



PAIN

proposal

Improving the current and future
management of chronic pain













A European consensus report



Acknowledgements

The Pain Proposal Steering Committee

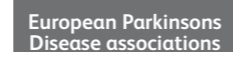
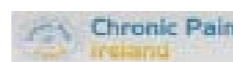
The Pain Proposal Steering Committee is an independent group of European experts, from a range of backgrounds, with a shared interest in chronic pain. The Steering Committee has taken a leading role in the development and implementation of the Pain Proposal initiative. Committee members have contributed their time and expertise, hosting a meeting with the Executive Committee; reviewing the questions for the patient and healthcare professional surveys commissioned for this project; and assisting in the development of content for this report. The recommendations within this document represent a consensus from the Steering Committee of steps that could be taken to improve the management of chronic pain in Europe for the benefit of all involved.

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Can You Feel My Pain is a Europe-wide coalition campaign designed and implemented by patient advocacy groups across Europe while raising awareness of Chronic Pain and providing a channel for 'real-life' patient stories for inclusion within the Pain Proposal.

The Pain Proposal Steering Committee would like to thank the members of patient advocacy group advisory board who worked in partnership with Pfizer to develop and implement the Can You Feel My Pain, European health awareness campaign.



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- Liisa Mikkonen, [insert organisation]

The Pain Proposal Executive Committee

The management of chronic pain varies widely across European countries. In order to gain a wide and representative range of perspectives, a Pain Proposal Executive Committee of experts - including patient groups, clinicians, policy experts and health economists - was formed. Executive Committee members conducted work at a national level to develop a series of national Pain Proposal 'Country Snapshot' reports providing greater detail around the chronic pain challenges in individual European countries. They also fed insights into the overall European Consensus Report. The Pain Proposal Steering Committee would like to thank the Executive Committee for their time and input on this important project.

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Mr Neil Betteridge, Chief Executive, Arthritis Care and Vice President of the European League Against Rheumatism (EULAR)

The Pain Proposal Consensus Report has been developed by a range of European experts in the field of chronic pain in partnership with Pfizer. All the content in this report has been informed by the opinions and guidance of The Pain Proposal Steering and Executive Committees. The report offers a consensus of opinion on chronic pain and should not be interpreted as a direct representation of the views of any one party.

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Foreword

Introducing The Pain Proposal

According to recent surveys, one in five Europeans (19%) are estimated to suffer from chronic pain according to past surveys. Many people will find that a shocking statistic, however, for individuals with chronic pain the reality is more than shocking. Chronic pain is a terrible burden that many are left to carry alone, day in and day out. We cannot feel their pain but we can empathise and recognise the impact that the consequences of chronic pain have on society and on the wider economy. Although attempts have been made to address the problem, so far they have only achieved mixed success.

Members of the Steering Committee behind The Pain Proposal believe this situation cannot be allowed to continue. In their view it is unacceptable that more effort is not being focused on tackling chronic pain. For this reason the committee has put together a consensus report with key recommendations on how this situation can be addressed. The report is intended for the for managers of pain services, healthcare organisations, policy-makers, politicians, healthcare professionals and all those involved in the management of chronic pain.

The Pain Proposal initiative has brought together a broad range of perspectives from 15 countries across Europe including those of people with chronic pain, clinicians from different medical specialties, policy experts, industry members and health economists. This broad group of experts have experienced, and continue to experience the problem of chronic pain from different viewpoints and have come together as concerned stakeholders with a shared goal to ensure change and better management of chronic pain.

New surveys of people with chronic pain and primary care physicians were commissioned throughout Europe in order to obtain an accurate, up to date, snapshot of how pain is affecting the lives

of Europeans today. The surveys also sought to establish how pain management services are performing to better inform our calls for action. The results reveal the issues many people face in receiving a diagnosis or adequate management of their chronic pain and the resultant impact on their ability to work and also their productivity whilst at work.

Currently, access to pain management services is highly inconsistent in Europe, both within and across nations. Moreover, available health services for pain differ markedly in the type of care they offer. We believe a new minimum standard of care is required to which all people with chronic pain in Europe should have access.

The current cost of chronic pain to the European economy is significant and is, arguably, unsustainable. With factors such as rapid ageing of the population, the costs of pain are set to escalate. With the effects of the global financial crisis still evident in Europe, the need for economic efficiencies has rarely been greater. Governments in all countries are reining in spending in all departments including healthcare. Money for healthcare services is tight and what little money there is must be used well to extract maximum value. The Pain Proposal includes recommendations that, if implemented, could assist with efforts to reduce health expenditures through increased efficiency.

Chronic pain is arguably the medical condition with the greatest negative impact on quality of life. Indeed, some pain specialists regard it as a disease entity in itself and in 2001, the European Federation of IASP Chapters (EFIC) issued a declaration to the European Parliament to this effect.

Certainly, many stakeholders wish to see chronic pain afforded as much attention as other major diseases such as heart disease, breast cancer and diabetes. It behoves us all to take action throughout Europe to improve the way it is perceived and managed.

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“Political leadership is required to mandate improved pathways of care for patients, so that the current fragmented approach can be changed to a more integrated model from primary to secondary care with the patient at the centre having treatment according to their needs.” Dr Beverly Collett, Consultant in Pain Management & Anaesthesia, Leicester Royal Infirmary NHS Trust, Chair of the Chronic Pain Policy Coalition (CPPC), Executive Officer, International Association for the Study of Pain (IASP)

Executive Summary

Chronic pain presents a substantial challenge to the citizens and the economy of Europe – one that is likely to worsen as the population ages. In a 2006 Europe-wide survey, one in five respondents reported chronic pain¹ with most experiencing it for over two years and some people enduring it for up to 20 years or longer.¹

Living with Chronic Pain

Pain is a subjective and personal experience, which can make it difficult to define and measure, but this in no way reduces the devastating impact chronic pain can have on the lives of those it afflicts. A heavy burden in itself, chronic pain may also result in physical and psychological disability and is associated with serious co-morbidities and psychological disorders such as anxiety and depression.² The negative impact of chronic pain frequently extends beyond the sufferer to affect loved ones and dependents.

The Pain Proposal reveals:³

- 27 % of chronic pain sufferers feel socially isolated and lonely because of their pain
- Half of sufferers worry about the effect of their chronic pain on their relationships
- 29 % worry about losing their job
- 36 % say their chronic pain has a negative impact on their family and friends

Pain sufferers frequently feel their condition is compounded by a lack of understanding among the general public: nearly two-thirds (62 %) of patients surveyed for the Pain Proposal felt that public understanding and awareness of chronic pain are low.³

The complexities involved in measuring chronic pain, with its differing manifestations and causes, can make it difficult to diagnose the root cause of an individual's pain or define how best to manage it. Chronic pain patients' journeys through the healthcare system can be lengthy, convoluted and inefficient.

Pain Proposal survey data from across Europe show:³

- On average, chronic pain sufferers must wait 2.2 years between seeking help and diagnosis, and 1.9 years before their pain is adequately managed.
- A quarter (26 %) of people had to wait up to five years to receive a diagnosis or reason for their pain - and a further 11 % waited longer than this.
- 38 % of people with chronic pain report that their pain was not adequately managed.
- Chronic pain patients make an average of nearly 7 visits to healthcare professionals a year, with 22 % having to make 10 visits or more.
- Nearly half those surveyed were dissatisfied with the time it took to reach a diagnosis (49 %), to get adequate management of their pain (48 %) or the number of visits to the doctor it took to achieve adequate management (50 %).

Chronic Pain: a High Cost to Europe

Pain is more than a burden on sufferers and their families alone. Chronic pain costs Europe billions of euros: perhaps as much as €300bn across the EU⁴, or around 1.5 % -3 % of GDP (gross domestic product).^{5,6}

The direct cost of chronic pain to healthcare systems is significant. Consultations with healthcare professionals make up the largest share of healthcare system costs estimated at €187m for Belgium,⁷ \$368m (€289 million) for the Netherlands,⁸ rising to over £1.6billion (€1.9 billion) for the UK.⁹

According to new survey data in German, France, Italy, Spain and the UK:¹⁰

- 93 % of people with chronic pain had visited a healthcare professional in the last month
- Patients with severe pain visited healthcare professionals an average of 13 times in the past six months
- 25 % of those with severe pain had visited an emergency room in the past six months and 22 % had been hospitalised due to their pain

Inappropriate and ineffective management and treatment generating repeat visits to primary care physicians, and referrals to specialists, have been identified as important drivers of avoidable healthcare costs.^{6,11}

However, while direct costs are high, it has been estimated that nine-tenths of the burden of pain may fall on the broader society: employers, taxpayers (through welfare payments, for example), patients and their families.⁸ The scale of these indirect costs greatly exceeds the direct costs of managing pain, and ensures that even small increases in the effectiveness of pain management reap large economic rewards.

New Pain Proposal data shows that:³

- 21 % of Europeans with chronic pain are unable to work at all as a result of their chronic pain and, of those that are able to work, 61 % state their employment status is directly affected by their condition.
- People with chronic pain felt their pain negatively affected their ability to do their job for more than a quarter (28 %) of the time they were in work.
- Studies have indicated that chronic pain sufferers may be seven times more likely than other individuals to leave a job because of ill health and are less likely to return to employment: as few as 10 % ever return to work according to one estimate.^{12,13}

Examples from Europe show that expenditure on chronic pain management can be cut while improving services and patient satisfaction. For instance a Pain Clinic in the UK pioneering multidisciplinary pain management techniques generated per patient cost savings of 35 %, largely driven by lower expenditure on GP visits and physiotherapy, while patient satisfaction increased to 75 %.^{14,15} However, so far leading examples such as this remain isolated in Europe.

Despite the positive return on investment in improved pain management demonstrated by such examples, a frequent obstacle to the broader implementation of such strategies is fragmented budgeting and management. Better coordination within health services, between levels of government (central, regional and local) and between government departments (e.g. health and welfare) will be critical to realising these savings on a larger scale. Learning from innovative approaches to budgeting already being practised in some European countries such as Sweden should be a priority.

Physician Training is Paramount

A large majority of doctors in Europe feel they would benefit from improved training to equip them to manage their patients' pain more effectively. There is potential for pain-specialist curricula and training for general healthcare professionals on pain to be improved in much of Europe.^{16,17} In addition, most countries lack specific clinical guidelines for managing chronic pain, leading to variable or inconsistent advice on pain management. A significant number of doctors do not feel fully confident in understanding and using guidelines where they exist.¹⁷

The results of the Pain Proposal survey reveal:¹⁷

- Only around half (53 %) of PCPs are confident managing chronic pain.
- Forty seven per cent lack confidence in knowing when to change pain treatments
- Over half (54 %) are not confident about what to do when a person still complains of pain.
- 85 % of primary care doctors expressed a desire to receive additional training on the identification, treatment and management of chronic pain

Better training, which acknowledges the difficulties inherent in managing a patient with chronic pain, combined with assistance in navigating current guidelines, could play an important role in improving management pathways.

Management & Treatment

There are a range of different medications and therapies available to people with chronic pain and it is important to ensure that patients receive the treatment that is most appropriate for their pain type and circumstances. Clinicians need to work through the options in collaboration with patients to identify the optimal therapy for each individual. It is also critical that patients receive management as soon as possible, as evidence suggests that patients who wait 6 months for treatment experience deterioration in quality of life, psychological well being and depression.¹⁸

Pain clinics are specialised in diagnosing and treating patients with chronic pain. However, access to pain clinics is inconsistent and the provision of pain services varies significantly, while waiting times for treatment are also very variable.¹⁹

Access to appropriate services and treatments is key to realising tangible improvements in pain management in Europe. Several countries have set up national strategies to address the challenges presented by the management of chronic pain. This offers an important opportunity to learn about which strategies offer the greatest benefit.

The Pain Proposal – What Needs to Change?

Given the scale of the economic challenges facing Europe, it has never been more important to tackle inefficiencies in pain management, that could result in savings to health budgets and a productivity boost to Europe's economies, not to mention the positive impact on the lives of patients suffering from chronic pain.

