



# 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 primary care physician 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.

-  **Dr. Mary Baker, MBE**  
President, European Federation of Neurological Associations (EFNA)
-  **Dr. Beverly Collett**  
Consultant in Pain Medicine, University Hospitals of Leicester  
Chair, Chronic Pain Policy Coalition (CPPC)
-  **Mrs Andrea Fischer**  
Independent Consultant,  
Former German Federal Minister of Health
-  **Dr. Volker Herrmann**  
Vice President, CNS and Pain European Marketing, Pfizer
-  **Professor Frank J. P. M. Huygen**  
Professor of Anaesthesiology (in particular Pain Medicine), Erasmus Medical Centre
-  **Professor Thomas Tölle**  
Professor of Neurology and Psychology, Department of Neurology, Technische Universität München
-  **Professor Paul Trueman**  
Professor of Health Economics, Brunel University
-  **Professor Giustino Varrassi**  
President, European Federation of IASP Chapters (EFIC)  
Professor and Chairman, Department of Anaesthesiology and Pain Medicine, L'Aquila University Medical School
-  **Professor Pablo Vázquez**  
Executive Director, Applied Economics Studies Foundation (FEDEA)
-  **Dr. Kees (C. J.) Vos, MD**  
Primary Care Physician, Spijkenisse and Investigator Department of General Practice, Erasmus Medical Centre



'Can You Feel My Pain?' is a Europe-wide coalition campaign designed and implemented by patient advocacy groups across Europe - 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 the 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.






 borsstkankervereniging nederland

 Deutsche Schmerzliga e.V.

Annelies Vanbrabant, De Vlaamse Pijnliga  
Liisa Mikkonen, Suomen Kipu Ry

## 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. Experts came from the 15 countries listed below and the majority of insights and examples included in this report come from these countries. The Pain Proposal Steering Committee would like to thank the Executive Committee for their time and input on this important project.

