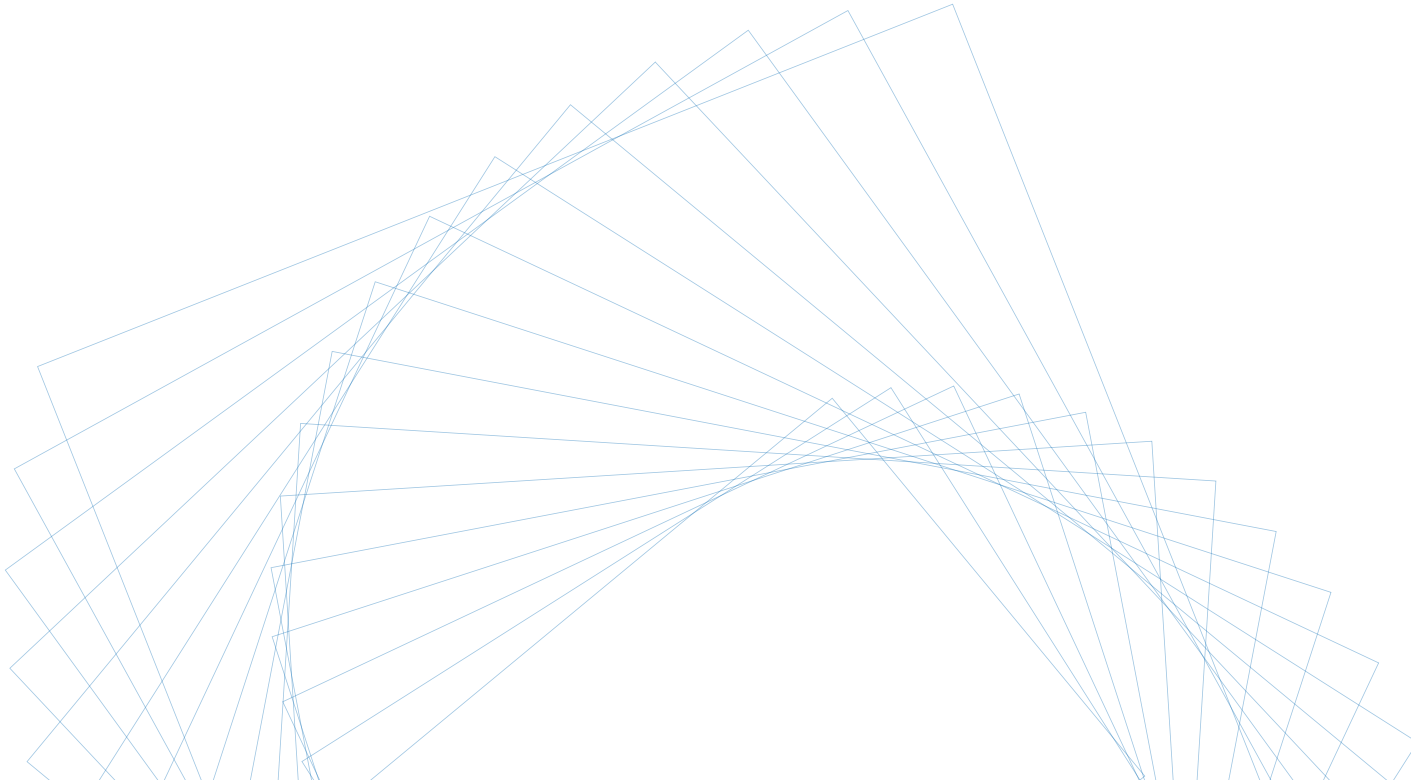
A Societal Impact of Pain (SIP) Book of Evidence





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Executive Summary

Pain stands as one of the most widespread medical issues across Europe as well as globally. It ranks as the primary reason for seeking healthcare and serves as the leading cause of disability and diminished quality of life. Currently, approximately 150 million individuals in Europe endure chronic pain, a figure akin to the combined populations of Germany and France. A significant portion of those affected lack adequate pain management, with previous estimates suggesting rates as high as 40%. Understanding the origins and impacts of various pain conditions remains incomplete, with noticeable deficiencies in research efforts persisting across numerous European nations.

This 'Book of Evidence' was created for individuals from a non-scientific background (e.g. policymakers and funding organisations) to gain an insight into what pain is, understand different definitions used (e.g. acute pain, neuropathic pain, nociceptive pain), and the debilitating effects pain has on patients and societies.

Pain is an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage. According to the International Association for the Study of Pain (IASP), pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.

Pain is now best considered a biopsychosocial experience. The biopsychosocial model is a crucial part of contemporary pain assessment and treatment. The model argues that pain is a personal experience that emerges from a dynamic interplay between biological, psychological, and social factors. This replaces the biomedical model where pain was always thought to be caused by biological factors and disease pathology only.

The 'Book of Evidence' proceeds to unveil a series of patient testimonies, each sharing their journey dealing with different types of pain and articulating their lived experiences. We hope, via these examples of common pain types and testimonies, to offer an understanding of the diversity and commonalities within pain. For the non-scientist approaching pain for the first time, examining conditions such as low back pain, cancer pain and post-surgical pain will perhaps shed light on what has previously been ignored or misunderstood. While pain conditions vary in their pathology and how they are experienced, one factor that often unifies them is the lack of attention given to them within the healthcare system and within policy frameworks. The Societal Impact of Pain platform aims to change this by raising awareness of pain and changing pain policies.

Thus, the Societal Impact of Pain Platform (SIP) calls upon national policymakers to recognise the burden and impact of pain on societies and patients, and increase its priority within healthcare systems, funding and policymaking; ensure the effective implementation of ICD-11, as its use allows international agreement on the use of standardised diagnosis and tools and improves the recollection of data for both primary and secondary use; develop instruments to assess the impact of pain; initiate policies addressing the impact of pain on employment and work productivity and include pain in relevant existing initiatives and develop interoperable digital health ecosystems featuring accessible digital solutions for pain evaluation, monitoring and management (apps, online resources etc.) and legal and regulatory frameworks for data sharing.

The Purpose of this Document

This 'Book of Evidence' was created for individuals from a non-scientific background (e.g. policymakers and funding organisations) to gain an insight into what pain is, understand different definitions used (e.g. acute pain, neuropathic pain, nociceptive pain), and the debilitating effects pain has on patients and societies.

The document explains distinct types of pain conditions (e.g. headaches, low back pain), how common they are, treatment approaches, and common co-occurring health problems.

The document explains crucial concepts and challenges in the pain field, including pain measurement and assessment, chronic pain stigma, the importance of acknowledging the personal multidimensional nature of pain that requires an appreciation of the interplay between myriad biological/physical, psychological, and sociocultural factors.

Overall, this document should describe what pain is and draw attention to the need for urgent policy action and increased funding for research. In particular, the Recommendations highlighted at the end of this document are a call to action to the European Commission, European Parliament, European Council and civil society to address the disastrous societal impacts of pain.

The Societal Impact of Pain (SIP) Platform will continue to raise awareness about the devastating impact pain has on sufferers, societies and economic systems; exchange information and best practices across all members states of the European Union; and develop and foster European-wide policy strategies and activities for an improved pain care paradigm in Europe.

Endorsers



MEP Cerdas (S&D)

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Mental health/mood conditions/disorders and pain frequently co-occur, due to shared molecular, neurophysiological, lifestyle and environmental factors. Therefore, addressing pain in mental health policies and increasing research funding on the topic, is key to establishing a gold standard for self-management programmes, and increasing access to high quality care.



MEP Montserrat (EPP)

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The biological, psychological and social factors of pain, are not mutually exclusive, and interact with each other. Therefore, a comprehensive application of the biopsychosocial model of pain in clinical care (assessment and management), research, education and policy, is key.



MEP Kypouropoulos (EPP)

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Pain not only has a significant impact on the individual, but its occurrence and the vast number of people living with pain, can also have a significant impact in the society. We need to raise awareness about the devastating impact pain has; reduce disparities among Member States by exchanging information and best practices across the European Union; and support European-wide policy strategies and activities for an improved pain care.