The Pain Proposal Steering Committee believe that the following recommendations, encompassing managers, policy-makers, healthcare professionals, patients and the wider community, would, if adopted, generate tangible and immediate progress towards the goal of more effective and efficient management of chronic pain.

Within pain management...

- **Clear patient management pathways must be established for people with chronic pain – individuals in the community with chronic pain must be recognised and early intervention provided to prevent worsening**

At policy-making level...

- **Pain must be identified as an important issue in European societies – the magnitude of the challenge must be acknowledged and systems set up to support better outcomes**

For professional pain specialist associations and patient organisations...

- **The rights of people with chronic pain must be protected and championed to ensure they can regain, or continue to live, fulfilling and productive lives**

For all those involved in chronic pain...

- **To work together to improve the management of chronic pain across Europe**

The development of this report and the recommendations within it are only a first step towards effecting change in the way chronic pain is currently managed. This may not always be easy but examples of good practice show that improvements can be accomplished. If governments, clinicians, patients groups and all those involved in the chronic pain arena work together then real change is a possibility. Ensuring that people with chronic pain receive the right treatment from the right healthcare professional at the right time could result in huge benefits, not only for those with chronic pain but for European economies and society in general.

Chronic Pain

Chronic Pain Affects One in Five Adults in Europe¹















“Pain is going to become more of a problem as the population lives longer. To support the economy we will need to raise retirement ages and limit welfare spend on incapacity benefit. If people are held back by uncontrolled chronic pain, this won’t be possible.” Professor Vázquez, Executive Director, FEDEA

Chronic pain is a substantial challenge to the citizens and the economy of Europe and is likely to worsen as the population ages. Chronic pain is expected to have a two-fold impact as the population ages, first; the number of people affected by pain is expected to increase and second; pain will frustrate the economic need for people to remain in employment for longer.

Estimates of prevalence vary widely according to definition and methodology but by any measure it is clear that a significant proportion of Europeans suffer from chronic pain.¹ In a 2006 Europe-wide survey, one in five people in the general population reported having chronic pain,¹ with some people enduring it for up to 20 years or longer and most experiencing it for over five years.¹ Nearly half of all patients (46%) said they experienced chronic pain at all times¹ and many of these claimed to be so weighed down by pain they could not continue to tolerate it.¹ Another survey, the 2007 Eurobarometer “Health in the European Union” survey, states that exactly a quarter of all EU respondents say they have experienced chronic restrictive pain at some point in their life.²⁰

While prevalence may vary across countries and the scale of the problem can be difficult to quantify, it is clear that a significant proportion of the European population are currently struggling with chronic pain.

The prevalence of Chronic Pain in Europe

Country	Chronic Pain
 Denmark	16 – 20 % ^{1,12,21}
 Finland	19 – 48 % ¹
 France	15 – 32 % ^{1,22}
 Germany	17 – 45 % ^{1,23}
 Netherlands	18 – 25 % ^{1,24}
 Norway	26 – 30 % ^{1,25}
 Spain	12 – 23 % ^{1,26}
 Sweden	18 – 54 % ^{1,27}
 UK	13 – 50 % ^{1,28,29,30}
 Ireland	13 % ¹
 Switzerland	16 % ¹
 Austria	21 % ¹
 Belgium	23 % ¹
 Italy	26 % ¹

The Complexities of Diagnosing Pain

Chronic pain is a subjective and personal experience, which can make it difficult to define and measure. Patients experience their personal pain journeys in their own unique way. Pain is not confined to the physical manifestations but it is also impacted by psychological and social factors.

Not surprisingly there are only subjective measures of pain and therefore measurement must rely on a healthcare professional’s interpretation of a person’s account of their pain. The assumption is often made that because the measurement is subjective it is of little value.³¹ Existing definitions of pain and how long it must be present to qualify as ‘chronic’ are also somewhat ambiguous. The most widely adopted definition is the one used by the International Association for the Study of Pain (IASP) which describes chronic pain as “pain without apparent biological value that has persisted beyond the normal tissue healing time (usually taken to be three months)”.³²

“Pain is a major healthcare problem in Europe. Although acute pain may reasonably be considered a symptom of disease or injury, chronic and recurrent pain is a specific healthcare problem, a disease in its own right” EFIC First Declaration, 2001³³



Chronic pain may result in varying amounts of disability, physical and psychological, and is associated with co-morbidities and psychological disorders such as anxiety and depression.² Biological, psychological, social, cultural, and developmental factors can impact on attitudes to pain and its management.³⁴ The prevalence of chronic pain increases with age, affecting up to half of the over 65s.³⁵

Chronic pain may originate from a variety of causes, both physical and psychological. Physical causes may involve musculoskeletal, vascular, neurological and oncological conditions as well as injury to organs and tissues from other disease processes and from surgical interventions. Chronic pain can be nociceptive, neuropathic or a combination of both. Nociceptive pain is pain associated with tissue damage. Neuropathic pain is more complex and occurs when nerves, or part of the nervous system malfunction. If pain has a neuropathic element it can be resistant to some commonly used treatments and may require a different approach.³⁶

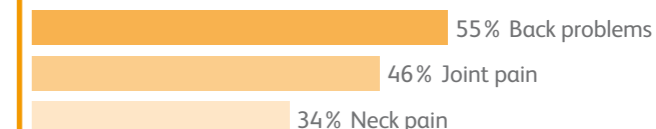
The back is the most common location for pain, according to market research conducted in five European countries in 2010, accounting for 70% of cases of severe pain, 65% of moderate pain and 52% of cases of mild pain.¹⁰ These findings mirror a recent survey from across Europe, which listed back problems as most common, followed by joint pain and neck pain.³

People with chronic pain face a variety of treatment options which may often be focused primarily on management of the key aspects of the patient’s primary disease. The complexity of measuring pain together with its many different manifestations can make it difficult to establish a specific diagnosis as to the root cause of an individual’s pain or how best to manage it. As a result health care for people with chronic pain can be fragmented and identifying an optimal treatment approach may take considerable time.^{3,37}

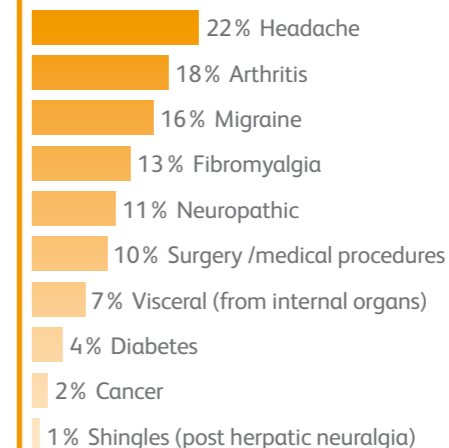
The vast majority of chronic pain patients identify more than one cause for their pain, with some identifying up to seven different causes.

Chronic Pain Origins³

Most common causes:



Other common causes:



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Living with chronic pain

People with chronic pain can find interacting with the healthcare system complicated and stressful, and often results in high use of healthcare services and unrelieved pain.³⁷ The pathway for people with chronic pain through the healthcare system can be lengthy, convoluted and inefficient with many patient experiences testifying to this.

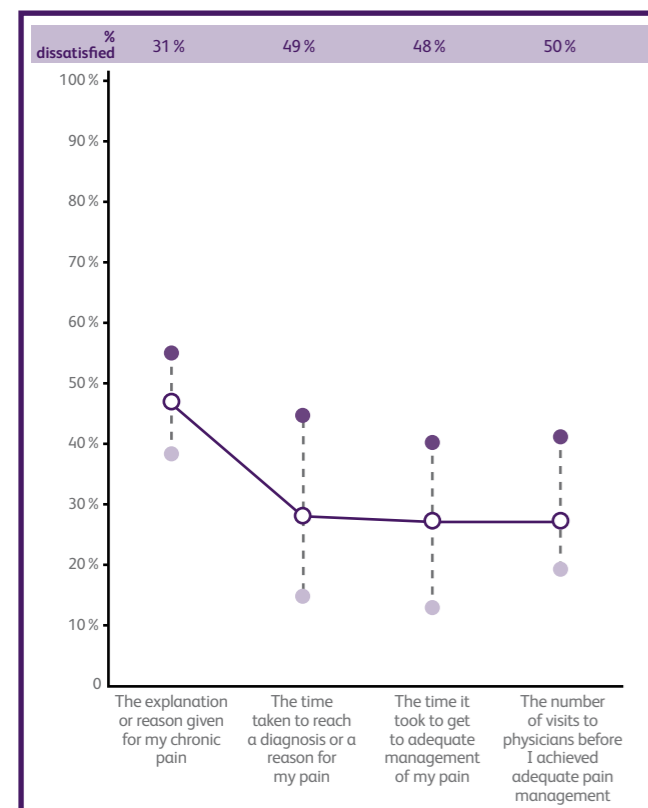
In a recent survey of people with chronic pain from around Europe, a quarter (26%) of people had to wait up to five years to receive a diagnosis or reason for their pain and a further 11% waited longer than this. Nearly half those surveyed were dissatisfied with the time it took to reach a diagnosis (49%), to get adequate management of their pain (48%) or the number of visits to the doctor it took to achieve adequate management (50%).³

The number of visits to a healthcare professional was also high, an average of nearly 7 visits a year, with 22% having to make 10 visits or more. Despite this, a significant 38% of people reported that their pain was not adequately managed.³

Chronic pain treatment – Satisfaction of diagnose

Q. Please indicate on a scale from 1 to 5 (where 1 is 'completely dissatisfied' and 5 is 'completely satisfied') how satisfied you are with each of the following aspects? scores are top 2 boxes

Satisfaction of diagnose (top 2 boxes) – Overall

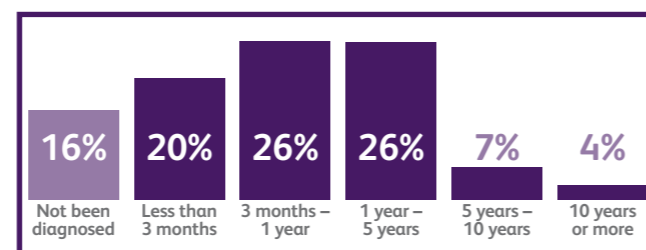


Chronic pain treatment – Time until diagnose

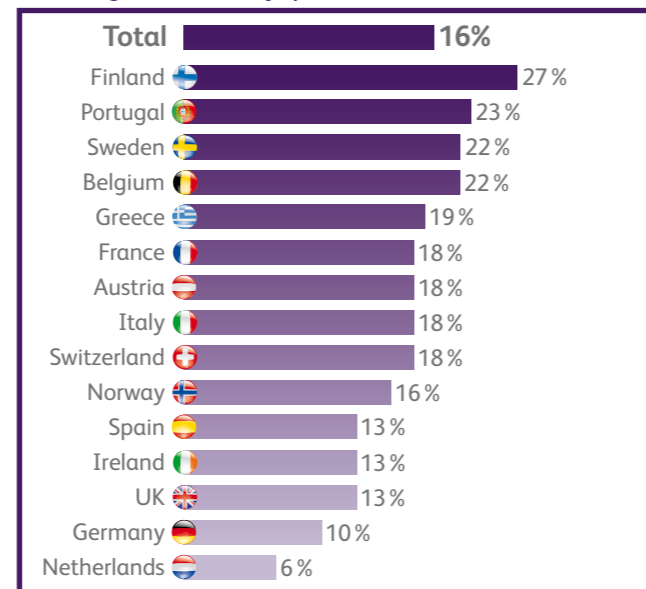
Though 46% is diagnosed within the year, some had to wait much longer (11% waited for 5 years or longer before diagnose) or are still waiting (16% is not been diagnosed yet)

Q. How long was it from the time you first sought help for your pain to the time when you were given a diagnosis/reason for the pain?