-  **Professor Burkhard Gustorff**, Head of Anaesthesiology and Intensive Care, Vienna Wilhelminenspital, Scientific Head of Post-Graduate Programme on Interdisciplinary Pain Treatment, Vienna Medical University  
**Korinna Pawloff**, Vienna Nursing and Patient Advocacy
-  **Professor Dr. Steven Simoens**, Associate Professor, Research Centre for Pharmaceutical Care and Pharmaco-economics, University of Leuven  
**Johan Tourné**, Secretary, De Vlaamse Pijnliga  
**Dominique Michelet**, Lawyer and Political Officer, Humanist Democratic Centre, Maison des Parlementaires
-  **Liisa Mikkonen**, Chair, Suomen Kipu Ry (Finnish Pain Association)  
**Dr. Minerva Krohn**, Development Director, General Medicine, Terveystalo, Member of the Helsinki City Council  
**Anne Santalahti**, Chief Medical Officer, Primary Health Care, City of Turku
-  **Matilde Crespo**, Member of Association Francophone pour Vaincre les Douleurs (AFVD)  
**Professor Alain Serrie**, Head of Department, Lariboisière Hospital, Paris, Professor, National College for Hospital Medicine, Associate Professor, University Paris VII  
**Françoise Laroche, MD**, Rheumatologist and Pain Specialist at the Centre of Evaluation and Treatment of Pain, Saint-Antoine Hospital, Paris  
**Laurence Carton**, Vice-chairman, Association Française de Lutte Antirhumatismale (AFLAR)
-  **Harry Kletzko**, Deutsche Schmerzliga (German Pain League)  
**Professor Thomas Kohlmann**, Head of Department "Methods of Community Medicine" at the Medical Faculty of the University of Greifswald  
**Dr. Reinhard Sittl**, Chief Consultant Specialist in Anaesthesiology Pain Centre, Erlangen University Hospital
-  **Professor Dimitrios Kouvelas**, Professor of Pharmacology and Clinical Pharmacology, School of Medicine, Aristotle University, Thessaloniki  
**Professor Athina Vadalouka**, Associate Professor of Anaesthesia, Pain Relief and Palliative Care, University of Athens, President of the Hellenic Society of Palliative and Symptomatic Care of Cancer and Non Cancer Patients  
**Dr. Kostas Athanasakis**, Research Fellow, Department of Health Economics, National School of Public Health
-  **Michael Bohill**, Chronic Pain Ireland  
**Dr. Liam Conroy**, Director, Department of Pain Medicine, Mercy University Hospital, Cork  
**John Church**, Chief Executive Officer, Arthritis Ireland
-  **Professor Federico Spandonaro**, Scientific Coordinator, Centro Italiano di Solidarietà di Roma (CeIS), University Roma Tor Vergata  
**Sabrina Nardi**, Cittadinanzattiva  
**Guido Fanelli**, Director, Department of Anaesthesiology, Parma University
-  **Marcel C Kuin MBA MSc**, Independent Healthcare Manager, Kuin Zorgmanagement  
**Riet van der Heide**, Borstkanker Vereniging Nederland (Dutch Breast Cancer Association)  
**Mart A. F. J. van de Laar, MD, Ph D**, Professor of Rheumatology Medisch Spectrum Twente and University Twente  
**Ditte Kuijpers**, Borstkanker Vereniging Nederland (Dutch Breast Cancer Association)
-  **Per Egil Haavik**, Consultant MD, Head of The Pain Clinic, Stavanger University Hospital  
**Professor Harald Breivik**, Professor of Anaesthesiology, Rikshospitalet, University of Oslo
-  **Pedro Saramago Goncalves**, Centre for Health Economics, University of York  
**Professor Jose Manuel Castro-Lopes**, Institute of Histology and Embryology, Faculty of Medicine, University of Porto  
**Dr. Jose Manuel Soares Malheiro Romao**, Chronic Pain Unit, Hospital de Santo Antonio  
**Maria da Luz Macario Paiva**, National Association of Rheumatoid Arthritis Patients (ANDAR)
-  **Professor Josep Darba**, Department of Economics, University of Barcelona  
**Dr. Ana Miquel**, Conserjera de Sanidad de la Comunidad de Madrid  
**Dr. Alfredo Perucho**, Ramon y Cajal University Hospital  
**Antonio Torralba**, Coordinadora Nacional de Artritis
-  **Jan Bagge**, Swedish Rheumatology Association  
**Anders Gustavsson**, Associate Director, I3 Innovus  
**Jan-Rickard Norrefalk MD, PhD**, Senior Consultant Physician, Department of Clinical Sciences Karolinska Institutet, Division of Rehabilitation Medicine, Danderyd Hospital
-  **Professor Dr. Jules Desmeules**, Associate Professor of Clinical Pharmacology, Department of Anaesthesiology Pharmacology & Intensive Care, University Hospitals, Geneva  
**Professor Dr. Eli Alon**, Professor of Anaesthesiology, University of Zurich, Swiss Society for the Study of Pain  
**Dr. med. Andrea Macak**, Executive Committee Member, Swiss Association for the Study of Pain  
**Dr. Valérie Piguët**, Head, Multidisciplinary Centre for the Evaluation and Treatment of Pain
-  **Ian Semmons**, Chairman, Action on Pain  
**Neil Betteridge**, Chief Executive, Arthritis Care, Vice President of the European League Against Rheumatism (EULAR), representing People with Arthritis and Rheumatism in Europe (PARE)

The members of the Executive Committee listed above fed insights into the Pain Proposal initiative. All experts were acting as independent consultants and their views do not necessarily represent the views of the organisations they work for or represent.

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.