MEP Maxova (S&D)

“

Pain is the most prevalent non-communicable medical condition in Europe and worldwide. At present, 1 in 5 people experience chronic pain in Europe. It is the most common reason people seek health care and is the number-one cause of disability and reduced quality of life. Chronic pain is more prevalent in women than in men, with some estimates suggesting that women are twice as likely to experience chronic pain as men.

Foreword

Pain is the one of the most prevalent medical conditions in Europe and worldwide. It is the most common reason people seek health care and is the number-one cause of disability and reduced quality of life. There is a strong socio-economic gradient in terms of prevalence and impact, particularly for work disability and sickness absence. Disability burden due to pain is escalating, threatening the sustainability of European healthcare and social systems. However, pain research is significantly underfunded compared to other areas of health research and this underinvestment is considered a key factor contributing to the burden. The European Commission has called many pain conditions high-burden and under-researched, requiring substantial attention.

According to the Global Burden of Diseases, Injuries, and Risk Factors Study 2020, which includes a comprehensive assessment of incidence, prevalence, and years lived with disability (YLDs) for 354 causes in 195 countries and territories from 1990 to 2017, pain related conditions such as headache disorders (e.g. migraine) and musculoskeletal pain disorders (e.g. low back pain, hip and knee osteoarthritis, neck pain) are two of the largest contributors to years lived with disability (YLDs). Back pain and migraine are responsible for 57.6 million and 45.1 million years of life lost, due to disability, respectively.

In Europe there are approximately 740 million people, most of whom experience an episode of severe pain at some point in their life. For approximately 20 percent, that pain persists for longer than three months and these have chronic pain. Therefore, at present, 150 million people are experiencing chronic pain across Europe, this is approximately equal to the population of Germany and France combined.

Statistics do not truly show the impact pain has on the individual or their loved ones. Pain has a devastating impact on those who are suffering. It can take hold of one's life, destroying one's ability to engage in hobbies, walk short distances, work, or go out with friends (e.g. going out to the cinema because it is too painful to sit for a long time). Pain often wakes people up and ruins the ability to sleep. Constant feelings of excessive tiredness, in addition to pain, mean people struggle to concentrate and manage everyday tasks. The pain often becomes the dominating factor in the sufferer's life. It contributes to diminished well-being, limitations in mobility and social marginalisation across their lifespan, and it is associated with depression, cancer and cardiovascular-related mortality, as well as with a lower life expectancy.

Loved ones are also negatively affected in numerous ways such as emotional stress (e.g. feeling helpless when they see someone they care about in pain), changes in relationship dynamics (e.g. reduced quality time due to the person being limited in what they can do), financial problems (the cost of tests and treatments for the person with pain), and increased caregiving responsibilities (helping a person manage their pain can be physically and emotionally demanding) leading to burnout and exhaustion over time.

Large proportions of individuals in Europe with chronic pain have inadequate pain control with previous estimations being as high as 40%. There are substantial gaps in our understanding of the causes and consequences of many pain conditions, and a noticeable lack of research persists across many European countries. This scarcity of data makes it challenging to generalise research findings to all EU member states. The uptake of the Recommendations presented at the end of this document, is critical to advancing the knowledge on the societal impact of pain.

What is Pain?

This section outlines common definitions used when explaining pain, its duration, and type.

Pain is an unpleasant sensory and emotional conscious experience associated with, or resembling that associated with, actual or potential tissue damage. According to the International Association for the Study of Pain (IASP), pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors. Through life experiences, individuals learn the concept of pain. A person's report of an experience as pain should be respected. Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being. Verbal description is only one of several behaviours to express pain; inability to communicate does not rule out the possibility that a human or a nonhuman animal experiences pain.

Nociception is the nervous system's encoding of potentially damaging events (e.g. touching a hot stove, accidentally cutting yourself). Nociception does not equal pain. One can have nociception but not have pain, while one can have pain and not nociception. This speaks to the complexity of the pain experience. Nociception is objective (it can be measured with instruments), but pain is subjective (it is self-reported) and does not emerge solely from activity in sensory neurons. The pain experience often includes these nociceptive signals, however, the brain also considers other factors, such as an individual's beliefs, past experiences and psychological state, when considering a painful response. This means that pain itself is not a biological process, it is a biological, psychological and sociological experience of which nociception can be part of.

Acute pain is pain that resolves reasonably quickly. Definitions of acute pain vary. Some state that acute pain lasts less than 30 days, while others state that acute pain can refer to any pain that resolves before 3 months. Acute pain is often seen as adaptive- a useful survival mechanism that serves a protective and healing function.

Chronic pain is pain that persists or reoccurs for more than 3 months, although definitions are not always agreed upon.

Chronic primary pain is pain which recurs for longer than 3 months, is associated with significant emotional distress or functional disability, and is not better accounted for by another medical condition. Here, chronic pain is the dominant clinical problem and is considered a condition in its own right. The causes of many chronic pain conditions are unclear, and their emergence is best understood as an interplay between various biological, psychological and social factors which vary from person to person. Some examples are chronic widespread pain (such as fibromyalgia), complex regional pain syndrome and chronic musculoskeletal pain (e.g. non-specific chronic low back pain).

Chronic secondary pain is pain which is a symptom arising from a specifically classified underlying disease. Examples of chronic secondary pain conditions are chronic cancer pain, chronic secondary musculoskeletal pain (e.g. osteoarthritis, rheumatoid arthritis) and chronic secondary visceral pain (e.g. ulcerative colitis, endometriosis).

Nociplastic pain is pain that arises from altered nociception despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain. This pain is also called 'Functional pain' Examples include fibromyalgia/ chronic widespread pain, non-specific chronic low back pain, irritable bowel syndrome, and bladder pain syndrome.

Chronic neuropathic pain (CNP) refers to pain due to a disease/lesion/injury in the somatosensory nervous system. When it lasts for three months or more, it is called chronic neuropathic pain. Examples include sciatica, diabetic neuropathy, spinal cord injury, pain after shingles (postherpetic neuralgia), and chemotherapy induced neuropathy.

The Biopsychosocial Model of Pain

Pain is now best considered a biopsychosocial experience. The biopsychosocial model is a crucial part of contemporary pain assessment and treatment. The model argues that pain is a personal experience that emerges from a dynamic interplay between biological, psychological, and social factors. This replaces the biomedical model where pain was always thought to be caused by biological factors and disease pathology only.

Biological

(or physical factors) include genetics, magnitude of injury or disease, tissue health/damage, medication effects, nervous system characteristics (pain threshold, pain tolerance, predisposition to peripheral, and central sensitisation), and sleep.

Psychological

factors include low mood, depression, anxiety, anger, perceived injustice, coping skills (e.g. avoidance, endurance), fear, self-efficacy, catastrophising, cognitive beliefs, emotional stress, negative attitudes, and acceptance

Social

factors include social expectations, job satisfaction, social support system (financial support, instrumental support, emotional support), living status, employment, past pain experiences, health insurance, substance abuse, language, and cultural barriers.

These factors are not mutually exclusive, and interact with each other. The Societal Impact of Pain (SIP) Platform recommends the comprehensive application of the biopsychosocial model of pain in clinical care (assessment and management), research, education and policy.

The biopsychosocial nature of pain is promoted in the 11th revision of the International Classification of Diseases (ICD-11) and applies to all pain-related conditions. Particularly through the inclusion of the diagnosis of Chronic Primary Pain, which is defined as pain in one or more body systems, and in any body site, or in a combination of body sites that: (a) persists or recurs for longer than 3 months, (b) is associated with significant emotional distress (e.g. anger, anxiety, or depressed mood) and/or significant functional disability (impacts on one's activities of daily life, hobbies, and participation in social roles), and (c) includes symptoms that are not better accounted for by other diagnosis.