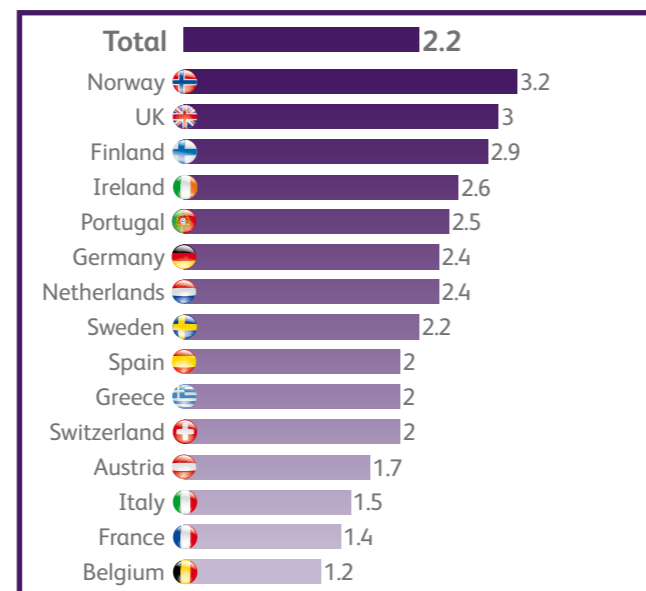
Time until diagnose – Overall



% not diagnosed – country split



Time until diagnosis (years) – country split



Chronic pain treatment – Time until adequately managed

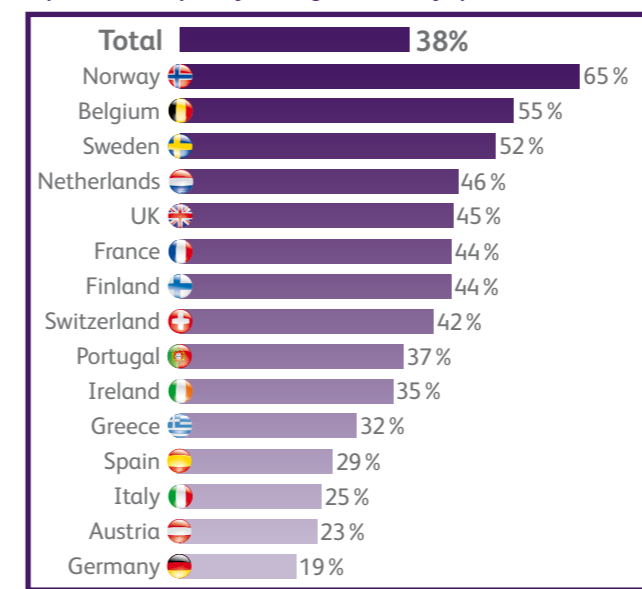
Though 35% mentions that pain is adequately managed within 1 year after diagnose, a staggering 38% states that their pain is not adequately managed!

Q. How long was it from the time you first sought help for your pain to the time when you felt your pain was adequately managed?

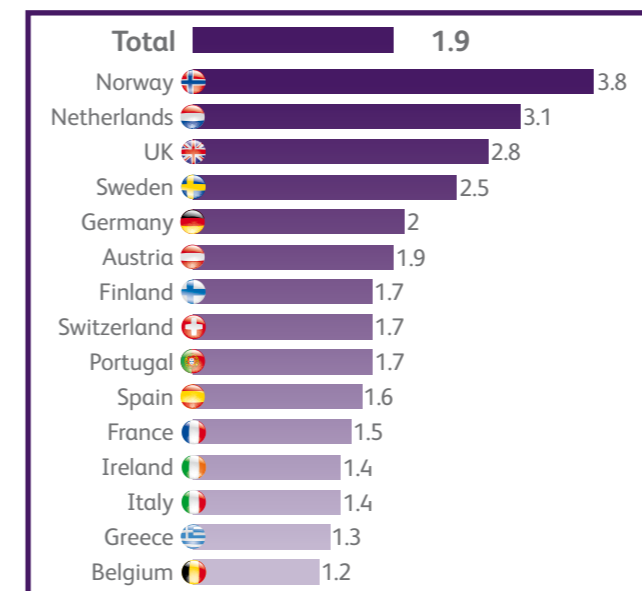
Time after diagnose before adequately managed – Overall



% pain not adequately managed – country split



Time after diagnose before adequately managed



A Personal Perspective – Paula's story

Paula from Ireland has suffered chronic pain in her lower back for more than ten years. "My first stop when I got the chronic pain was obviously my GP and for five to six years it was a case of back and forth to the GP and the orthopaedic surgeon, to GP, to another orthopaedic surgeon, to GP and really getting nowhere," she says. Eventually she was referred to a pain management clinic where a pain specialist diagnosed chronic pain. Paula says: "He was the first person in the five or six years who said to me, 'I think I know what's wrong with you.' I felt that nobody believed me for so long; that was the first glimmer of hope I had."

A Personal Perspective – Aneka's story

Thirty-five year old Aneka from The Netherlands suffered from severe chronic pain caused by a blockage of the sacro-iliac joint (sacro-ilitis). Her quality of life had decreased significantly and it was impossible for her to sit or stand for longer than 15 minutes. She followed the convoluted referral pattern from GP to the neurologist, to exclude a herniated disc, back to the GP; she was then referred to a rheumatologist, and back to her GP. No clear cause for her pain could be found, so she was told it was probably psychosomatic and advised to see a psychologist. In the mean time, she had lost not only her job, but also her confidence in doctors. As the cause remained unexplained, no doctor was willing to refer her to a pain clinic.

Living with chronic pain

The Emotional Toll of Chronic Pain

Chronic pain can have a devastating impact on individuals' lives. It can limit ability to participate in work and social life, shattering confidence and impairing quality of life.^{1,3} Particularly worrying aspects of chronic pain are the associated risks of depression and suicide.³⁸ People report that chronic pain can have no limits and can repressively permeate all aspects of their existence: social, practical, and emotional.³⁹

The lack of public awareness of chronic pain and its impact is well recognised by patients.³ This leaves people ill-equipped to seek help or take appropriate action to manage their condition from its onset.

More than a quarter (27%) of individuals with chronic pain were found in one survey to suffer in silence without seeking medical help; over a third of these (38%) were in constant pain or experienced it daily.⁴⁰

A Personal Perspective – Niall's Story

Niall Finn from Cork in Ireland has suffered chronic pain induced by a spinal cyst steadily compressing his nerves. He frequently suffers cramping, burning, muscle twitching and very strong skin crawling sensations. "The epicentre might be in my spine but it shocks my entire nervous system, even in places where it doesn't seem like it should," he says. With each day Finn finds it a struggle in self-control to deal with his pain, but he tries to hide his condition from others. "I don't talk about my pain as people can't see it so they don't understand it," he says.

The Devastating Impact on Quality of Life

The substantial impact that chronic pain has on quality of life is often overlooked. Latest data from the Pain Proposal patient survey tells us that over a quarter (27%) of people with chronic pain feel socially isolated and lonely because of their pain, with half (50%) worrying about the effect of their chronic pain on relationships with other people and 29% worrying about losing their job.³

65% of those with severe pain feel their general activities are impaired due to their pain.¹⁰

Impact on daily functioning & mental wellbeing

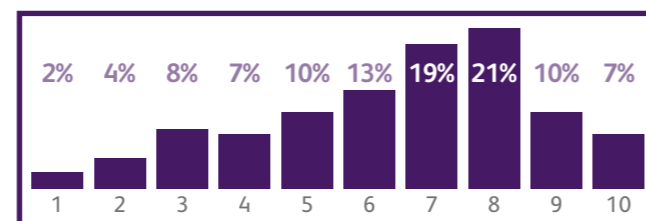
Untreated chronic pain impacts on people's emotional and physical health, and as a result, their ability to work productively and engage in family life is restricted.¹ Half of European chronic pain sufferers felt tired all the time and 40% felt helpless, or unable to think or function normally. Pain was also found to impact on everyday activities, with half of people less able to take exercise or sleep.¹

Chronic pain – impact chronic pain affecting daily life

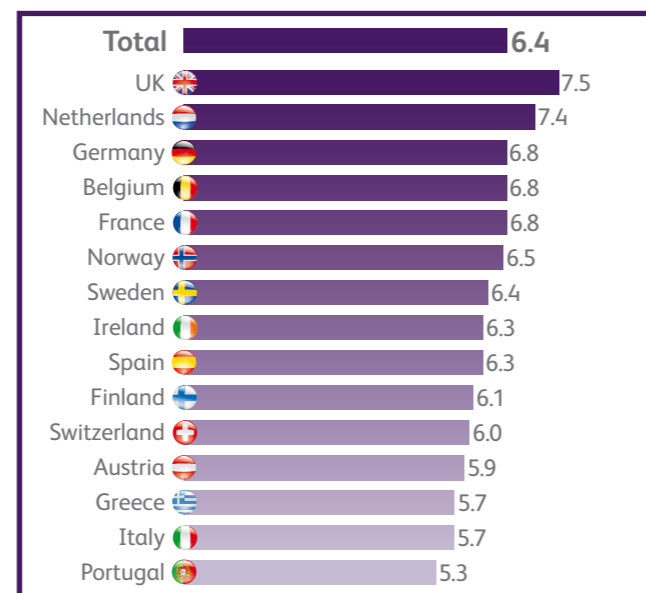
Chronic pain is not only impacting work life, social life is also impacted to quite an extent (on average 6.5 on 10 point scale). UK (7.5) and the Netherlands score highest, Austria (5.9) and Italy (5.7) lowest.

Q. In the past year, how much did your chronic pain affect your ability to do your regular daily activities and the things that you enjoy?

Level of chronic pain affection daily life – Overall



Level of chronic pain affecting daily life – country split



The risk of death by suicide has been shown to be at least double in chronic pain patients compared to those without chronic pain. (Tang 2006) Nearly one in six chronic pain sufferers in a European survey said that their pain was sometimes so bad they wanted to die. (Breivik 2006)

Impact on Relationships

Surveys show one quarter of chronic pain sufferers feel that they couldn't take as much care of themselves or others as they would have liked.¹ Twenty seven per cent said that they were less able or unable to maintain relationships with friends and family, 30% were less able to maintain an independent lifestyle and 19% were no longer able to have sexual relations.¹

Impact on Relatives

There is also evidence of a wider impact on those who look after or know someone with chronic pain⁴¹ and new European data shows that 36% of people with chronic pain agreed that their chronic pain has a negative impact on their family and friends.³

Chronic Pain Impact – Social Effects

Q Please indicate on a scale 1 to 4 (where 1 is disagree completely and 5 is agree completely) how strongly you agree with the following statements? scores are top 2 boxes

Social effects – Overall



A Personal Perspective – Lucy's story

The first symptom that Lucy, a patient in Portugal, experienced at the start of her chronic pain journey was mild hand joint pain while performing basic daily activities. The pain became more frequent and, a few months later, extended to other joints. She was only 27 years old when she was diagnosed with rheumatoid arthritis. Her pain and stiffness was so intense that, sometimes she was unable to get up in the mornings. For ten years, the disease worsened progressively. Medication and physiotherapy were unable to halt the progress of the arthritis. Lucy was hospitalized several times and was subject to a number of surgical procedures. Meanwhile, she had to keep working because she was too young for retirement, even though working was becoming increasingly difficult. It was not until 10 years later when Lucy was 37 that she took early retirement. Now 46 years old she struggles to survive on her small pension. Although she takes nearly 30 pills daily and goes to physiotherapy every day – biological medication and hydrotherapy help her control her pain. With no family support, she depends on a helper to carry out activities of daily living. Fortunately, she can also find support at the National Association of Rheumatoid Arthritis Patients (ANDAR) that she considers to be her own family now. After 20 years of pain, she expects to live now with a much better quality of life.