## Contents

<b>Foreword: Introducing the Pain Proposal</b>	<b>5</b>
<b>Executive Summary</b>	<b>6</b>
<b>Chronic Pain</b>	<b>8-9</b>
<ul style="list-style-type: none"><li>• Chronic Pain Affects One in Five Adults in Europe</li><li>• The Complexities of Diagnosing Pain</li><li>• Causes of Chronic Pain</li></ul>	
<b>Living with Chronic Pain</b>	<b>10-15</b>
<ul style="list-style-type: none"><li>• The Emotional Toll of Chronic Pain</li><li>• The Devastating Impact on Quality of Life</li><li>• Perceptions of Pain</li></ul>	
<b>Chronic Pain: A High Cost to Europe</b>	<b>16-23</b>
<ul style="list-style-type: none"><li>• How Much Does Chronic Pain Cost Us?</li><li>• Direct Costs of Chronic Pain</li><li>• Indirect Costs of Chronic Pain</li><li>• Chronic Pain Imposes a Heavy Burden on Employers and Employees</li><li>• Welfare Budgets Bear the Costs of Incapacity</li><li>• Meeting the Challenge: Improvements in Pain Management Can Save Money</li><li>• Joined-up Government Approach Needed to Tackle Hidden Costs</li></ul>	
<b>Physician Training is Paramount</b>	<b>24-27</b>
<ul style="list-style-type: none"><li>• Improved Clarity Around Guidelines is Needed</li><li>• National Frameworks and Strategies May Provide a Platform for Change</li></ul>	
<b>Access to Appropriate Services and Treatment</b>	<b>28-29</b>
<ul style="list-style-type: none"><li>• The Problem is Not Solved in All Cases</li><li>• The Role of Specialist Pain Clinics</li></ul>	
<b>The Pain Proposal Recommendations: What Needs To Change?</b>	<b>30</b>
<b>A Final Word from the Steering Committee</b>	<b>31</b>
<b>References</b>	<b>32</b>

## Foreword

### Introducing The Pain Proposal

One in five Europeans (19%) is estimated to suffer from chronic pain. As well as undermining the ability of those affected to lead productive working, social and family lives, it also represents a significant burden to wider society and to European economies. Estimates of the direct and indirect costs to Europe run into the billions. With an ageing population and greater pressure for people to stay in work for longer, the problem is set to escalate. Yet awareness, understanding and intervention are limited.

As the Steering Committee of the Pain Proposal, we believe it is unacceptable that more is not being done to tackle chronic pain head on. We cannot feel the pain of those living with the condition. However, we can empathise with them, recognise the scale of the problem and commit to mobilising change. This was the impetus for the Pain Proposal initiative, which represents perspectives from a range of stakeholders from across 15 European countries, including people with chronic pain, clinicians from different medical specialties, policy experts, industry members and health economists.

This Consensus Report demonstrates our commitment to and outlines proposals for action. It is intended to provide practical advice and a motivation to deliver more effective and efficient management of chronic pain to key stakeholders:

- managers of pain services
- healthcare organisations
- policy-makers
- politicians
- healthcare professionals

The pressure chronic pain places on individuals, economies and society is indisputable. Many argue that chronic pain is the medical condition with the greatest negative impact on quality of life and some pain specialists regard it as a disease entity in itself. In 2001, the European Federation of IASP Chapters (EFIC) issued a declaration to the European Parliament to this effect. Many stakeholders wish to see chronic pain afforded as much attention as other major diseases such as heart disease, breast cancer and diabetes.

Yet, currently, access to pain management services is inconsistent in Europe (both within and across nations) and available health services for pain differ markedly in the type of care they offer. The result is fragmented care for patients and significant avoidable healthcare costs for governments. We believe a new minimum standard of care is required to which all people with chronic pain in Europe should have access.

Our proposals should be read in the context of the need for economic efficiencies in Europe. With the effects of the global financial crisis still evident, governments in all countries are reining in spending across departments including healthcare. Money for services is tight and must be used well to maximise patient outcomes. The report includes recommendations that, if implemented, make the needs of the patient a priority while supporting efforts to reduce health expenditures through increased efficiency.

The time is right to take collective action throughout Europe to improve the way chronic pain is perceived and managed, to better support people in chronic pain and drive healthcare efficiencies.