By acknowledging the role of emotional distress and function in the definition of chronic primary pain, the ICD-11 recognises that numerous factors affect pain and hence advocates a comprehensive biopsychosocial model of assessment and treatment.

The Societal Impact of Pain

Pain not only has a significant impact on the individual, but its significant frequency and the vast number of people living with pain also causes the impact of pain to be seen on a societal level.

Measuring elements of the societal impact of pain within Europe proves difficult, partly due to a lack of data, however, research has attempted to estimate the burden of pain from many perspectives such as employment, financial, disability, and individual quality of life.

Pain can interfere with a person's quality of life and general functioning. People in pain can experience impairments in attention, control, working memory, mental flexibility, problem solving and information processing speed.

It is estimated that the overall financial burden of pain in Europe may be in the range of 1.5% - 3% of GDP, and that direct and indirect burden, falls on the wider society (i.e. employers, taxpayers, patients and their families) and accounts for significant healthcare expenditure.

Pain can not only limit an individual's ability to work, which has a negative impact on employment productivity and absenteeism, but it can also increase relative costs of care, which then directly impacts the quality of life of patients and their families. Over 40 million EU workers have musculoskeletal disorders caused by their work. This, in turn, results in nearly 50 percent of all absences from work lasting three days or longer in the EU and 60 percent of permanent work incapacity. The direct and indirect costs are estimated to be €240 billion a year.

Therefore, increased investment in research on the societal impact of pain is needed, to fully understand the wide range of aspects of patients' lives affected by pain, as well as to increase their quality of life and access to pain management and treatment.



Stigma Adds to the Burden of Lived Chronic Pain

Stigma is an ongoing challenge in the lives of those living with pain. Its high prevalence displays how the complexity of pain is not understood, and still rooted in an outdated biomedical model. Stigmatising sufferers devalues their personal struggles with managing pain and its associated impacts on individual behaviours. They are essentially robbed of basic human dignity simply because their experiences deviate from societal norms. People will often encounter disbelief from romantic partners, family members, and friends, who may not fully understand or acknowledge the extent of their pain. There's a prevailing sense that healthcare professionals may doubt the legitimacy of their pain, viewing it as exaggerated or even imaginary. This scepticism can lead to self-blaming and doubting that can result in a low self-esteem, besides facing the ignominy of having their narrated experiences dismissed during interactions with healthcare providers. Additionally, individuals with pain often experience stigma in their workplace, receiving hostility from colleagues who may not comprehend the impact of their condition. Raising awareness about what pain is, particularly the biopsychosocial and personal nature of all pain, is crucial to tackling stigma.

Vicious Cycle of Pain and Mental Health Conditions

Mental health/mood conditions/disorders and pain frequently co-occur, potentially due to shared molecular, neurophysiological, lifestyle and environmental factors. For instance, mood disorders such as depression and anxiety, and pain have an estimated co-morbidity rate of up to 80%. In individuals with bipolar disorder, pain prevalence is close to 30% (mainly chronic musculoskeletal pain and migraine). This is over double the risk of people without a mental health condition.

Moreover, people without a mental health condition are at substantial risk of developing one if they still have moderate to severe pain after 12 months. People who suffer from both pain and mental health conditions, such as major depression, bipolar disorder and schizophrenia have substantially poorer physical health, increased risk of cancer and cardiovascular-related disease- all contributing to a lower life expectancy.

Unfortunately, pain is not routinely assessed or addressed in people with mental health conditions, and pain communication and assessment might be hidden by the nature of the mental health condition (e.g. severe mental conditions like psychosis). Further, mental health conditions like depression are often underrecognised and thus frequently undertreated in people with chronic pain.

The importance of ICD-11 for the Pain Community

ICD-11, or International Classification of Diseases, 11th Revision, is a worldwide system used by doctors, healthcare providers, and researchers to classify and code various diseases, conditions, and health-related issues. It is a large list of different health problems and their codes that helps people in the medical field communicate about diseases and conditions consistently around the world. This classification system is created and maintained by the World Health Organization (WHO). ICD-11 was a big step forward for pain as it introduced specific codes that allow pain to be classified and recognised as a health condition, not just a symptom. The ICD-11 is a useful tool for adequately categorising pain-related health conditions which not only supports better management for those with chronic pain, but it also supports the healthcare professionals who provide such care.

In ICD-10 (the predecessor to ICD-11), various chronic pain conditions, such as chronic low back pain, were inaccurately registered, which translated to a lack of standardisation in recording and reporting pain diagnoses. Therefore, ICD-11 implementation, contributes to the delivery of appropriate treatments and supports good quality of life for those with pain conditions. With ICD-11 and its significant increase in ways to categorise pain conditions, we are now able to better support the policymaking process, as well as the clinical management, monitoring, research, and teaching of various pain conditions.



How is Pain Assessed and Measured?

Assessing or diagnosing pain is essential to ascertaining the successfulness and prognosis of recovery. Pain is a complex and often difficult thing to measure accurately, therefore, it is recommended that healthcare professionals use multiple measures to assess an individual's pain.

Pain is self-reported by the individual experiencing pain. It cannot be measured objectively, in the way health professionals measure blood pressure or blood sugar levels. The only way of assessing an individual's pain, is if they tell you. Therefore, patient-reported outcome measures (PROMs)- tools or instruments used in healthcare to collect information directly from individuals about their health conditions, symptoms, functional status, and quality of life, are really important. PROMs are designed to capture the patient's perspective on their own health, providing valuable insights into the impact of a condition or treatment from the patient's point of view. PROMs are often questionnaires or surveys that patients complete to express their experiences, preferences, and concerns related to their health. PROMs related to pain might include questions not only about the intensity of pain, but also its impact on quality of life, daily activities, emotional well-being, and the effectiveness of various treatments. By incorporating PROMs, healthcare providers can better understand the patient's experience, engage in shared decision making with persons in pain to tailor treatment plans to individual needs, and monitor changes in symptoms and overall well-being over time.

There are currently no validated objective measures for pain, and our overall understanding of what causes pain in many individuals is poor. Research is desperately needed to identify biological measures (biomarkers) to better understand the development and progression of various pain conditions. In particular, why do some people develop chronic pain and can we find ways of preventing it? A combination of biomarkers and patient reported measures will be the most promising way of finding better, and personalised treatments for people with pain



Pain Treatments

Many treatments are available for pain, and they aim to improve, maintain or modify pain, pain-related distress, or pain-related functioning. The evidence supporting various treatments is highly variable. While some treatments for some specific pain conditions have high quality evidence of some effectiveness, there is high uncertainty regarding the effects of certain treatments that are used. It is of utmost importance to ensure all treatments for pain are robustly evaluated to understand the benefits and harms of each. Treatments are to be broadly grouped into the following categories: complementary and alternative medicine; electrotherapy; exercise therapy; interventional pain management; manual therapy; participation directed therapies; patient education; pharmacotherapy; psychological therapy; surgical management; and thermotherapy. Note: the treatments below are listed in alphabetical order, not in order of importance or effectiveness.

Complementary and Alternative Medicine: Treatment which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine. Examples include acupuncture, herbs, probiotics, dietary supplements.

Electrotherapy: Various types of electrical stimulation and electromagnetic radiation. Examples include Transcutaneous Electrical Nerve Stimulation (TENS), Shockwave Therapy, and Laser Therapy.

Exercise Therapy: Exercise treatment encompasses a diverse set of treatments prescribed or planned by a skilled health professional that include conducting specific activities, postures, or movements (or all). Examples include general physical fitness programmes delivered in a group setting, aerobic exercise in the form of walking programmes, stretching, and strengthening of specific muscles or groups of muscles, and graded activity.

Interventional Pain Management: Application of interventional techniques focusing on potential pain generators to try to eliminate them. Examples include Injections – e.g. peripheral injections, Soft-tissue, intra-articular, neuraxial injections; Intravenous, sublingual, oral, or epidural patient controlled analgesia; intrathecal analgesia; analgesia by major peripheral nerve blocks; plexus analgesia; paravertebral nerve blocks; plane blocks; electrical stimulation (e.g. percutaneous electrical nerve stimulation); electroacupuncture; ablative techniques; chemical, electrical/thermal; neuromodulation; spinal cord stimulation; dorsal root ganglion stimulation; deep brain, motor cortex, transcranial magnetic stimulation; epiduroscopy.