Living with chronic pain

Perceptions of Pain

Public views around chronic pain are not always sympathetic and the subjective nature of pain, and difficulties in expressing it, may lead to doubts as to its severity. A recent survey shows that 41 % of those living with chronic pain feel that people often doubt the existence of their condition.³

Despite the fact 80 % of people living with chronic pain are keen to be active members of society, a quarter have been accused of using their chronic pain as an excuse not to work and only 27 % feel their employer has been understanding about their chronic pain.³ It is perhaps unsurprising that two-thirds (62 %) of those surveyed feel that public understanding and awareness of chronic pain are low.³

People with chronic pain need confirmation that their chronic pain is “real” and want to feel empowered through access to consistent and reliable information.³⁷ There is a need for improved communication between patients and HCPs and for evidence based resources for chronic pain sufferers and their families to ensure effective management.³⁷ One study highlighted that people with chronic pain are often reluctant to return to their physician for further advice or treatment when their prescribed medication was ineffective, with fewer than 40 % choosing to return to their doctor.⁴²

“In my experience many patients are reticent in asking for help for their chronic pain and they see it as a burden that they have to put up with. A common misconception among patients is that doctors are only able to prescribe painkillers that don’t work. A lack of awareness of the increasing treatment possibilities keeps the patient away from his doctor and a lack of understanding and empathy drives patients and doctors further apart. Dr Kees Vos, Primary Care Physician, Spijkenisse and Department of General Practice, Erasmus University, Rotterdam

Advice, information and support are available to people with chronic pain through a range of patient advocacy groups across Europe. However there is a need to bring these important groups together to make it easier for patients to navigate and access the support available for them. If the general public is better educated about chronic pain then not only will patients be met with more understanding from those around them but people will be better able to recognise symptoms. With better education and recognition comes more accurate diagnoses and the potential for greater self-management.

The media and online channels can play an important role in raising the awareness of chronic pain and ensuring that people affected know where to go for support and information. Dr Kees Vos, Primary Care Physician, Spijkenisse and Department of General Practice, Erasmus University, Rotterdam

There is growing recognition of the need to champion the rights of people living with chronic pain with several complementary initiatives at national, European and international levels. IASP recently issued the Declaration of Montreal at the 13th World Congress on Pain, with healthcare providers and researchers calling for access to pain management as a fundamental human right.⁴³ At a National level, Chronic Pain Ireland has issued its own Charter of Rights, which has, in turn, been used as a basis for a European Bill of Rights.⁴⁴



The “Can You Feel My Pain?” Awareness Raising Initiative⁴⁵

The “Can You Feel My Pain?” campaign has been developed to give a voice to people living with chronic pain and drive change to ensure the **right patient** receives the **right management** and treatment at the **right time**. There are three main elements to the campaign: a Bill of Rights, a photography initiative and the sharing of experiences by people in chronic pain. The Bill of Rights draws upon content from the European Charter of Patients’ Rights and Chronic Pain Ireland’s Charter of Rights.

To encourage people across Europe to sign up to the Bill of Rights, and to raise awareness of chronic pain, social media channels such as Facebook have been employed to maximise the opportunities presented by the internet.

The “Can You Feel My Pain?” campaign has been developed by patient advocacy groups and citizen organisations across Europe in partnership with Pfizer.

1 Right to be Understood

For chronic pain to be understood and accepted as a condition by:

- the general public
- employers (with appropriate changes made to encourage continued working)

2 Right of Access to Information

To be provided with accurate and improved information about their chronic pain

3 Right to Professional Support

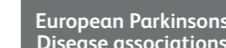
To have access to healthcare professionals who have been adequately trained and fully understand chronic pain; specifically how to diagnose and appropriately manage the condition to limit it worsening

4 Right to Early Intervention and Optimal Pain Management

Access to healthcare professionals who can help identify the best possible pain management and support for each patient at the earliest possible stage

5 Right of Pain Relief as a Fundamental Human Right

Declare “The Relief of Pain’ a fundamental human right echoing the core principles set out by ISAP, EFIC and the WHO at a conference in Geneva on 11th October 2004.



Annelies Vanbrabant, De Viaamse Pijnliga
Harry Kletzko, Dutsche Schmerzliga
Melody Ross, Cittadinanzattiva
Ditte Kuijpers, Borstkanker Vereniging Netherlands
Martin Aebi, VSP Vereinigung Schweizer Schmerzpatienten
Liisa Mikkonen, [insert organisation]

Chronic Pain: A High Cost to Europe

How Much Does Pain Cost Us?

“I believe that we are not using the resources that we have to treat chronic pain efficiently. I think that there are better ways to use resources and save money in the system.”

Professor Vazquez, Executive Director FEDEA

“Quote from” Professor Trueman to be inserted

Chronic pain costs Europe billions of Euros: estimates of the total annual cost of leading causes of chronic pain such as back pain and musculoskeletal disorders have ranged from €1.1bn in Finland to nearly €50bn in Germany.^{4,6} While a lack of data makes it hard to estimate the total cost of chronic pain across Europe, the available estimates imply an overall burden in the hundreds of billions – perhaps as high as €300bn at the upper end for the whole of EU (extrapolating the results of the German study).⁴ This is consistent with estimates of chronic pain costing around 1.5% – 3% GDP.^{5,6}

While the burden on healthcare resources – the direct cost – of chronic pain is significant, it has been estimated that as much as 90% of the burden falls on the broader society: employers, taxpayers (through welfare payments, for example), patients and their families.⁸ By any estimate, the scale of these indirect costs greatly exceeds the direct costs of managing pain, and ensures that even incremental increases in the effectiveness of pain management reap large economic rewards.

Given the scale of the economic challenges facing Europe, it has never been more important to tackle inefficiencies in pain management, thereby realising savings to health budgets and a productivity boost to Europe’s economies. Examples from Europe show that expenditure on chronic pain management can be cut while improving services and patient satisfaction.¹⁴ Moreover, given the direct relationship between chronic pain and both incapacity and workforce productivity, we can reasonably expect the broader economic benefits of better pain management to be felt in the near to medium term. The economic case for prioritising pain management is therefore compelling. The need is for comprehensive action to realise the benefits that have been demonstrated in a number of trailblazing examples around Europe on a more ambitious scale.

Direct Costs of Chronic Pain

Direct costs of chronic pain encompass the cost of medications, other treatments or interventions and the healthcare staff time needed to administer them. Pain accounts for a significant proportion of healthcare resource. A Finnish study, for example, has found that pain accounted for 40% of GP consultations.⁴⁶ Patients with chronic pain are greater users of both primary and secondary care health services than those without long-term pain⁴⁷ and there is a direct relationship between pain severity and health resources consumed.⁴⁸

Pain Accounts for Significant Healthcare Expenditure

Past estimates have pointed to direct costs of pain of around €187million for Belgium,⁷ \$368million (€289 million) for the Netherlands, rising to over £1.6billion (€1.9 billion) for the UK.⁹

The costs of drugs for managing pain in England alone in 2009, including over 57 million prescriptions for analgesics, amounted to £449 million (€540 million).⁴⁹ The vast majority were for non-opioids (38 million prescriptions at a cost of £150 million (€180 million)⁴⁹ and NSAIDs (16 million prescriptions at a cost of £96 million (€115 million).⁴⁹ In addition to prescription drugs, an estimated 23-59% of people in England take non-prescription drugs for their pain.⁴⁰

Nonetheless, studies have consistently pointed to the volume of consultations with healthcare professionals, particularly specialists, as the most significant driver of costs attributable to chronic pain.⁶ A 1998 German study estimating the annual direct costs of back pain to German health services at DM10 billion (€4 billion) concluded that the cost was primarily for medical consultations rather than medication.⁵⁰

New data from a survey carried out in France, Germany, Italy, Spain and the UK demonstrate the significant burden that chronic pain places on healthcare resources; 93% of people with chronic pain have visited a healthcare professional in the last month. This is compounded by the frequency of visits to healthcare professionals; those with severe pain have visited healthcare professionals an average of 13 times in the past six months, while this number remains high in those with moderate and mild pain, visiting healthcare professionals 9 and 6 times respectively. Furthermore, 25% of those with severe pain had visited an emergency room in the past six months and 22% had been hospitalised due to their pain.¹⁰

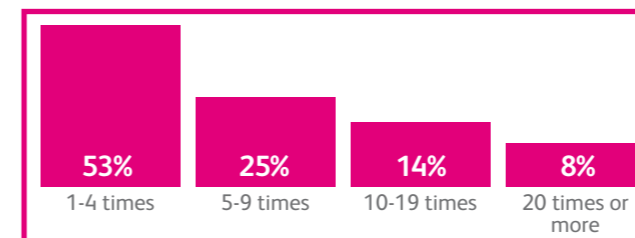
Ineffective Pain Management is Generating Avoidable Costs

Much of the available evidence on the direct costs of pain indicates that ineffective or inefficient management of pain is responsible for a significant proportion of costs. A UK study in 2002 estimated there were 4.6 million primary care consultations per year involving chronic pain.¹¹ This consultation time amounted to employment of 793 full-time GPs at a cost of approximately £60 million (€73 million). The study highlighted inadequate management with use of ineffective or poorly tolerated medications as a major factor in the number of consultations.¹¹

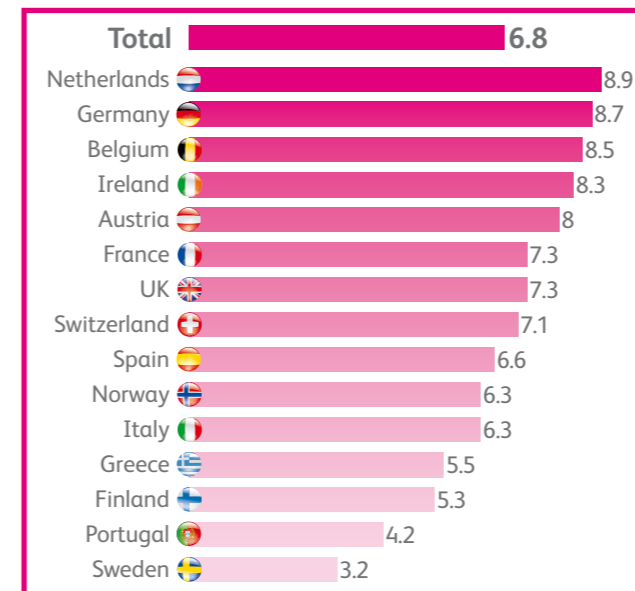
The lack of clear pathways for those with chronic pain is also likely to be playing a significant role in the accumulation of costs. Chronic pain spans a wide range of medical specialisms, which can result in a fragmented approach to management, where no one group is accountable for improvements or outcomes. Field research with primary care physicians across Europe indicates significant uncertainty around referrals from primary to secondary care with over a third (36%) of primary care doctors lacking confidence in knowing when to refer a person with chronic pain to a specialist or which specialist to refer a patient to.¹⁷ Countries such as Norway, in which a significantly higher than average proportion of primary care physicians reported uncertainty over which specialist to refer a patient to, also showed relatively high rates of early referral.¹⁷ It can be inferred that inappropriate referrals to specialists – a key driver of costs – are likely to be taking place. These findings indicated that direct costs are higher than they need to be. The fact that relatively high levels of uncertainty over referral and high rates of early referral seem to correspond to relatively low levels of pain management training for GPs indicates that education may have an important role to play in controlling the direct costs of pain. Indeed 85% of primary care physicians express a desire for more training to equip them better to manage chronic pain patients.¹⁷

Q How many times in the last year have you visited a healthcare professional specifically due to the chronic pain you feel?