**“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, University Hospitals of Leicester  
Chair of the Chronic Pain Policy Coalition (CPPC)*

### About the Pain Proposal Patient and Primary Care Physician (PCP) Surveys

To support the Pain Proposal initiative, two separate market research surveys were conducted by InSites Consulting between July and September 2010. The surveys were conducted online using computer aided web interviewing (CAWI), with the exception of Greece where 64 of the interviews were conducted face to face. 2,019 people with chronic pain and 1,472 primary care physicians (PCPs) were surveyed across the following 15 European countries: Austria (100 patients, 100 PCPs), Belgium (101 patients, 100 PCPs), Finland (100 patients, 81 PCPs) France (204 patients, 100 PCPs), Germany (201 patients, 100 PCPs), Greece (100 patients, 94 PCPs), Ireland (101 patients, 101 PCPs), Italy (200 patients, 100 PCPs), Netherlands (101 patients, 100 PCPs), Norway (101 patients, 100 PCPs), Portugal (100 patients, 96 PCPs), Spain (201 patients, 100 PCPs), Sweden (103 patients, 100 PCPs), Switzerland (103 patients, 100 PCPs) and the UK (203 patients, 100 PCPs). The error margins were 9.8% for the patient survey and 9.6% for the primary care physician survey, with confidence intervals of 19.6% and 19.2% respectively. Respondents for the patient survey were screened to include only people with chronic pain, defined as pain lasting more than three months. Respondents for the physician survey were screened to be physicians working in primary care with at least three years experience, spending at least 50% of their time treating patients and seeing at least 10 patients with chronic pain in a month. The surveys were funded by Pfizer Ltd.

### A note on studies used within the report

There are a number of chronic pain conditions and different examples are used throughout this report. The Pain Proposal Patient survey includes people with a range of different chronic pain types. Other studies referred to in the report relate to specific pain types such as chronic back pain or musculoskeletal pain - these have been used to provide an indication of impact on the general chronic pain population.

# Executive Summary

Chronic pain presents a major challenge to the citizens and the economy of Europe – one that is likely to worsen as the population ages. A 2006 survey shows that one in five Europeans suffer from chronic pain, with most experiencing it for over two years and some people enduring it for up to 20 years or longer.<sup>1</sup>

## 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 affects. 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.<sup>2</sup> The negative impact of chronic pain frequently extends beyond the sufferer to affect loved ones and dependents.

The Pain Proposal survey reveals:<sup>3</sup>

- 27 % of people with chronic pain feel socially isolated and lonely because of their pain
- 50 % 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

People with chronic pain 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 is low.<sup>3</sup>

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:<sup>3</sup>

- On average, people with chronic pain 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 wait 1-5 years to receive a diagnosis or reason for their pain – and a further 11 % wait longer than this
- 38 % of people with chronic pain report that their pain is not adequately managed
- People with chronic pain make an average of nearly seven visits to healthcare professionals a year, with 22 % making 10 visits or more
- Nearly half those surveyed were dissatisfied with the time it took to reach a diagnosis (49 %), the time to get adequate management of their pain (48 %) or the number of visits to the doctor taken to achieve adequate management (50 %)

## Chronic Pain: A High Cost to Europe

Pain is more than a burden on individuals and their families alone. Chronic pain costs Europe billions of euros: perhaps as much as €300 billion across the EU<sup>4</sup>, or around 1.5 - 3 % of GDP (Gross Domestic Product).<sup>5,6</sup>

The direct cost of chronic pain to healthcare systems is significant. Taking back pain as an example, consultations with healthcare professionals make up the largest share of overall healthcare system costs which are estimated at €187 million for Belgium,<sup>7</sup> \$368 million (€289 million) for the Netherlands,<sup>8</sup> and over £1.6 billion (€1.9 billion) for the UK.<sup>9</sup>

According to new survey data in France, Germany, Italy, Spain and the UK:<sup>10</sup>

- People with severe pain visited healthcare professionals an average of 13 times in the past six months, double the average number of visits made by the general adult population
- 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 – more than double the percentage for the general population in both instances

Inappropriate and ineffective management and treatment, which can generate repeat visits to primary care and referrals to specialists, have been highlighted by the Pain Proposal Steering and Executive Committees as important drivers of avoidable healthcare costs.