Manual Therapy: Skilled hand movements and skilled passive movements of joints and soft tissue. Examples include massage, manipulation, mobilization.

Participation Directed Therapies: Promoting engagement in daily activities linked to work, self-care, productivity and leisure.

Patient Education: Any advice, education or information given by a healthcare professional to improve a patient's understanding of their pain or appropriate management. This includes advice about being physically active, graded return to activities, pacing, load management (including education about appropriate assistive devices), healthy lifestyle, advice about how to self-manage and cope with pain, prognosis, pain management education, pain science education. The advice can be delivered in any mode (verbal, written, technology-based or a combination of these).

Pharmacotherapy: Any analgesic drug delivered by any route and dose, including adjuvant therapies.

These include Nonsteroidal anti-inflammatory drugs, Acetaminophen, Antidepressants, Anticonvulsants, Opioids, Corticosteroids, Muscle Relaxants. Some can be taken orally, some by injection and some by application to the skin.

Psychotherapy/Psychological Therapy: Psychological or psychotherapeutic treatment that delivers recognizable psychological content to alter thoughts, emotions, behaviours, and bodily processes. Examples include Cognitive-behavioural therapy (CBT), behavioural therapy (BT), and acceptance and commitment therapy (ACT).

Surgery: Use of operative manual and instrumental techniques on a person to address or correct anatomical abnormalities assumed to affect pain. Examples include Joint arthroscopy [keyhole] (debridement ± synovectomy ± chondroplasty), Joint arthroplasty, Joint replacement, Percutaneous surgery versus open surgery, Rhizotomy, Tenotomy, Radiosurgery, Cordotomy, MRI-, US-, laser- guided ablations, Stereotactic surgical techniques, and Other CNS surgical techniques for pain treatment.

Thermotherapy: Application of heat or cold to joints and/or muscles to improve the symptoms of osteoarthritis and can be done with packs, towels, wax, etc. Heat may work by improving circulation and relaxing muscles, while cold may numb the pain, decrease swelling, constrict blood vessels and block nerve impulses to the joint.

Self-care and Self-management of Pain

Individuals living with pain spend most of their lives outside the health care system and it is in this context that they manage the consequences of their pain condition on their lives, every day. Effectively self-caring for, or self-managing pain, is an educational journey that requires support and the mastering of many aspects including: dealing with flare-ups/exacerbations of symptoms, knowing when to consult with a healthcare professional, making test and treatment decisions, building or maintaining positive coping strategies including stress and sleep management, physical activity, and social engagement. A key ingredient to successful self-management is building people's confidence or self-efficacy to manage pain and its impact on their lives. Currently, we lack a clear definition of what good self-management/self-care looks like. Healthcare professionals need to be better equipped with the skills to help people with pain confidently self-manage. This includes good listening and communication skills, providing self-management information to individuals early in the pain journey to help prevent chronic pain or prevent its negative effects. A crucial challenge that needs urgent attention is ensuring individuals suffering with pain – regardless of location or income – have easy access to affordable self-management programmes/options.

Types of Pain Conditions

Lots of different pain conditions exist. Please find below several types of pain conditions listed alongside information about what the pain is, how it might be diagnosed and other useful information. Conditions listed are very high burden.

It is worth noting that this list is not exhaustive and does not cover all acute and chronic pain conditions.

It is also worth noting that although all conditions have their individual classification, it is common that individuals may present with more than one condition and will likely meet the diagnostic criteria for multiple conditions. In this case, assessment and treatment can become difficult due to consideration of which condition is the primary cause, or if all conditions share an underlying pathology. This complex intertwinement of comorbidity is to be considered.

Wherever possible, we have presented data reflecting the incidence and prevalence of pain-related conditions within Europe. To explore the comprehensive list of acute/chronic pain conditions, please visit the ICD-11 official website.

Musculoskeletal Pain

What is it: Pain presenting in areas consisting of bones, muscles, joints or related soft tissues is considered musculoskeletal pain. The most common musculoskeletal pain conditions are low back pain, neck pain, hip and knee pain secondary to osteoarthritis, shoulder pain, and multisite pain (pain in multiple body parts).

Prevalence: It affects an estimated 1.71 billion people globally and is the leading cause of disability in Europe and worldwide. It is also the largest contributor to years lived with disability (YLDs) – larger than mental health, diabetes, cancer (approximately 149 million YLDs, accounting for 17% of all YLDs). Osteoarthritis (OA), the most common type of arthritis, affects more than 40 million people across Europe. It has a lifetime risk of 45% for knee OA and 25% for hip OA. OA is the fastest-growing cause of disability worldwide. Low back pain is the most common and disabling musculoskeletal pain condition. In Europe, the highest age-standardised rate of prevalence per 100 000 individuals for low back pain is in Central Europe (12,800; 11,500–14,400), followed by Eastern Europe (11,200; 10,100–12,500), and Western Europe (9,540 (8,510 –10,700)). It is projected that globally in 2050, more than 800 million people will have low back pain.

Treatment options: Treatment can include patient education (e.g. about risk factors, self-management), pharmacotherapy (e.g. non-steroidal anti-inflammatories), exercise therapy, psychological therapies, interventional pain management (e.g. injections), surgery, manual therapy (e.g. massage), complementary and alternative medicine, thermotherapy (e.g. heat), and work and social therapies.

Likely comorbidities: Musculoskeletal pain and its related disability is often associated with multisite pain, obesity, mental health disorders (e.g. depression), and sleep disorders (e.g. insomnia).

“ Testimony from a Person with Lived Experience of Pain ”

- **Name:** Anonymous
- **Age:** 76
- **Nationality:** Romanian

- **Name of illness/pain:** Severe Arthrosis

- **How long have you lived with your pain condition and how did it begin?** 15 years. I had unbearable pain around the rotula (ball joint) of both legs and, without some analgesics I could not step up and down the stairs. The pain was sometimes even present during reclining positions.

- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** Stabbing, aching while walking and/or stepping down the stairs and in the reclining position pins and needles followed by numbness.

- **How does pain impact your daily life?** My quality of life decreased quite a lot. From the state of an extremely energetic woman, I had to slow down to the extent of walking with a cane. This makes me unhappy and I feel a lot of anxiety.

- **How do you manage and/or treat your pain?** With analgesics and for the last four years, injections in both knees. I refused to take an operation for the replacement of my knees out of fear.

- **What is the biggest challenge you face while living with the condition?** Mobility and stress free.

- **How does your pain affect your mood and mental health?** Yes, it does. I feel anxiety, unhappiness and lack of enjoyment for the daily life as I used to before.

Neuropathic Related Pain

What is it: Neuropathic pain is caused by a lesion or disease of the somatosensory nervous system. Common reported symptoms might include either localised or referring shooting, burning, or stabbing pains. Neuropathic pain can be of central (e.g. post stroke, multiple sclerosis, Parkinson's disease) or peripheral nature (e.g. trigeminal neuralgia, diabetic peripheral neuropathy, sciatica, post-surgical, post-herpetic).

Prevalence: Neuropathic pain affects approximately 7-10% of the population. For herpes zoster (shingles), the current estimated lifetime risk in Europe is 23–30%, with a reported lifetime risk of recurrence of <5%. Regarding postherpetic neuralgia (residual neuropathic pain after herpes zoster) 10% and 30% of patients develop it; this increases to 60–70% in those age 60 years. Regarding sciatica (radiating leg pain caused by inflammation or compression of the lumbosacral nerve roots (L4-S1) forming the sciatic nerve), the prevalence varies between studies. In a primary care study in the UK (609 patients) about 60% of patients with back and leg pain were clinically diagnosed with sciatica. Phantom limb pain (painful sensations referred to the absent limb) occurs in 50-80% of all amputees. Regarding painful diabetic polyneuropathy, the prevalence is not well established but according to available data the prevalence of pain is 10% to 20% in patients with diabetes and from 40% to 50% in those with diabetic neuropathy. In a study in Italy (816 patients), 36% had a diabetic polyneuropathy associated with male sex, age, and diabetes severity.