Number of times healthcare professional visited last year – Overall



Number of times healthcare professional visited last year – Country split

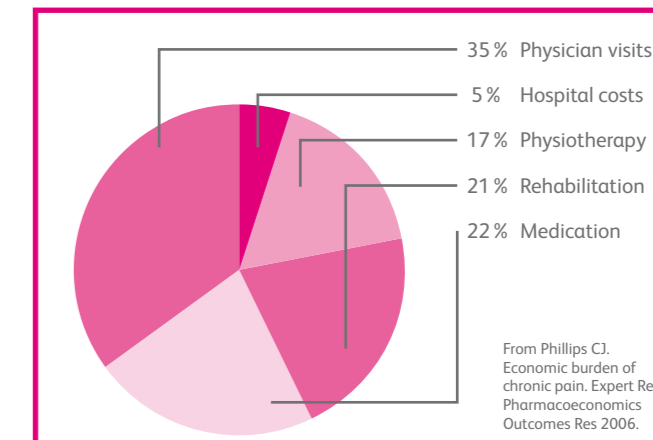


Summary of direct costs of pain and pain management

- Costs of interventions and therapies for treating pain (e.g. drug and costs of therapists)
- Costs related to ineffective interventions (e.g., additional general practitioners consultations)
- Costs incurred by health services, patients and their families due to lack of appropriate facilities locally
- Costs resulting from inappropriate self-medication and treatment by patients (e.g., costs of treating overdoses)
- Costs of treating and preventing adverse events that arise as a result of prescribing decisions (e.g., costs of treating NSAID-induced gastrointestinal bleeds)

Adapted from Phillips CJ. Economic burden of chronic pain. Expert Rev. Pharmacoeconomics Outcomes Res 2006; 6(5); 591–601.

Direct costs of backache in Germany



Chronic Pain: A High Cost to Europe

Indirect Costs of Chronic Pain

The direct medical costs of chronic pain management are substantial but are only part of the problem when compared with the impact of indirect costs attributable to chronic pain on the overall economy. Major indirect costs include the cost to the individual and society (notably employers) of lost productivity, and the cost of social security welfare payments. Indirect costs may also include travel expenses of patients seeking treatment, and the cost of relatives sacrificing work and leisure when required to take care of a relative suffering disabling chronic pain.

Taking back pain as an example, a UK study reports direct healthcare costs as £1,632 million (€1,947 million) compared to the much larger £10,668 million (€12,725.12 million) attributed to informal care and production losses.⁹ It has been estimated that as much as 90% of the burden of chronic pain can be attributed to indirect costs.⁸

The impact of chronic pain should not, however, be viewed simply in economic terms. Chronic pain has a major detrimental effect on the quality of life of the millions of people with chronic pain and their families in Europe. Without adequate treatment people with chronic pain are often unable to work or even to perform the simplest of tasks. As a consequence, they often endure psychosocial as well as physical hardship.⁵¹

Summary of indirect costs of pain management

- Costs of disability benefits resulting from individuals' inability to work
- Costs to economy of reductions in productivity and absenteeism
- Costs of providing social care and support to people suffering with pain (e.g., home care and respite care)
- Costs of informal care provided by families (e.g. loss of earnings)
- Costs of lower quality of life for patients and their families
- Travel expenses of patients seeking treatment

Despite the significant impact of chronic pain on economies across Europe, evidence on indirect costs is variable. Methods of calculating indirect costs and the types of costs included vary significantly across studies. There also appears to be a notable bias towards Northern Europe as regards the geographical scope of comprehensive studies of pain costs: analyses focussing on the UK, Ireland, Germany the low countries and Scandinavia are far more evident in the literature than analyses of Southern or Eastern European countries. As a result, the task of estimating the total burden of chronic pain across Europe is not an easy one.

There is a clear need for further research to assess the full impact of chronic pain. It is nonetheless evident that the indirect costs of pain are a major drag on European economies. Key studies agree that the cost to society of chronic pain amounts to billions of Euros, even in the smaller European economies such as Finland.⁶ Societal cost estimates reach figures as high as €50bn a year in Germany for back pain alone.⁴ Extrapolated to the 500m population of the EU, this finding would point to a total cost approaching €300bn, even without taking into account other causes of chronic pain. The map below presents a selection of estimates of the direct and indirect costs of pain in European countries.

Reference – Sheehan J, McKay J, Ryan M, Walsh N, O'Keefe D. (1996) What Cost Chronic Pain? Irish Medical Journal 89⁵²
Year – 1995
Country – Ireland
Type of Pain – Chronic non-cancer pain
Scope of study – Cost of 95 patients surveyed at a multidisciplinary pain clinic. Costs include those to health service, social welfare payments received and lost earnings. Costs from chronic pain are the totalled over the life of patient, from onset to referral to the clinic. Costs do not account for the prevalence of pain in society.
Cost estimate – Total costs of £1.9 million for 95 patients at the time of referral
 Mean cost per patient: £19,917 for all patients up to £32,755 for patients with chronic non-malignant pain.

Reference – Mantyselka, PT et al. Direct and indirect costs of managing patients with musculoskeletal pain-challenge for healthcare EJM (2002) 6: 141-148⁶
Year – 2002
Country – Finland
Type of Pain – Musculoskeletal Pain
Scope of study – Covers visits to 28 General Practitioners throughout Finland over 4 separate weeks (one in each season), totalling 1123 patient visits. Costs include consultations, investigations, treatment, referrals and sick leave.
Cost estimate – Mean cost per patient visit: €534
 Range €42 to €6952
 10% of patients generated 64% of total costs.
 Implied total annual national cost (Finland): €1.1bn, or 3% GNP

Reference – van Tulder MW, Koes BW, Bouter LM (1995) A cost-of-illness study of back pain in the Netherlands. Pain 62:233-240.⁸
Year – 1991
Country – Netherlands
Type of Pain – Back Pain
Scope of study – Direct (healthcare expenditure) and indirect (productivity loss) costs of back pain in the Netherlands
Cost estimate – Total annual cost: \$4.967 bn
 Direct Costs: US\$367.6 million.
 Indirect costs: US\$4.6 billion; (US\$3.1 billion due to absenteeism and US\$1.5 billion to disablement)
 Indirect costs account for 93% of total cost

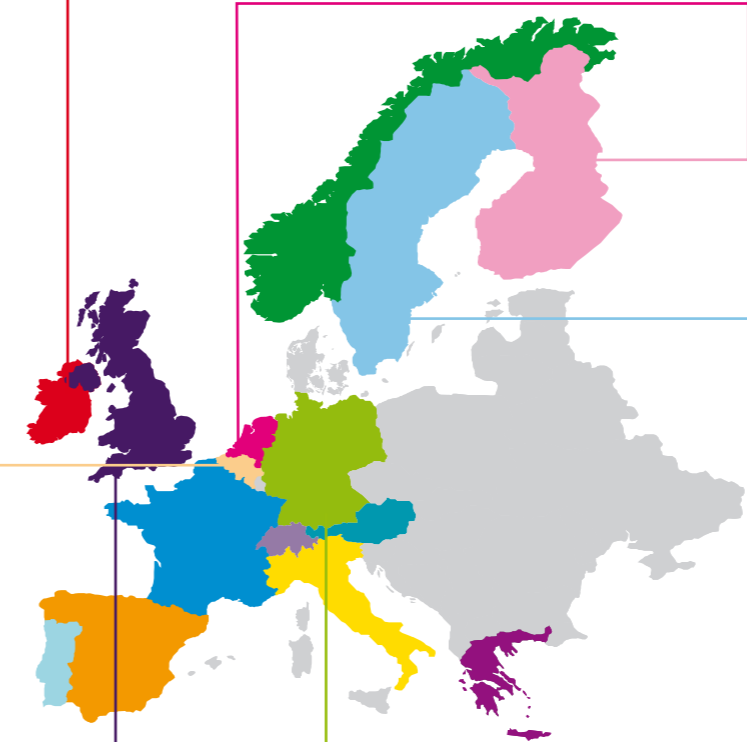
Reference – Ekman, F. Johnell, O. Lidgren, L. (2005). The Economic cost of low back pain in Sweden in 2001. Acta Orthopaedica 2005; 76 (2): 275-284⁵⁴
Year – 2001
Country – Sweden
Type of Pain – Lower Back Pain
Scope of study – Measured direct treatment costs and indirect costs from lost productivity. Prevalence, absence and treatment utilisation data were sourced primarily from national level sources and costs were estimated in a top down approach.
Cost estimate – Total annual costs: €1.86bn.
 Indirect costs: €1.55bn.

Reference – Wenig CM et al. Costs of back pain in Germany. EJM (2008) 13(3):280-6⁶
Year – 2008
Country – Germany
Type of Pain – Back Pain
Scope of study – Total societal costs of back pain in the German population. Costs included direct treatment costs and workplace absence costs.
Cost estimate – Total annual cost: €48.9 bn

Reference – van Zundert, J. van Kleef, M. 2005. Pain Practice. 5(3):179-189⁷
Year – 1999 and 2001
Country – Belgium
Type of Pain – Back Pain
Scope of study – Measures of the cost treatments for back pain based on health treatment utilisation data and also the cost of absenteeism from national workplace surveys. Loss of income, patient costs and costs of care not included.
Cost estimate – Total annual cost: €1.80bn
 Direct costs of back pain treatment = € 187.0m
 Costs of absenteeism = €992.6m

Reference – Slead et al. The economic impact of chronic pain in adolescence: methodological considerations and a preliminary cost-of-illness study. Pain 199, 183 – 190⁵³
Year – 2004
Country – UK
Type of Pain – Chronic pain in adolescents
Scope of study – Surveys used to assess direct, indirect and intangible costs to society from 52 families with adolescents suffering from chronic pain. Data was used to extrapolate cost data to all adolescents suffering from chronic pain in the UK.
Cost estimate – Total annual cost: £3.84million
 Mean cost per individual per year: £8,000

Reference – Maniadakis N, Gray A. The economic burden of back pain in the UK. Pain 84, 95-103 (2000)⁹
Year – 1998
Country – UK
Type of Pain – Back Pain
Scope of study – Cost-of-illness study for back pain in the UK. Attempts to assess overall societal costs including costs to patients, NHS and the economy. Draws on prevalence data and treatment utilisation data from national surveys conducted by the Office of Populations Censuses and Surveys.
Cost estimate – Total annual cost: £6.65bn (friction cost method) – £12.3bn (production loss cost) million
 Direct Cost: £1.632bn



Chronic Pain: A High Cost to Europe

Chronic Pain Imposes a Heavy Burden on Employers and Employees

Many of the indirect costs associated with chronic pain are related to the workforce. New data suggest that, on average, 21 % of Europeans with chronic pain are unable to work at all as a result of their chronic pain and, of those that are able to work, 61 % state their employment status is directly affected by their condition.³ This is reinforced by another European survey which found that a fifth (19 %) of those with chronic pain have lost their jobs as a result of their condition.¹

Interestingly, the research revealed dramatic apparent disparities between European countries in the proportion of chronic pain patients who class themselves as unable to work due to chronic pain, from only 1 % in Portugal to 42 % in the UK.³ While several factors could contribute to this finding, including cultural differences, one possible explanation is the generally higher workforce participation rate, particularly at older ages, in Northern European countries. This would support the plausible conclusion that later retirement will substantially increase the incapacity burden of chronic pain – and equally that chronic pain is a major obstacle to the changes in labour force structure (notably increased old age participation rates) that Europe needs to maintain productivity in an era of demographic ageing.

There is no doubt that chronic pain seriously reduces people's ability to work. A recent survey of UK employers found that back pain is the second most common cause of short term absence, and is one of the principle causes of long-term absence in both manual and non-manual workers.⁵⁵ New data from five countries in Europe shows that 27 % of people with chronic pain have been absent from work in the last seven days alone.¹⁰ Even when people do manage to attend work, loss of productivity or 'presenteeism' is a problem. Of those questioned in the 2010 survey, 54 % with severe pain, and 32 % of those with moderate pain felt that their overall work had been impaired due to their pain, impacting the individuals themselves, employers and the wider economy.¹⁰

This is supported by new data from across Europe showing that, on average, people with chronic pain are likely to take around 14 days off work due to their condition. In addition, people with chronic pain felt so impaired by their pain that it impacted on their ability to do their job for more than a quarter (28 %) of the time they were in work.¹⁰

Welfare Budgets Bear the Cost of Incapacity

The negative economic impact of chronic pain on capacity to work falls not only on pain sufferers and employers but also on government welfare budgets. Danish studies show that chronic pain sufferers are seven times more likely than other individuals to leave a job because of ill health and are less likely to return to employment.¹² In the UK musculoskeletal conditions are the most common reason for people to receive incapacity benefit. As many as 3000 UK citizens are added to the number receiving incapacity benefit each week; of these only 10 % ever return to work.¹³ Leaving paid employment to be dependent on welfare payments or family members also has obvious repercussions on household incomes and standards of living.¹³

As European populations age, we expect people to remain productive and work longer; but the likelihood is that the number of older people with chronic pain will continue to increase significantly.³⁵ This will put an even greater strain on those affected, their families, society, healthcare resources and the European economy.