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), people with pain and their families.<sup>8</sup> The relative scarcity of consistent data on the indirect costs of pain highlights a need for more systematic research to gain a more accurate picture of the current impact of chronic pain on a national and Europe-wide basis. However, the scale of these indirect costs greatly exceeds the direct costs of managing pain and suggests that even small increases in the effectiveness of pain management could reap large economic rewards.

Pain Proposal data show that:<sup>3</sup>

- 21 % of Europeans with chronic pain are unable to work at all as a result of their chronic pain
- 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
- Of those that are able to work, 61 % state their employment status is directly affected by their condition

Studies have indicated that people with chronic pain 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.<sup>11,12</sup>

Examples from Europe show that it is possible to improve services - boosting effectiveness and improving outcomes for people with chronic pain, while also cutting unnecessary expenditure. For instance, a Pain Clinic in the UK pioneering multidisciplinary pain management techniques increased patient satisfaction by 75 % and generated per patient cost savings of 35 %. However, 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 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.<sup>15,16</sup> 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.<sup>16</sup>

The results of the Pain Proposal survey reveal:<sup>16</sup>

- Only around half (53 %) of primary care physicians are confident managing chronic pain
- 47 % 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.

## Access to Appropriate Services & Treatment

There are a range of different medications and therapies for 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 people with chronic pain receive intervention as soon as possible, as evidence suggests that people who wait six months for treatment experience deterioration in quality of life, psychological wellbeing and depression.<sup>17</sup>

Pain clinics are specialised in diagnosing and treating patients with chronic pain. However, the number of pain clinics varies across regions and in many countries access to timely care is a growing problem.<sup>17</sup>

Access to appropriate services and treatments is key to realising tangible improvements in pain management in Europe. Several countries, such as Portugal, Italy and France, 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?

The current picture of chronic pain management across Europe – characterised by significant waiting time to diagnosis and treatment, multiple healthcare professional visits and suboptimal pain management – impacts on the quality of life of people with chronic pain and their ability to work. This needs to change. The scale of the increasing economic challenges facing Europe, provides further argument for tackling inefficiencies in pain management

today. If the right action is taken, there is the potential to deliver improvements in quality of life, savings to health budgets and a productivity boost to Europe's economies.

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

The development of this report and the recommendations within it are only a first step towards changing the way chronic pain is currently managed but examples of good practice show that improvements can be accomplished. If governments, clinicians, patient groups and all those involved in chronic pain 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.

### 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

# Chronic Pain















## Chronic Pain Affects One in Five Adults in Europe<sup>1</sup>

Chronic pain presents a significant challenge to the citizens and the economy of Europe. With an aging population, the impact of chronic pain is likely to be felt even more strongly. While there will be an economic need to keep people in employment for longer, a rise in the numbers affected by chronic pain is likely to hinder this.

Estimates of prevalence vary widely according to definition and methodology but, by any measure, the reach and impact of chronic pain is significant. In a landmark 2006 Europe-wide survey, one in five people in the general adult population reported having chronic pain - with most living with it for over five years and some for 20 years or longer.<sup>1</sup> Nearly half of all those surveyed (46%) said they experienced chronic pain at all times and many of those admitted they were so weighed down when their pain was at its worst they could not continue to tolerate it. Those below 40 years of age appeared to suffer less with chronic pain, with those in the 41 – 60 age group more likely to experience chronic pain.<sup>1</sup>

The 2007 Eurobarometer 'Health in the European Union' survey states: "Exactly a quarter of all EU respondents say that at some point in their life they have experienced chronic restrictive pain."