Treatment options: Treatment options include both pharmacological and nonpharmacological approaches, such as patient education, supportive education, pharmacotherapy, exercise therapy, psychological therapies, interventional pain management, surgery, manual therapy, assistive devices, and social and work therapies. Opioids should be reserved for patients not responding to therapeutic alternatives with a lower risk of adverse effects. The Herpes Zoster vaccine can be provided to prevent the incidence of postherpetic neuralgia (nerve pain that persists after a shingles outbreak has healed).

Likely comorbidities: Potential comorbidities of neuropathic pain include depression, sleep disturbance and depressed mood or anxiety. These comorbidities hinder a patient's enjoyment by negatively impacting functionality and quality of life.

“ Testimony from a Person with Lived Experience of Pain ”

- **Name:** Ruth Fitzmaurice
- **Age:** 52
- **Nationality:** Irish
- **Name of illness/pain:** Multiple pain conditions: Neuropathic pain; Spina bifida; Scoliosis; Irritable Bowel Syndrome (IBS); Endometriosis; and Orofacial Pain.
- **How long have you lived with your pain condition and how did it begin?** 38 years. I was born with spina bifida and had surgery the day after I was born. My pain started at the age of 14 when I started studying. Unfortunately my pain has progressed since then and is now a condition that I'm living with full-time.
- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** My normal day to day pain I described as burning and aching. When I experience a flare it is usually pins and needles stabbing and throbbing.
- **How does pain impact your daily life?** As I've gotten older my pain has impacted my life more and more. Now at 52 I can no longer work and my activities are dictated by my pain levels. I try to walk on the beach every day, I go to the pool to do physiotherapy usually two to three times a week, those two activities are constant in my life, everything outside of those, as dictated on my pain levels.
- **How do you manage and/or treat your pain?** I manage my pain with a combination of positivity and mindfulness and as little medication as I can manage. Over the years I have taken all of the medications, such as opioid-based medications, topped up with anti-inflammatories. My personal choice was to stop taking medication and that was the point of which I had to stop working, unfortunately it became a quality-of-life issue. Now I take two tablets every day, they are a combination of anti-inflammatory and painkiller, and I try to get away with those two tablets or nothing else. Positivity and mindfulness play a huge role in my life and without them I would spiral down the medication route again.
- **What is the biggest challenge you face while living with the condition?** Fear of the future. Fear of the unknown. Fear of how bad my condition will get.
- **How does your pain affect your mood and mental health?** I do everything in my power not to allow my pain to affect my mood and my mental health. I do everything to ensure that I put a positive spin on my pain whether that be day to day or a flare.

Cancer Related Pain

What is it: Cancer related pain is pain which is caused by the primary cancer itself or metastases. Causes of cancer related pain include the tumour itself or inflammation or eroding bone, viscera or nerves from its metastases. It can also include pain related to tissue or nerve damage induced by cancer treatments. Pain in cancer survivors must be monitored closely as changes in pain can indicate recurrence of the initial malignancy. Much cancer related pain can be caused by cancer treatments such as surgery that may result in chronic neuropathic pain, chemotherapy induced peripheral neuropathy, radiotherapy induced peripheral neuropathy. As bigger proportions of patients luckily survive cancer, the impact of cancer treatment becomes more visible.

Prevalence: Pain is the one of most common symptom for cancer patients at diagnosis. Approximately 30-40% of cancer survivors suffer from chronic pain. 1.7 million European cancer patients die from their cancer each year, of whom at least 66% will experience pain before death and 55% will experience moderate to severe intensity pain.

Treatment options: Treatment options include pharmacotherapy (e.g. simple analgesia, non-steroidal anti-inflammatories, opioids, anti-depressants, corticosteroids, monoclonal antibodies, radiation therapy, chemotherapy), education, surgery, exercise therapy, psychological therapies (including spiritual support), interventional pain management (e.g. nerve blocks), work and social therapies. Sometimes it can be difficult to distinguish between cancer specific and pain specific treatments. For example, radiotherapy can be curative or pain treatment.

Likely comorbidities: Clinical assessment must distinguish between cancer pain, cancer treatment pain and pain from comorbid conditions. Comorbidities impacting pain may include chronic disease, surgery, trauma, mood, cognitions, substance use disorder, and medications.

“ Testimony from a Person with Lived Experience of Pain ”

- **Name:** Ernesto Carreiro
- **Age:** 72
- **Nationality:** Portugal

- **Name of illness/pain:** Cancer related pain

- **How long have you lived with your pain condition and how did it begin?** 10 years. It started before my diagnosis.

- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** Stinging and needles.

- **How does pain impact your daily life?** Weakness, less eating although with appetite, weight loss, bad sleeping.

- **How do you manage and/or treat your pain?** Oral medications.

- **What is the biggest challenge you face while living with the condition?** Lack of will for daily activities, losing strength to do my daily activities.

- **How does your pain affect your mood and mental health?** Yes, frustration for not being able to do my daily activities.

Headache and Orofacial Pain

What is it: Headache or orofacial pain is defined as headaches or mouth or facial pain. Chronic symptoms are those that occur for more than two hours per day on at least 50% of the days during the last 3 months. Symptoms range from mild pain and jaw dysfunction that may resolve over time, to chronic conditions of intractable pain and limitations in jaw function that are severely debilitating.

Prevalence: Chronic headache — headache occurring on 15 or more days per month for at least 3 months — is a major cause of pain and disability. Chronic migraine affects around 1%-4% of the population and chronic tension-type headache about 2.2%. Approximately 25%-50% of those affected also have medication overuse headache, which has a population prevalence of 1%. Temporomandibular joint pain affects approximately 31% of adults and 11% of children/adolescents.

Treatment options: Treatment options include patient education, supportive education, pharmacotherapy, interventional management (e.g. injection), exercise, psychological therapy (e.g. relaxation, biofeedback), thermotherapy, electrotherapy, and social and work therapies. Surgical intervention may also be indicated when non-surgical therapy proves ineffective.

Likely comorbidities: Higher frequency of headaches, allergies, depression, fatigue, degenerative arthritis, fibromyalgia, autoimmune disorders, sleep apnoea, and gastrointestinal complaints were prevalent among those affected.

“ Testimony from a Person with Lived Experience of Pain ”

- **Name:** Anonymous
- **Age:** 62
- **Nationality:** Belgian
- **Name of illness/pain:** Orofacial pain.
- **How long have you lived with your pain condition and how did it begin?** 3 years. It started with a cyst against the nasal bone in the region of tooth 21-22 upper teeth. When the cyst was removed there was bone damage. I have been living with the pain condition for 3 years.
- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** Burning pain.
- **How does pain impact your daily life?** Constant burning pain, but especially after eating, drinking, etc.
- **How do you manage and/or treat your pain?** By brushing teeth and rinsing afterwards with special products and sometimes, by taking anti-inflammatory medication.
- **What is the biggest challenge you face while living with the condition?** Eating has become hell for me, I can no longer taste food.
- **How does your pain affect your mood and mental health?** N/A

Postsurgical Pain

What is it: Pain after surgery. Chronic postsurgical pain (CPSP) is defined as chronic pain that develops or increases in intensity after a surgical procedure or a tissue injury and persists beyond the expected healing process. The pathophysiology of postoperative pain is unique, and the consequences are specific to the individual. Pain is often localised to the area of the surgery or referred in dermatomal patterns and other causes, such as pre-existing conditions or infections, must be excluded.

Prevalence: The largest European prospective trial on this topic shows that around 10% of patients develop CPSP after surgery (with many differences between surgeries). Another study highlighted that three months or more after surgery, 40.4% reported pain. Moderate or severe pain was reported by 18.3% of people. There are large discrepancies in the reporting of CPSP, therefore, it's suggested these numbers can vary.