Most people afflicted by chronic pain want to contribute to the economy and be active members of society.³ They are keen to disprove any perceived suspicions that they are malingering. Improvements in pain management that enable people with chronic pain to remain in work, and to work more productively, promise to have a significant impact both on workforce productivity and welfare dependency.

Meeting the Challenge: Improvements in Pain Management Can Save Money

Anecdotal evidence from people with chronic pain and healthcare professionals suggests that clinical pathways are complex and costly, involving inefficient referral between primary and secondary care and even within secondary care itself. Patient and Primary Care Physician Surveys conducted in support of the Pain Proposal appear to corroborate this. Only a quarter of European chronic pain patients are satisfied with the length of time it took to reach a diagnosis or achieve adequate management for their pain.³ Meanwhile over a third (36 %) of primary care doctors lack confidence in knowing when to refer a person with chronic pain to a specialist, or which specialist to refer a patient to.¹⁷

Evidence from the UK suggest that well-managed patients with chronic pain consume fewer healthcare resources (an estimated £1117, €1336 saving per patient per year).⁵⁶ The practical example of the Southampton Pain Clinic in the UK appears to validate this, with per patient cost savings of 35 %, largely driven by lower expenditure on GP visits and physiotherapy.¹⁵ These saving apply to healthcare costs alone: the savings to patients, employers and welfare bills documented above are not always considered when costing affordability of new healthcare strategies, but should not be overlooked.

Establishing a clear management pathway is one clear step that could be taken to improve the current situation. Clear guidance around appropriate referral and better co-ordination of care could help ensure that people with chronic pain see the right person at the right time.

By simplifying the route to diagnosis and effective treatment – intervening early to avoid costly complications – there is added potential to improve quality of life, save resources and boost the workforce.

Spotlight on... Benefits of the Multidisciplinary Approach

The Southampton Pain Clinic

The Southampton Pain Clinic in the UK has shown that problems of inappropriate referrals and poor patient access can be overcome through a radical service redesign based on chronic disease management principles. (Price 2006)

The emphasis has been to ensure that primary care practitioners have the appropriate skills and resources to manage the vast majority of patients. Only a few are taken into specialist care for treatment but that treatment has clear end points. (Price 2006)

Principal changes have been establishing treatment and referral guidelines for general practitioners, a care pathway stretching across primary and secondary care, effective triage of referrals and increased self-management programmes in the community. (Price 2006) Strong communication between primary and secondary care has been critical to the success of the service. (Price 2006)

The service has improved patient care with patient satisfaction at 90 %⁵⁷, reduced waiting times to consistently around six-to-eight weeks and reduced drug spending within the Trust.¹⁴ It has also been cost effective with cost savings per patient averaging £204.¹⁵

The cost effectiveness of the Southampton Pain Management Programme

Healthcare Resource	Before Pain Management Programme (£)	After Pain Management Programme (£)	Savings (£)
GP visits	307	197	109 (35 %)
Physiotherapy Units	124	45	78 (63 %)
Medication	153	137	17 (10 %)

Welsh Assembly Government. Designed for People with Chronic Conditions: Service Development and Commissioning Directives. June 2008¹⁵



Chronic Pain: A High Cost to Europe

Joined-up Government is Needed to Tackle 'Hidden' Costs

As demonstrated above, the costs to the public purse of chronic pain do not fall solely within the healthcare budget. Welfare expenditure in particular bears a heavy burden as a result of pain, both through incapacity and unemployment benefit and potentially the provision of local support services. Health budgets themselves are also often siloed, meaning that reductions in even the direct cost of chronic pain may primarily benefit parts of the health system other than those generating the savings. As has been shown, referrals to secondary care account for a major share of the direct costs of chronic pain, whereas the responsibility for better pain management often sits primarily within primary care.

Improved management of chronic pain – crucially in the current economic climate – promises to generate tangible savings for the taxpayer in the short term as well as the longer term. However, coordination both within the health service and within government as a whole – in many countries between levels of government (central, regional and local) as well as government departments (for instance health and welfare) are likely to be critical to realising these savings. Such coordination can be challenging, but there are examples in Europe of innovative approaches to budgeting supporting better management of chronic pain, notably in Sweden (see box). Wider adoption of such approaches is likely to be key to releasing the savings across government, and indeed society, promised by better pain management.



Spotlight On... A Rounded Approach to Management

The Dutch Pain Clinic Carousel

The Netherlands has made a significant breakthrough in patient assessment with the introduction of the Erasmus University Pain Carousel, a multidisciplinary model implemented in the Erasmus Pain Clinic.

The principle of the model or 'pain clinic carousel' is that a patient is seen on the same day by several physicians, enabling them to be diagnosed and receive treatment without having to make additional appointments on different days.

A patient is assessed and referred to the pain carousel by their GP, after which they have a consultation with a specialist (e.g. pain specialist or neurologist) and, in some cases, a second consultation with another doctor. It is then decided if they are suitable for the carousel. People who are deemed unsuitable are referred back to their doctor but may apply for a carousel at a later date.

If accepted they then see a range of different specialists in a short space of time and a number of lab tests will be carried out.

A consensus meeting is then held between specialists to decide on the best management plan for that patient.

This 'carousel' approach presents a more efficient process for patients, avoiding numerous trips to various specialists over a prolonged period of time. The disadvantages are that currently only one third of patients get accepted onto the carousel and there is a waiting time of around 6-8 weeks. Consequently many patients opt for private care at this stage.

Although there is still some work to be done to improve access to the model, it demonstrates what can be achieved through a consolidated approach to patient care.

Spotlight On... Making Better Use of Budgets

Swedish Rehabilitation Guarantee

The economic impact of chronic pain is felt across government departments and budgets, particularly healthcare and welfare budgets, but can also have a negative impact on the productivity of a country's workforce through absenteeism and presenteeism. The Swedish Government has taken an important step to address the impact of long-term conditions, including chronic pain on the workforce through budget reallocation.

The Swedish 'Rehabilitation Guarantee' scheme is one of a series of measures to provide more ways to return from sickness absence to work and thereby reduce the economic impact of chronic conditions such as pain. A rehabilitation chain has been introduced, where people's ability to work is reviewed regularly and they receive support in returning to work.

The scheme involves reallocation of funds from the central government budget to local county councils to provide medical treatment and rehabilitation for those off work on sick leave, to allow them to return to work and once again contribute to society.

The programme aims to provide patients with rehabilitation within 6-8 weeks of the start of sick

leave. County councils will be reimbursed per patient who begins rehabilitation such as physiotherapy or treatment interventions within the scheme. County councils, in collaboration with research organisations can also apply for additional funds for research projects to investigate the effectiveness of these treatment and rehabilitation efforts.

The Swedish government committed 600 million SEK in 2009 and SEK 1 billion in 2010 to the project. There is a maximum reimbursement allowed per county based on the county's population. Additional funds are available to county councils per patient completing treatment and should be used to implement organisational changes to establish a long-term rehabilitation system.

In practice, the availability of rehabilitation strongly varies between different regions, however there are some good examples. In Stockholm there are around 20 primary care clinics using multidisciplinary rehabilitation teams and the Swedish Council on Health Technology Assessment claim that there is strong scientific support for multi-disciplinary rehabilitation having better long-term effects compared to less comprehensive efforts

Spotlight on... getting people back to work

German Integrated Care Agreements

In Germany, integrated care agreements for the treatment of persistent back pain (enduring over several weeks) give patients access to early-onset combination therapy via sickness funds, rather than via primary care physicians. The scheme enables workers to regain their ability to work in 88 to 100 per cent of cases. However, these agreements are not widely available.

Physician Training is Paramount

“We know from studies that pain is not understood as well as it should be and that much needs to be done to raise understanding to the same level as chronic heart failure, COPD and diabetes.” Professor Huygen, Anaesthesiologist and Head of Erasmus MC Pain Clinic, Rotterdam

“One of the most important things we have learned from this project is the absolute necessity to achieve better education for healthcare professionals at all levels, doctors, nurses, physiotherapists and others – this is one of the greatest unmet needs.” Professor Varrassi, EFIC President, L’Aquila University

Healthcare professionals are the people best placed to help individuals with chronic pain, at all stages of their condition. However, although most patients see a GP first, only around half (53%) of PCPs are confident managing chronic pain. Forty seven per cent lack confidence in knowing when to change pain treatments and over half (54%) are not confident about what to do when a person still complains of pain.¹⁷

Because pain is subjective and difficult for patients to describe, in the absence of further training, primary care physicians find it difficult to understand patients’ experiences. This limits their ability to have useful conversations with patients⁵⁸ or uncover the type and cause of pain and, therefore, establish the best management approach.

Patients’ expectations of treatment may be unrealistic and need to be managed to avoid disappointment with treatment results.³⁷ Supporting healthcare professionals in setting appropriate pain management objectives with their patients could help achieve better outcomes (Woolf 2008).

Current levels of training and education do not always leave medical practitioners equipped to carry out best practice managing pain. The ability of physicians is also likely to vary across Europe because the number of hours in undergraduate medical school curricula devoted to managing chronic pain varies from country to country. Doctors themselves express a desire to receive additional professional training on the identification, treatment and management of chronic pain.¹⁷

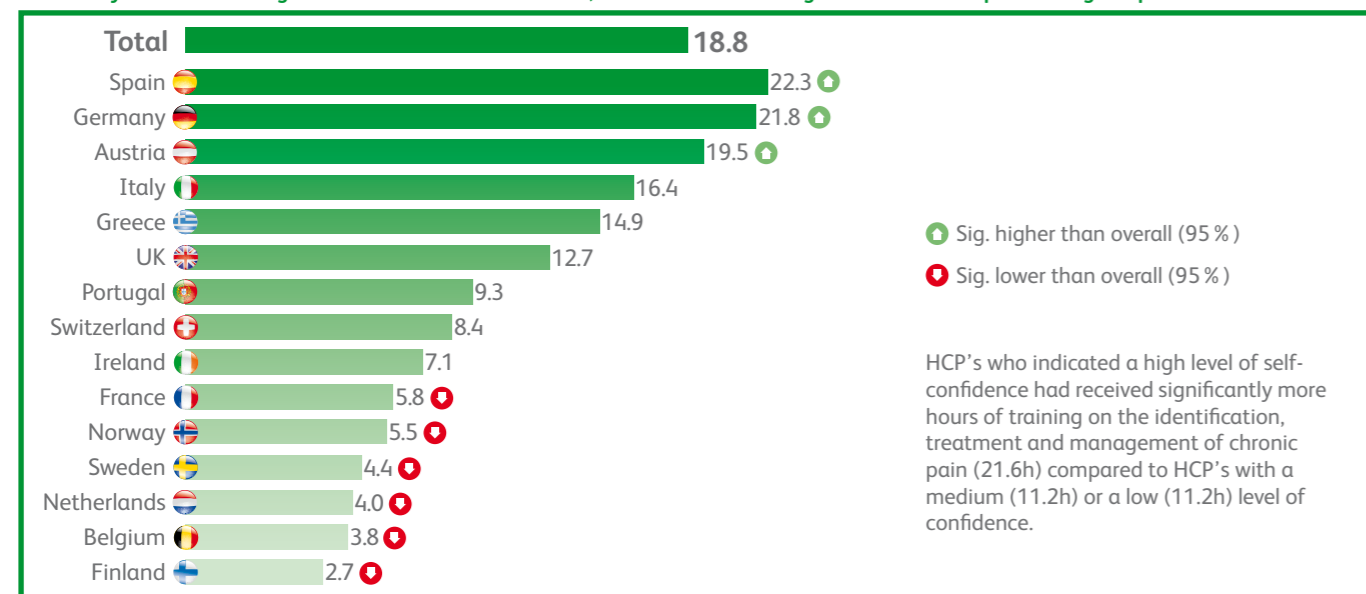
Inadequacies in pain-management training have been acknowledged since as far back as 1988 when IASP developed an outline curriculum on pain for medical schools to service as a flexible model to be used as a guideline.⁵⁹ But over 20 years later, training for undergraduate medical students in pain management continues to vary both in terms of teaching about effective treatments and management strategies, and in the imparting of interpersonal skills and knowledge on the human aspects of care. Some patients report that their doctors failed even to ask about their pain.¹

In 2009, the UK’s Pain Society advocated that healthcare professionals should study pain management as a dedicated curriculum and that this should be included as a core part of basic educational standards and quality assurance in training.¹⁶ Knowledge and competence in pain management should be assessed separately. The society recommended that knowledge and skills for pain management should be promoted in a multidisciplinary context and that availability of pain educational resources and models of good practice in undergraduate pain education should be identified and shared.¹⁶ A number of resources have been developed and this report supports the use of the EFIC pain curriculum in Europe.¹⁶ EFIC has also issued a call for specialist training in Europe.⁶⁰

There are instances, therefore, of European countries where specific training or recommendations have been implemented. However new data illustrates a desire on the part of most European doctors to receive additional training on the identification, treatment and management of chronic pain.