### The Prevalence of Chronic Pain in Europe

Country	Chronic Pain
 Austria	21% <sup>1</sup>
 Belgium	23% <sup>1</sup>
 Denmark	16 – 21% <sup>1,11,18</sup>
 Finland	19% <sup>1</sup>
 France	15 – 32% <sup>1,19</sup>
 Germany	17 – 45% <sup>1,20</sup>
 Ireland	13% <sup>1</sup>
 Italy	26% <sup>1</sup>
 Netherlands	18 – 25% <sup>1,21</sup>
 Norway	26 – 30% <sup>1,22</sup>
 Spain	12 – 23% <sup>1,23</sup>
 Sweden	18 – 54% <sup>1,24</sup>
 Switzerland	16% <sup>1</sup>
 UK	13 – 48% <sup>1,25,26,27</sup>

## The Complexities of Diagnosing Pain

Pain is subjective and personal making it difficult to define and measure. It is also impacted by psychological and social factors.

Measures of pain are subjective and may therefore be seen as less valuable.<sup>28</sup> Assessment must rely on a healthcare professional's interpretation of a person's account of their pain. For many chronic pain conditions no valid diagnosis can be made; for example, the wide use of the term 'non-specific low-back pain' indicates the difficulty in identifying the source of pain and the pathophysiological mechanism behind it.

Existing definitions of pain and what constitutes chronic pain are also inconsistent. The most widely adopted definition is that used by the International Association for the Study of Pain (IASP). This classifies chronic pain as "pain without apparent biological value that has persisted beyond the normal tissue healing time (usually taken to be three months)".<sup>29</sup>

***"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, 2001<sup>30</sup>*

## Causes of Chronic Pain

Chronic pain can cause significant disability and is associated with co-morbidities and psychological disorders such as anxiety and depression.<sup>2</sup> Pain has a profound impact on quality of life and can have physical, psychological and social consequences.<sup>31</sup>

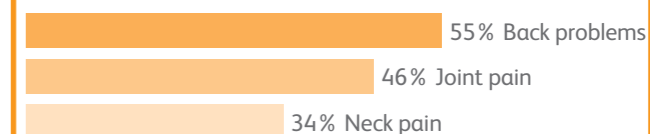
Chronic pain can be caused by a variety of physical or psychological factors. Physical causes include musculoskeletal, vascular and neurological conditions as well as injury to organs and tissues from surgical interventions or other diseases, such as cancer. Chronic pain can be nociceptive, neuropathic or a combination of both. Nociceptive pain is associated with tissue damage. Neuropathic pain 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.<sup>32</sup>

The most common location for pain is the back. According to market research conducted in five European countries in 2010, back pain accounts for 70% of cases of severe pain, 65% of moderate pain and over half the cases of mild pain.<sup>10</sup> The Pain Proposal survey of people with chronic pain, listed back problems as the most common cause of chronic pain, followed by joint pain and neck pain.<sup>3</sup>

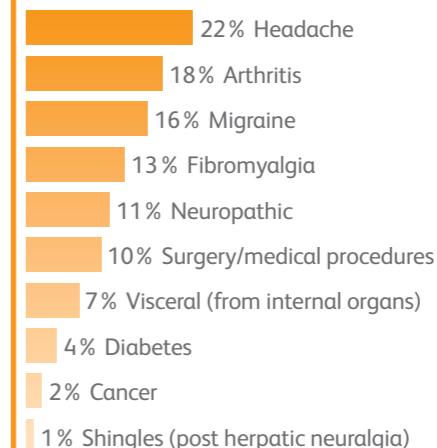
The complexity of measuring pain and its different manifestations can make it difficult to establish the root cause of an individual's pain or how best to manage it. As a result, healthcare for individuals with chronic pain can be fragmented and identifying the best treatment approach can take time.<sup>3,33</sup>