Treatment options: Treatment options include patient education, supportive education, pharmacotherapy, electrotherapy, exercise, and psychological therapies.

Likely comorbidities: Patients with preoperative chronic pain, particularly at the surgical site, are at increased risk of developing CPSP. Psychological risk factors, such as psychological distress, anxiety, catastrophising, reduced ability to cope with pain, depression and hypervigilance should also be of consideration.

“ Testimony from a Person with Lived Experience of Pain ”

- **Name:** Koert Hommel
- **Age:** 49
- **Nationality:** Dutch
- **Name of illness/pain:** Back pain; failed back surgery syndrome; and neuropathic pain.
- **How long have you lived with your pain condition and how did it begin?** 10 years. When I was a student at BUAS University, 1993, I got lower back pain for the first time. Actually my 'back' was not the biggest problem, but the radiating pain in my left leg. In 2013 this pain returned and never left since then.
- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** The pain I experience is aching, sometimes burning, sometimes stinging. It varies, but it never moves around my body.
- **How does pain impact your daily life?** The pain I experience has an impact on all facets of life. Of course this impact varies, but it touches my (volunteer) work, hobbies, relationship, family, sports- everything changes.
- **How do you manage and/or treat your pain?** After a long, gruelling and exhausting treatment search, I discovered the “multidisciplinary approach to chronic pain”. That knowledge started a shift in my thinking. Now I do a lot of volunteer work and play the piano.
- **What is the biggest challenge you face while living with the condition?** Not being able to do paid work, maintaining boundaries (especially for myself), managing the impact of my pain on others, my own impatience with pain.
- **How does your pain affect your mood and mental health?** Of course it does. Being in pain every day is top sport. Physically, but certainly also mentally. The capriciousness leaves you mentally reeling.

Visceral Pain

What is it: Pain from the internal thoracic, pelvic or abdominal organs. The respective location of pain may coincide with typical referral patterns from internal organs.

Prevalence: Chronic visceral pain represents a significant portion of all forms of chronic pain, as shown by epidemiological studies. Up to 25% of the population report visceral pain at any one time, leading to substantial health care costs.

Treatment options: Treatment options include patient education (e.g. about diet, lifestyle), supportive education, pharmacotherapy, exercise (e.g. stretching), manual therapies (e.g. massage), interventional approaches (e.g. neuromodulation and nerve blocks), psychological therapies (e.g. cognitive behavioural therapy), and surgery.

Likely comorbidities: Fibromyalgia is highly comorbid with several visceral pain disorders. It is also likely that the patient presents with multiple visceral pain syndromes or with chronic visceral pain and other chronic pain syndromes not linked to the viscera.

“ Testimony from a Person with Lived Experience of Pain ”

- **Name:** Anonymous
- **Age:** 40
- **Nationality:** Irish

- **Name of illness/pain:** Endometriosis

- **How long have you lived with your pain condition and how did it begin?** 19 years. It began gradually, symptoms intensifying over a number of months until I required emergency hospital care for suspected appendicitis that emerged to be ovarian torsion due to endometriosis and PCOS.

- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** Burning, sharp and severe pain.

- **How does pain impact your daily life?** Most days I can manage, there are 3 days per month where I can't function or leave the house.

- **How do you manage and/or treat your pain?** Heat pads, Pain medicine, Reflexology, Kinesiology, Craniosacral therapy.

- **What is the biggest challenge you face while living with the condition?** I cannot plan my life at all, constantly worried about what plans I can realistically make in case endometriosis flares up and I have to confine myself to the house.

- **How does your pain affect your mood and mental health?** At times, very demoralising to be so limited, and depressing to miss out on life events and activities when endometriosis is flaring up.

Functional Pain Disorders

What is it: Functional pain disorders (or non-specific functional somatoform disorders) can be referred to as complaints which cannot be categorised as belonging to a specific disease which affects an organ, or organ system, that persists for at least 6 months. Common examples of which are, irritable bowel syndrome (IBS, a functional gastrointestinal disorder characterised by recurrent abdominal pain associated with changes in stool frequency and form, with no recognised underlying pathological or organic aetiology) and temporomandibular disorders (TMD, a group of clinical conditions involving masticatory muscles, temporomandibular joint or both).

Prevalence: IBS affects up to 18% of adults in western countries, predominantly women, especially among those seeking health care. The overall prevalence of TMD is estimated at 31% for adults/elderly and 11% for children/adolescents, with the most prevalent TMD being disc displacement with reduction (DDwR) (roughly 41% in people with TMD), compared to without reduction.

Treatment options: Treatment options include patient education (regarding risk factors), supportive education, pharmacotherapy, psychological therapies (e.g. stress management, relaxation, cognitive behavioural therapy), exercise therapy, electrotherapy, thermotherapy, manual therapy, and social and work therapies.

Likely comorbidities: Some conditions associated with IBS include gastrointestinal disorders, such as functional dyspepsia, gastroesophageal reflux disease, functional constipation alongside fibromyalgia, chronic fatigue syndrome, and chronic pelvic pain. Examples of comorbidities related to TMD include, but are not limited to: fibromyalgia, systemic joint hypermobility, juvenile idiopathic arthritis, tinnitus, post-traumatic stress disorder, systemic osteoarthritis, trigeminal neuralgia, atypical facial pain, and migraines.

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Testimony from a Person with Lived Experience of Pain

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- **Name:** Kaat Cleenewerck
- **Age:** 57
- **Nationality:** Belgium
- **Name of illness/pain:** Multiple pain conditions: Irritable Bowel Syndrome (IBS); low back pain; and sciatic pain.
- **How long have you lived with your pain condition and how did it begin?** Low back pain and IBS: 25 years; neuropathic pain: 12 years; and sciatic pain: 2 years.
- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** A combination of aching, stabbing, pins and needles.
- **How does pain impact your daily life?** It is an invisible disability; it disables normal daily activities and things you do for pleasure. Chronic pain is very exhausting. By mid-afternoon, I am very fatigued and cannot do any physical activities anymore.
- **How do you manage and/or treat your pain?** Everything I and care givers can come up with: staying active despite the severe pain which means daily walks and/or doing errands/light household work; daily stretches and light yoga, physical therapy, dry needling, acupuncture, massages (when I can afford them) treatments at the pain clinic: infiltrations, radio frequency (nerve denervation); medication: (medium) strong painkillers; more recently: medicinal cannabis (which is amazingly helpful).
- **What is the biggest challenge you face while living with the condition?** Living alone most of my adult life, thus having to bear the chronic pain alone in a day-to-day basis, since I have no support from my family and barely from friends. Financial challenges since the so-called “alternative remedies” are rather expensive. This brings also extra stress. Solely professional support (luckily very good one). Even with them I often feel they “underestimate” the level of pain I am dealing with.
- **How does your pain affect your mood and mental health?** Tremendously! Being a rather psychiatric vulnerable person (since my teens), having chronic pain has an enormous effect on my mental health. Loneliness weighs heavily and can be terrible at moments. Living with chronic pain can trigger my chronic depression and make it very present during a certain period. In the past, the pain (among many other issues) contributed to an alcohol addiction, which - I am so lucky! - have been able to overcome. That has had a big effect on improving my mental health.

Chronic Widespread Pain

What is it: Chronic widespread pain (CWP) is pain which presents diffusely in at least 4 of the 5 body regions and in at least 3 body quadrants (upper-lower-left-right of the body) and axial skeleton (neck, back, chest, and abdomen). It is commonly categorised under musculoskeletal pain. Symptoms can include pain persisting for at least three months alongside signs of functional disability or emotional distress. A common example of which is fibromyalgia, an illness characterised by chronic widespread pain, sleep problems (including unrefreshing sleep), physical exhaustion and cognitive difficulties.