Surveys conducted for the Pain Proposal found that 85% of primary care physicians supported this stance. (Pain Proposal PCP survey) If examples of good practice can be identified and replicated across Europe there is the potential to improve consistency in the standard of training on offer and the management of chronic pain as a result.

How many hours of training received on the identification, treatment and management of chronic pain during the past 12 months



Spotlight On... Healthcare Professional Education

Specialist Pain Diploma – Austria

The pain diploma (Diploma Spezielle Schmerzmedizin) was introduced by the Austrian Medical Chamber (“Österreichische Ärztekammer”) at the beginning of 2008. The target groups for acquiring this certificate include both general practitioners and specialists, and particularly doctors working at pain centres or intending to work there.

The diploma’s underlying curriculum aims at improving the knowledge and skills of doctors working in the field of diagnosing and providing treatment to patients suffering from acute or chronic pain.

Specific education and training in pain management is now part of a broader further-training initiative and scheme offered and administrated by the Austrian Medical Chamber; it comprises theoretical as well as hands-on training with a 120-hour course plus 80 hours of practical work.

Since 2008, a number of doctors have acquired the pain diploma; but the Austrian authorities are not complacent. They acknowledge there is a long way to go until doctors possessing the diploma and its related specialised knowledge and expertise are so widely available as to be able to meet the Austrian population’s need for treatment of chronic pain.

“Pioneering training programmes are available in Austria with the recently introduced pain diploma and the post-graduate programme in interdisciplinary pain treatment we have established a sound basis. Now it is imperative to promote establishing pain management services throughout Austria.”

Prof. Burkhard Gustorff, a member of the Pain Proposal and Head of anaesthesiology and intensive care at the Vienna Wilhelminenspital, Professor Gustorff is also the scientific head of the first European post-graduate programme on interdisciplinary pain treatment at the Vienna Medical University

Physician Training is Paramount

Improved Clarity Around Guidelines is Needed

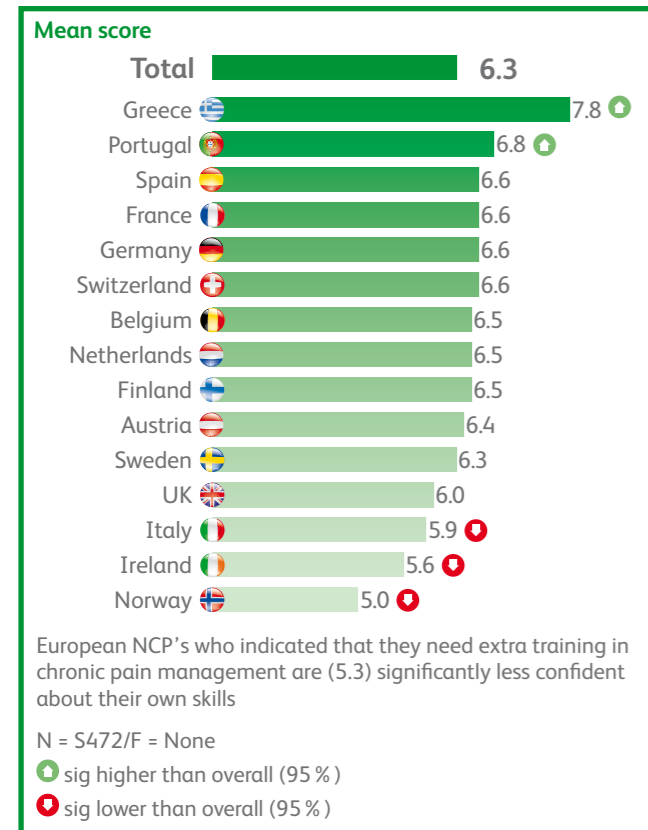
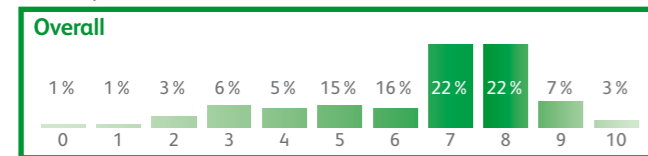
Specific clinical guidelines for managing chronic pain are sporadic. A WHO Steering Committee published a report on the scope of guidelines for chronic non-malignant pain in adults in 2008.⁶¹

Not all European countries have devised their own national guidelines. Usually, where advice on persistent pain does exist in Europe, it is incorporated in the management guidelines for specific medical conditions without reference to advice from specialist pain management bodies. As a result, advice on pain management may lack detail and leave potential for confusion. Doctors may not feel confident in understanding and using existing guidelines revealing a need for assistance in navigating what is currently available.¹⁷

Where guidelines do exist, implementation can be challenging. Unlike higher priority areas, such as diabetes or cardiovascular disease, managing pain is not incentivised and targets may not be set. In addition, international guidelines may be less relevant at a national or even regional level. Country-specific guidelines could encourage uptake and result in a more tailored approach.

Confidence level – understanding and using existing guidelines

Q. Please indicate on a scale of 0 to 10 (where 0 is 'not at all confident' and 10 is 'totally confident') how confident you feel understanding and using existing guidelines for the management of chronic pain



National Frameworks and Strategies May Provide a Platform for Change

While chronic pain remains a low priority for governments in many European countries, some have taken steps to address the management of chronic pain through establishing national strategies and frameworks. These are a huge step in the right direction, however the implementation of these strategies relies on the involvement and engagement of all those dealing with pain at a practical level. There is a need for clear directives, incentives for implementation and a coordinated approach to ensure engagement with and momentum for these important initiatives.

Spotlight on... Legislation – The Italian Perspective:

Italian Pain Law

This year Italy took positive steps to address pain management with the introduction of a new law. This makes provision of palliative care and pain treatment priorities of the Italian National Health Plan. The law protects peoples' rights to have access to palliative care and pain treatment as part of their right to an essential level of care. It also underpins fundamental principles such as ensuring patients' rights to receive help that will protect their dignity, self-sufficiency, and quality of life throughout; and is part of the Plan's pledge to support the patient and their family.

Unanimous approval of the law, clearly displays a common interest in boosting awareness of pain and willingness to implement change. This needs to be replicated across Europe. However, there is still progress to be made. A significant commitment is required to existing gaps that prevent the law reaching its full potential. Implementation of the law will be assessed each year, with particular focus on appropriate and efficient use of resources. With cooperation between national and local institutions, patient care in Italy has the potential to be revolutionized.

Spotlight On... Pain Programmes – The French Perspective

French Pain Strategy

Another country to already have made chronic pain a priority is France. Three national programmes to combat pain are being implemented, the last of which will be completed this year. Dates and objectives of the programmes:

- 1998-2000 Objectives: Funding of the implementation of multidisciplinary facilities for the assessment and treatment of persistent chronic pain, within the scope of health establishments.
- 2002-2005 Objectives: Continuation of the preceding plan, information from patients, creation of specialised facilities (including committees to combat pain, CLUD), training for professionals, improvement of practices (recommendations).
- 2006-2010 Objectives: Improved pain management for the most vulnerable people, strengthening of training for professionals, better use of treatments (drug and non-drug) and structuring of the health network).

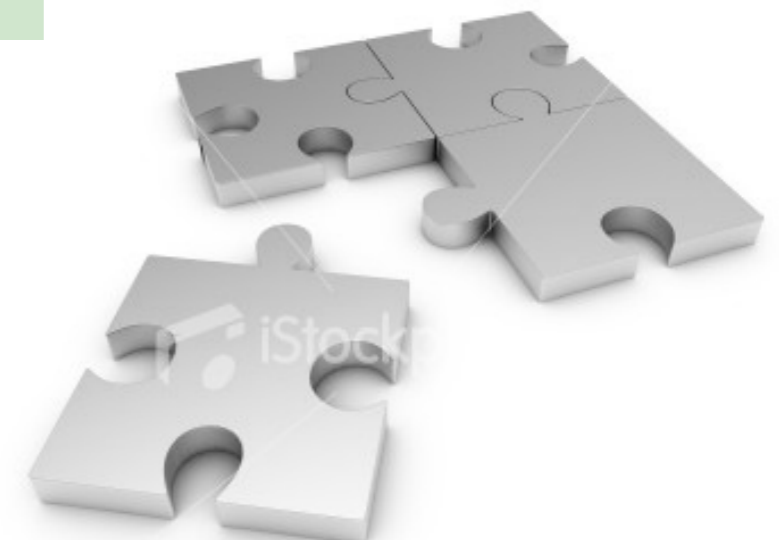
The implementation of these national directives and recommendations shows the willingness of institutions and professionals to maximise pain management. However, the level of adoption appears to be very uneven at a national level, which may be due, in part, to the exhaustive nature of the recommendations. It is currently acknowledged that better communication between healthcare professionals and sharing of good practice remains a key prerequisite for these directives to be really effective.

Spotlight On... National Strategies – The Australian Perspective

The Australian Pain Summit

Taking an example from outside Europe, significant progress has been made on chronic pain in Australia through the development of a National Pain Strategy. The strategy aims to improve the quality of life for people suffering from pain and their families and to minimise the burden of pain within the community. This has been supported by a national healthcare policy initiative, The National Pain Summit which has brought together more than 130 organisations representing Australia's leading authorities in pain medicine, united to back the strategy to ensure people with pain are considered a national health priority.

Through unifying all stakeholders and organisations involved in chronic pain, the Pain Summit has already achieved a primary goal of raising awareness of chronic pain, ensuring that chronic pain is seen as a healthcare priority in Australia. It is hoped that this recognition will provide the momentum required to achieve the goals outlined in the Pain Strategy to ensure adequate and effective management of chronic pain for those affected by the condition in Australia.