## Most common perceived causes of chronic pain, as identified by the Pain Proposal Patient Survey<sup>3</sup>

### Most common causes of chronic pain:



### Other causes of chronic pain:



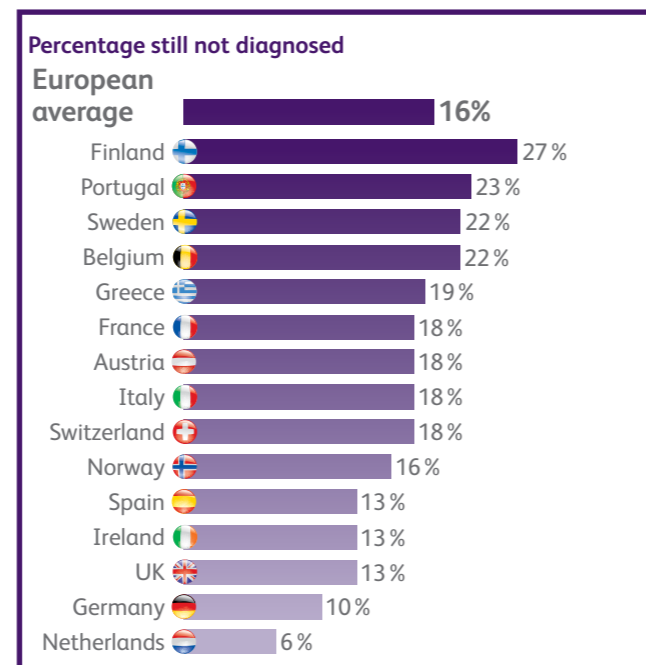
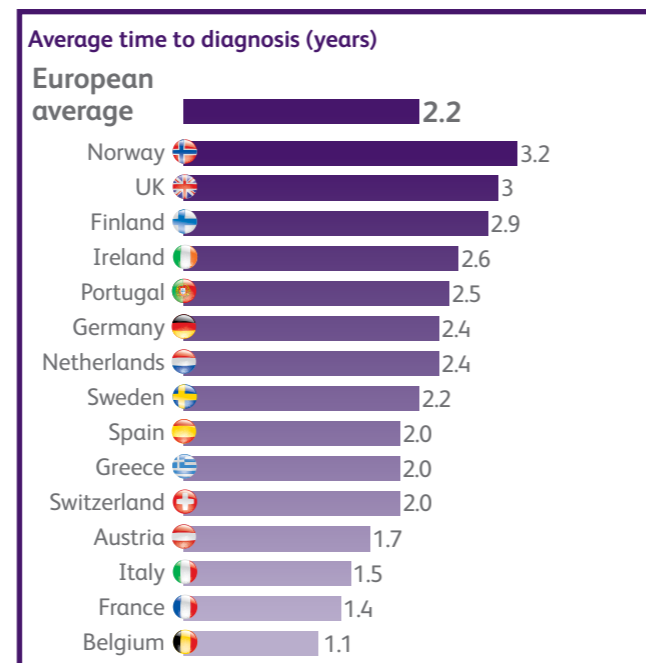
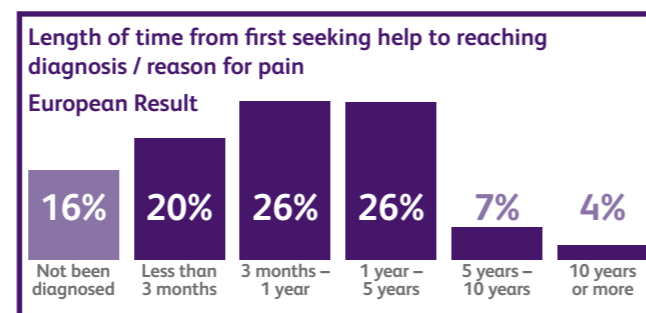
# Living with Chronic Pain

The pathway through the healthcare system can be lengthy, convoluted and inefficient for people with chronic pain, with conflicting advice and treatment approaches resulting in high use of healthcare services.<sup>33</sup>