Prevalence: The prevalence of individuals reporting symptoms of fibromyalgia is between 2% and 4% in the general population, however, the number of people who are diagnosed with the condition is significantly lower. This is due to diagnostics label related to chronic widespread pain being hotly contested, and consensus on diagnostic criteria and labels are yet to be concluded.

Treatment options: Treatments include patient education, supportive education, pharmacotherapy, exercise therapy, psychological therapies, manual therapies, thermotherapy, electrotherapy, social and work therapies.

Likely comorbidities: It is difficult to conclude the causes of this condition, but some contributing factors may be obesity, diabetes, depression, anxiety, headache, irritable bowel syndrome, chronic fatigue syndrome, systemic lupus erythematosus, and rheumatoid arthritis.

“ Testimony from a Person with Lived Experience of Pain ”

- **Name:** Tristan Vandepuuten
- **Age:** 27
- **Nationality:** Belgium

- **Name of illness/pain:** Fibromyalgia and Dystonia

- **How long have you lived with your pain condition and how did it begin?** 11 years. It started with the flu on a stressful moment. I'm still living with my pain condition. Day in day out. After 3 years and a lot of doctors I was diagnosed with dystonia, chronic pain.

- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** Like I'm being pulled inside out, constantly.

- **How does pain impact your daily life?** I can barely survive; I have a progressive condition.

- **How do you manage and/or treat your pain?** I'm not managing it very well. Playing music and the guitar give me some relieve. Bobath therapy, relaxation, breathing therapy, hot baths, walking, listening to audiobooks, infrared cabin and medicine such as, local anaesthetics, opioids, and antidepressants.

- **What is the biggest challenge you face while living with the condition?** Doing simple things.

- **How does your pain affect your mood and mental health?** Yes, isolation, not having a normal life and feeling like there is no future because there is not a lot of support in terms of the lack of research.

Complex Regional Pain Syndromes, Type I and II

What is it: Complex regional pain syndrome (CRPS) is a painful condition affecting a limb, associated with sensory, motor, autonomic, skin, and bone abnormalities. Symptoms will present differently in different people. Bone abnormalities include localised osteoporosis in parts of the affected limb, which usually resolves spontaneously. Skin abnormalities include reversible changes in texture or appearance of the skin, e.g. the skin might appear thin or shiny. In almost all cases CRPS is triggered by a trauma to a limb. CRPS can arise even after very small injuries. In 7% of cases there is no injury and CRPS arises spontaneously. CRPS affects both men and women, but women are more often affected. It can affect people of any age group including children; it most frequently affects women or men above the age of 40. There may be two types of this condition, which initially look the same. (a) About 80% of patients have a good prognosis. Their condition will get better. This type of CRPS may be contributed to by inflammation in the affected limb. (b) In about 20% of patients the pain will persist. This means that their pain does not get much better, whatever we/ they do. Recent evidence suggests that in these patients an autoimmune reaction may cause the condition. For clarity CRPS "Type 1" or "Type 2" in the literature refers to CRPS without damage to major nerve (Type 1) or with damage to such a nerve (Type 2, this is rare). Recent research has shown that this classification does not contribute much to scientific understanding or clinical practice, and management of these two "Types" is quite similar. This is different from those two types (a) and (b) discussed above.

Prevalence: In the general population 20-26 people out of every 100,000 will develop CRPS per year. Prevalence of CRPS is difficult to ascertain, however, it occurs acutely in approximately 7% of patients who suffer limb fractures, limb surgery, or other events such as sprains and elective surgery.

Treatment options: Treatment options include patient education, supportive education, pharmacotherapy, exercise therapy, and psychological therapy. Graded exercise in particular, helps to i) reduce CRPS severity, ii) shorten the duration of this type of CRPS, iii) minimise residual problems, and iv) when applied very early after a trauma may prevent this type of CRPS from occurring. It may be necessary to encourage conscious attention to the limb by encouraging looking; thinking; touching & re-engaging the limb before any movement. Mirrors can be used to highlight and correct movement control.

Likely comorbidities: Emotional factors related to CRPS may have a greater impact on pain intensity than in non-CRPS pain conditions, therefore, consideration of the presence of psychological comorbidities is important.

“ Testimony from a Person with Lived Experience of Pain ”

- **Name:** Juergen Werner
- **Age:** 56
- **Nationality:** German
- **Name of illness/pain:** Chronic regional pain syndrome Type II.
- **How long have you lived with your pain condition and how did it begin?** Since 2021. It started after a carpal tunnel surgery.
- **How would you describe the pain sensations you experience with your pain condition (e.g. burning, stabbing, numbness, aching, pins and needles, stinging, etc.)?** I have a constant vibration in my wrist and a burning, stabbing flash in my forearm 24/7.
- **How does pain impact your daily life?** It limits me every day because it doesn't take a break and it's also difficult to meditate or something similar because it's always present.
- **How do you manage and/or treat your pain?** It's hard to distract yourself. You learn to be an actor and cover up everything. However, it destroys you in the long run.
- **What is the biggest challenge you face while living with the condition?** It is difficult to cope with everyday life. Concentrating for longer than 30 minutes is almost impossible. People also withdraw from larger events.
- **How does your pain affect your mood and mental health?** It is difficult to concentrate for long periods of time and as a human being you lose joy and forget how to laugh. I am no longer the same person as I was before this illness. You lose hope because you are treated as a patient everywhere and in the end everyone tells you that the disease is unexplored.

CONCLUSIONS AND RECOMMENDATIONS

We hope, via these examples of common pain types and testimonies, to offer an understanding of the diversity and commonalities within pain. For the non-scientist approaching pain for the first time, examining conditions such as low back pain, cancer pain and post-surgical pain will perhaps shed light on what has previously been ignored or misunderstood. While pain conditions vary in their pathology and how they are experienced, one factor that often unifies them is the lack of attention given to them within the healthcare system and within policy frameworks. The Societal Impact of Pain platform aims to change this by raising awareness of pain and changing pain policies.

The Societal Impact of Pain (SIP) Platform, calls upon EU and national policymakers to:

1

Recognise the burden and impact of pain on societies and patients, and increase its priority within healthcare systems, funding and policymaking.

2

Ensure the effective implementation of ICD-11, as its use allows international agreement on the use of standardised diagnosis and tools and improves the recollection of data for both primary and secondary use.

3

Ensure patient registries are established and frequently used, as it will improve the understanding of pain and pain management and treatment.

4

Pain as a quality indicator: Develop instruments to assess the impact of pain.

5

Increase investment in research on better understanding the causes (pathophysiology) of various pain conditions, developing novel pain treatments, understanding and addressing comorbidity between pain and mental health conditions, increasing development and use of patient reported outcome measures for all pain conditions, establishing a gold standard for self-management programmes, and increasing access to high quality care.

6

Initiate policies addressing the impact of pain on employment and work productivity and include pain in relevant existing initiatives.

7

Prioritise pain education for healthcare professionals, patients, policy makers, and the general public.

8

Information technology for pain: Development of interoperable digital health ecosystems featuring accessible digital solutions for pain evaluation, monitoring and management (apps, online resources etc.) and legal and regulatory frameworks for data sharing.

About the Societal Impact of Pain (SIP) Platform

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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Disclaimer

The Societal Impact of Pain (SIP) does not endorse any treatment options mentioned in the present document. The information is not intended to replace a one-on-one relationship with a qualified healthcare professional and is not intended as medical advice. The Book of Evidence on the Burden of Pain provides general information and discussions about pain. The information and other content provided, or in any linked materials, are not intended and should not be construed as medical advice, nor is the information a substitute for professional medical expertise or treatment.

The patient testimonials appearing in the present document, are collected via email through Pain Alliance Europe member contacts. They are individual real-life experiences of those that have chosen to provide input to the Book of Evidence on the Burden of Pain. The testimonials are not necessarily representative of all of those who experience pain, and many more experiences can be given, even if not collected in the present document.

The testimonials displayed are given verbatim except for correction of grammatical or typing errors. Some have been shortened. This is done only when a testimonial is lengthy, or if the entire testimonial did not seem relevant for the public.