Management and Treatment

“An unmet need is to increase awareness of medicines for pain in the population. Medicines and pain treatments available are not well known. Even GPs don’t always know that patients can be referred to a pain specialist.” Professor Varrassi, EFIC President, L’Aquila University

According to international human rights law, governments must take steps to ensure that people have adequate access to treatment for their pain.³⁴ Failure to do so may result in the violation of a person’s right to health.³⁴

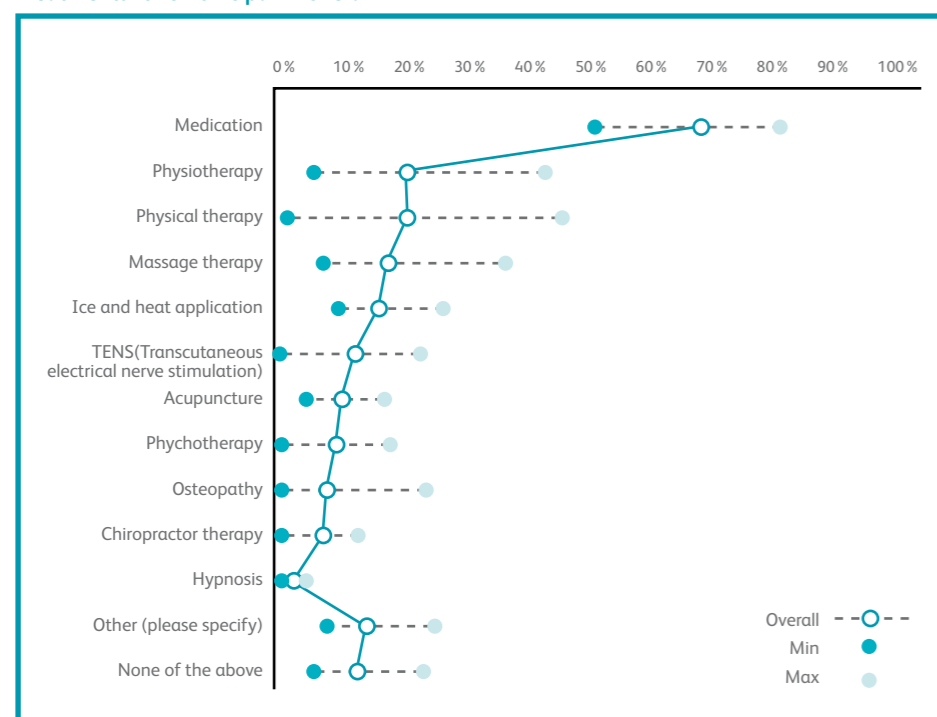
The most appropriate treatment for chronic pain will depend on the pain type and the needs of the specific patient, for example, pain with a neuropathic component will require a different approach to purely nociceptive pain. For many patients, optimal management of chronic pain may require a multidisciplinary team approach with appropriate behavioural therapy, as well as input from a broad range of healthcare professionals.⁶² These are obtainable at specialist pain clinics (see below) but access to them is limited and waiting times for referral can be long.

Chronic Pain – Treatment Type

Medication (69%) is by far the most often used treatment, followed by physiotherapy (21%) and physical therapy (21%)

Q Which type(s) of treatment are you currently on?

Treatments for chronic pain– Overall



Patients may receive conventional analgesic treatments in the first instance or treat their own pain with over-the-counter remedies and alternative therapies.

For more severe chronic pain, NSAIDs (non-steroidal anti-inflammatory drugs) or opioids may be used. The WHO has recommended the sequence of analgesic drugs to be used in cancer pain in its “pain ladder” and this sequence is also often followed for the treatment of non-malignant pain. However, if pain is neuropathic, it may be resistant to certain medications, such as NSAIDs, requiring the use of anti-depressants or anti-convulsants instead.³⁶

Availability of therapies alternative or complementary to medication is not uniform, as is the case regarding access to psychologically-based treatments. Some pain clinics offer Transcutaneous Electronic Nerve Stimulation (TENS) or acupuncture. By and large, clinicians prefer medication and conventional rehabilitation methods because their safety and efficacy is scientifically proven, usually in double-blind placebo-controlled clinical trials. Whether or not alternative treatments are effective for most people is more difficult to assess. They do not readily lend themselves to scientific evaluation and many rely on anecdotal reports of their success.⁶³

Spotlight On... Improving Management Through Recording & Reviewing

The Swedish National Register of Pain

The National Register of Pain of Sweden (NRS) was established in 1998 with the purpose of comparing the effects of rehabilitation programmes on patients suffering from pain. Data for the register is collected directly from different rehabilitation centres and patients reported outcomes are assessed on activity, quality of life and participation in work and leisure. Of the 30 rehabilitation centres in Sweden, 23 were part of the register in 2009.

At present the register is a pain-rehabilitation register and no pharmaceutical treatments are included, however, different departments and hospitals can distribute their own annual reports and also see results from others.

Other quality registers in Sweden include measures of chronic pain. One, which was developed by rheumatologists, is used to monitor the impact of biologic treatments. It contains three different elements; one to follow up new medical treatments, one for cost effectiveness and the last section is to serve as a Swedish quality register for rheumatoid arthritis.

The Problem is Not Solved in All Cases

While a range of treatments for chronic pain are available, we know that over a third (38%) of people say their pain is not adequately managed.³ This is particularly interesting given a new European survey of GPs shows that less than half (46%) are confident in knowing what to do if initial treatment is unsuccessful and pain persists.¹⁷

Appropriate training for doctors combined with an agreed follow up plan with patients could help ensure people are on the right treatment for their pain type. This could potentially avoid side effects, wastage from use of inappropriate treatment and the worsening of the inadequately managed pain.

Mrs K’s story

The case of Mrs K., a 50 year old scientist, has been treated for whiplash after a car accident 15 y. ago, illustrates a typical pain patient pathway in Switzerland. Three cervical vertebrae and the right hip were injured and she had a radiating nerve damage down the left shoulder and arm. The patient has been in constant pain ever since. Her posture is crooked and her hip joint is frequently blocked. Mrs K. gave up her career due to the pain, her living conditions deteriorated and she became depressed. It took Mrs K. over 1 year to find adequate help. The medical treatment and physiotherapy her GP prescribed did not help. After seeing a neurologist and rheumatologist to no effect, she consulted a rehabilitation centre. There she obtained a diagnosis, was prescribed anaesthetics (bi-weekly injections for 3 y.), had access to physiotherapy and was treated against depression. Since leaving the centre, she has had regular follow ups with her GP. Mrs K. started seeing positive results from the long-term therapies 2 years ago. Today, she receives a combined medication treatment, prescribed exercises, and massages. Due to partial disability pension (50%) she has resumed work as a part-time teacher.

The Role of Specialist Pain Clinics

Spotlight On... Effective Treatment Follow-Up

Turku University Pain Clinic, Finland

Turku University Hospital pain clinic has started to make follow-up calls after a patient has started a new medication. After meeting the patient face-to-face after the doctor's visit, the nurse calls the patient two-three times every one-four weeks.

During the phone call the nurse monitors how the medicine affects pain and sleep, possible adverse effects and records the daily functioning according to the patient. At the same time the patient has a chance to discuss any concerning matters.

If the patient has some mild side effects typical with that medicine, the nurse tells the patient how to treat them and will carefully encourage the patient to continue with the medication. If the follow-up shows unexpected adverse effects, or the medicine is unsuitable or ineffective for the patient, the nurse will inform the treating doctor who will decide about the further measures.

This operations model has increased the efficiency of implementing a patient's treatment regime and shortened any delays in the pain medication, especially when a patient has had adverse effects that have prevented him or her using the treatment.

Without any exceptions, patients have been satisfied with this practice. Many patients have revealed that they are less scared of starting a medication now. From a nurse's point of view, the new operations model has worked well and reduced the number of telephone calls for reassurance from patients.

Specialist pain clinics are specialised in diagnosing and treating patients with chronic pain. Good specialist pain clinics have a multidisciplinary team comprising a specialist in pain medicine, specialist pain nurse, primary care physician, clinical psychologist, physiotherapist, occupational therapist and pharmacist. The team may also have access when required to an orthopaedic surgeon, neurosurgeon, psychiatrist, rheumatologist and neurologist.

However, access to a good pain clinic is not available to all. Many major hospitals will operate a chronic pain-management service, but access depends on where patients live. In addition, pain services vary significantly. Some offer only a rudimentary service from a single anaesthetist while others offer a comprehensive service including behavioural therapy in "pain management programmes". A recent IASP survey found that there are significant problems with waiting times and access to pain services, resulting in deterioration of patients' pain.¹⁹

Pain clinics assess individuals' pain and work through the options. Difficult cases may be referred to an appropriate specialist for treatments such as surgery to remove nerve tissue, injections of corticosteroids into painful tendons or epidural infusions (long-acting local anaesthetics injected into the spinal column) as well as TENS, acupuncture, physiotherapy and individual psychological therapy.

With the extensive range of treatment modalities, it is important for patients to have medical assistance, to find and receive the optimal treatment. Obviously, clinicians need to work through the options in collaboration with patients to identify the optimal therapy for each individual. It is also critical that patients receive management as soon as possible, as evidence suggests that patients who wait 6 months for treatment experience deterioration in quality of life, psychological well being and depression.¹⁸

The Pain Proposal Recommendations: What Needs to Change?

1. Within Pain Management Services:

Establish clear management pathways for people with chronic pain

- Improve timeframes for diagnosing patients by giving primary care professionals guidance on who and when to refer and to whom – reducing healthcare utilisation costs
- Help healthcare professionals to have better conversations with people in chronic pain through appropriate training – to manage expectations and improve outcomes
- Ensure primary care professionals know what treatment options and specialist services are available, providing people with chronic pain access to the right pain specialists and community level services
- Intervene early with multidisciplinary treatment to prevent psychological co-morbidities and costly complications – helping patients return to their work and usual life activities as swiftly as possible

2. At Policy-Making Level (Medical Education Curriculum Planners; Hospital and National Policy Makers):

Have the vision and will to identify pain as an important issue in European societies

- Increase dialogue between government departments - identifying potential savings in welfare and workforce costs, as well as future demands on healthcare resources, that could be brought about by changes in the organisation of pain management services
- Agree criteria for evaluating the cost of chronic pain and generate data providing a comprehensive assessment both direct and indirect costs
- Conduct cost vs. benefit analysis of pain treatment and management options and implement plans and legislation to ensure access to the best
- Review and learn from examples of good practice already in place both nationally and in Europe
- Set minimal educational standards regarding pain management for doctors in training.
- Give qualified healthcare professionals sufficient postgraduate training or continuing medical education to enable them to feel confident in consultations involving people with chronic pain
- Develop and implement a national strategy for chronic pain

3. For Professional Pain Specialist Associations and Patient Organisations at National and European Levels:

Work together to protect and champion the rights of people with chronic pain to ensure they can regain, or continue to live, fulfilling and productive lives

- Encourage better implementation of existing guidelines by providing clarity on how best to navigate them
- Raise awareness of chronic pain through public education campaigns – making people aware of the advice, information and support available to them via health services and advocacy groups to encourage better self-management and improved quality of life
- Protect and champion the rights of people living with chronic pain through supporting the Can You Feel My Pain? Bill of Rights:

1 The Right to be Understood

2 The Right of Access to Information

3 The Right to Professional Support

4 The Right to Early Intervention and Optimal Pain Management

5 The Right of Pain Relief as a Fundamental Human Right

4. For All Those Involved in Chronic Pain to Work Together to Improve the Management of Chronic Pain Across Europe

A Final Word from the Steering Committee

The new survey data and analysis presented in this report have highlighted a number of inadequacies in the way chronic pain is currently managed in Europe. Patients have reported long waiting times for referral, persisting pain despite treatment, and difficulties communicating with health professionals. This, of course, has consequent ramifications on their ability to work, their relationships with partners and family, and their roles in the wider community.

Healthcare professionals have also reported dissatisfaction with aspects of chronic pain management and a desire for greater support. More specifically they cited confusion over guidelines, difficulties in communication, a lack of preparedness from their professional education and in many cases frustration from a slow and unwieldy referral system and a limited availability of specialist pain clinics.

Improving pain management will not only improve patients' quality of life but will bring substantial economic benefits: more efficient use of existing resources for pain management, less 'presenteeism' and 'absenteeism' at workplaces, greater productivity and a reduced burden on social security budgets. In the current economic environment, Europe cannot afford to allow inefficient management of chronic pain to continue to generate avoidable cost to healthcare systems and to undermine economic performance.

Everyone involved in the chronic pain arena from healthcare professionals to government departments needs to work together to improve pain management across Europe. The Calls to Action presented in this report provide an indication of the first steps we believe are needed to provide patients with more uniform access to effective pain management.

Achieving this objective will mean lower costs, greater satisfaction for healthcare staff and improvements for society as a whole – and of course the greatest benefit of all: an improved quality of life for the millions of European citizens who suffer from chronic pain.

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