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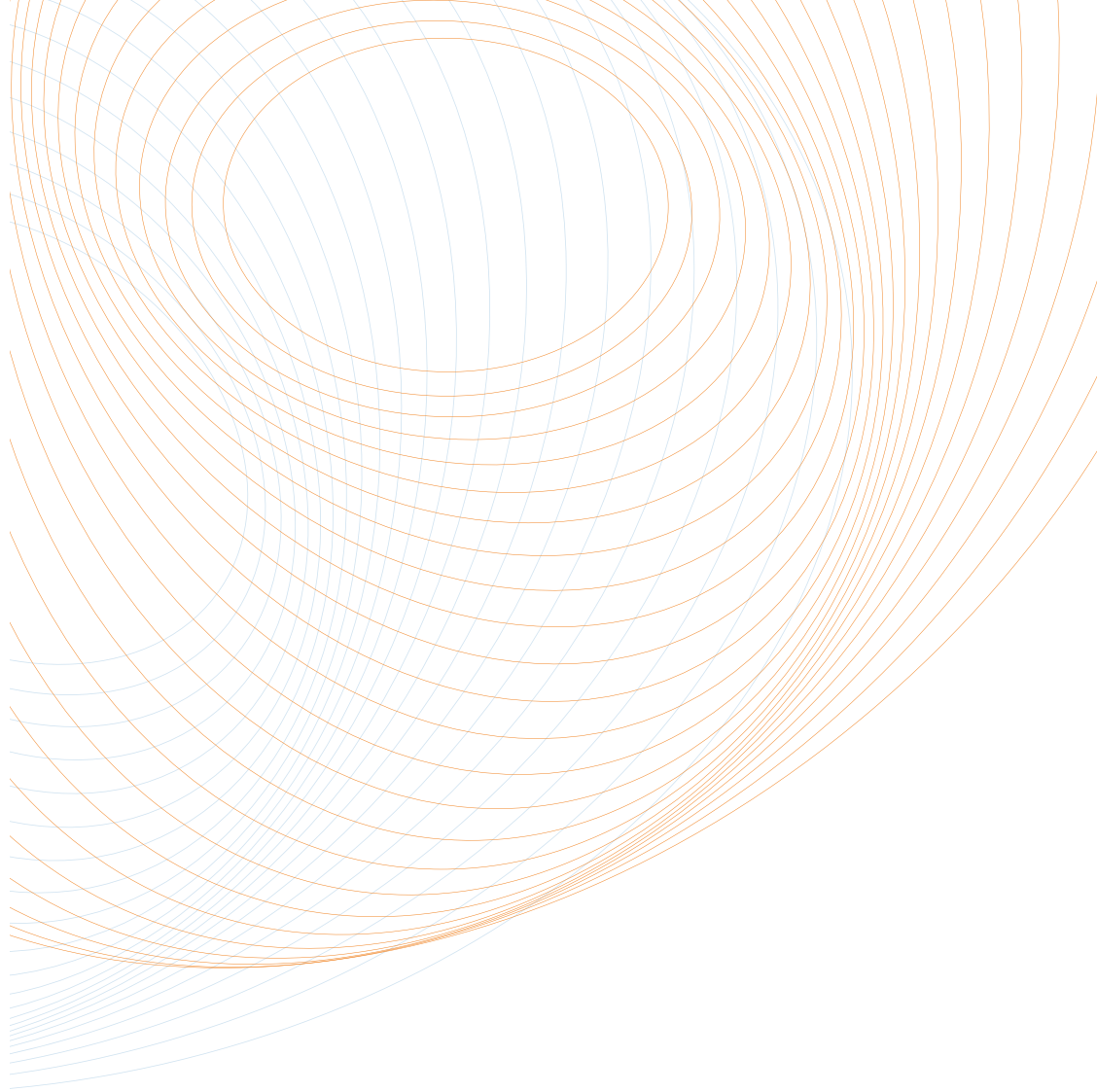
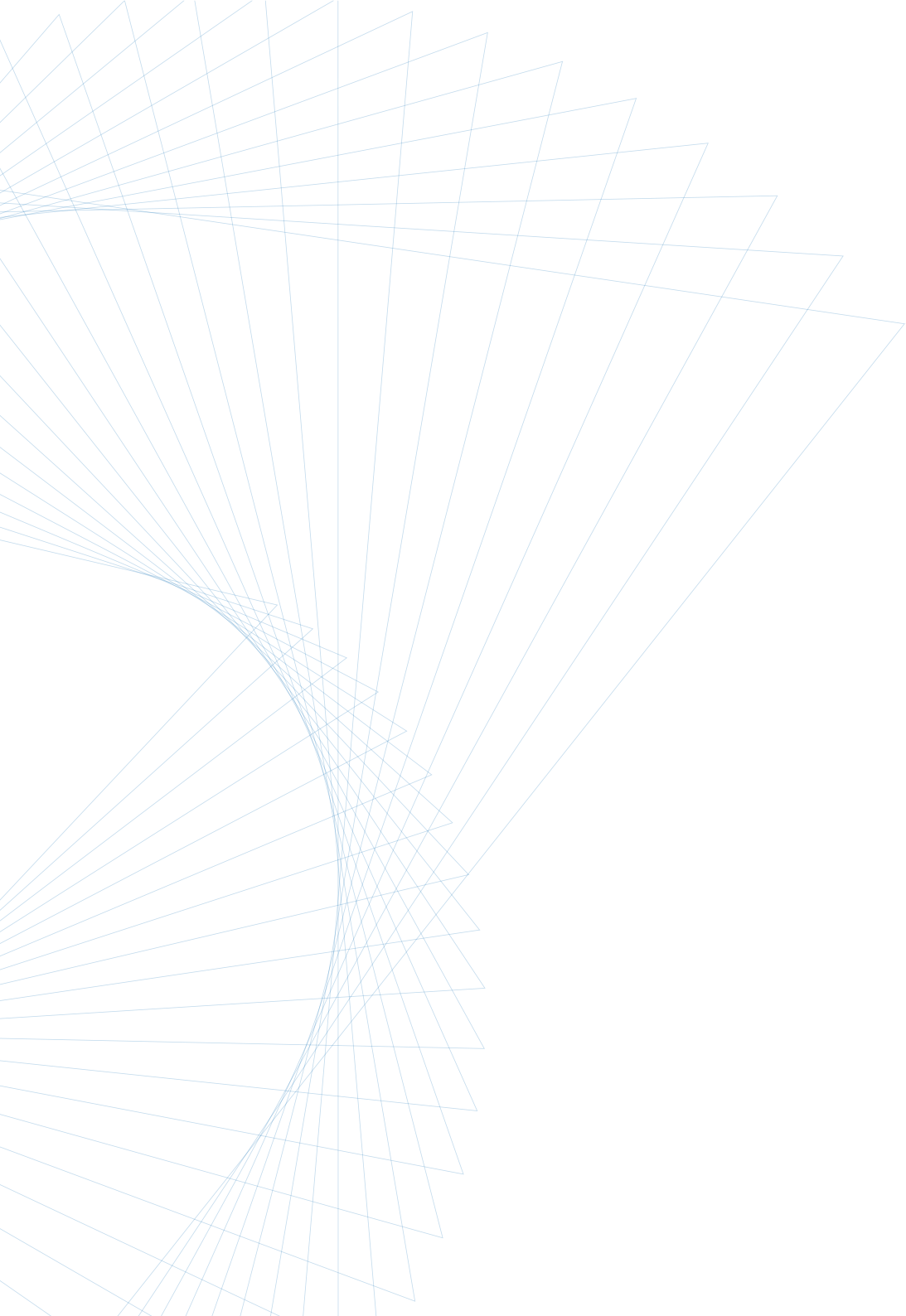
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The 'Societal Impact of Pain' (SIP) platform is a multi-stakeholder partnership led by the European Pain Federation EFIC and Pain Alliance Europe (PAE), which aims to raise awareness of pain and change pain policies. The scientific framework of the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