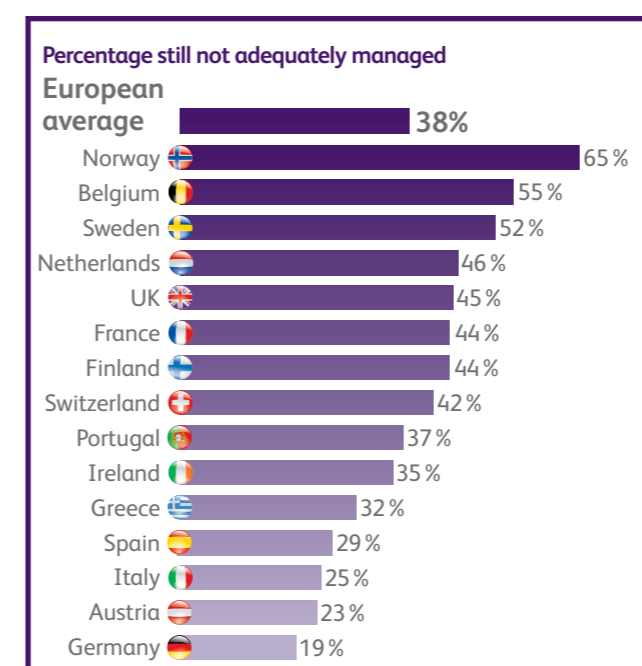
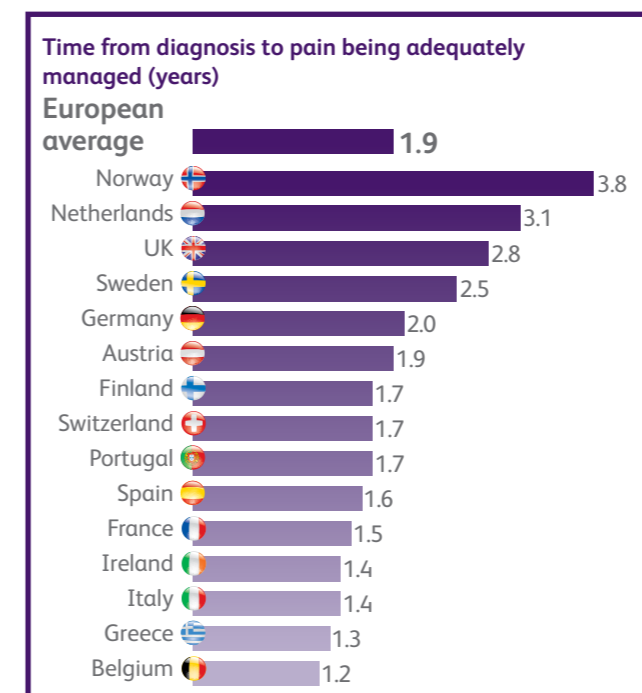
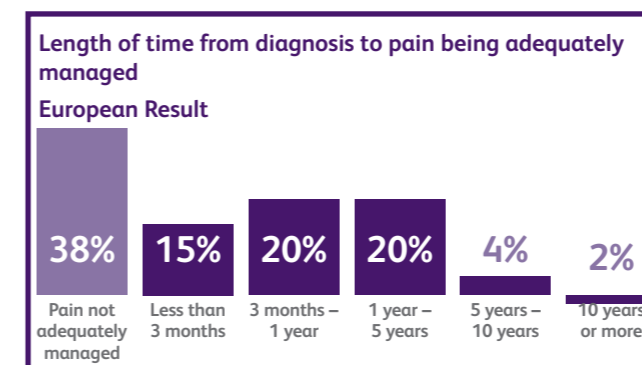
The Pain Proposal survey found that a quarter (26%) of people were forced to wait between one and five years to receive a diagnosis (or reason) for their pain and a further 11% waited even longer. Nearly half those surveyed were dissatisfied with the time it took to reach a diagnosis (49%), the time to get adequate management of their pain (48%) or the number of visits to the doctor required to achieve adequate management (50%).<sup>3</sup>

Overall, the number of visits by people with chronic pain to a healthcare professional were high - an average of nearly seven visits a year, with 22% having to make 10 visits or more. Despite this, a significant 38% of people still reported that their pain was not adequately managed.<sup>3</sup>

## Chronic Pain – Time to Diagnosis<sup>3</sup>



## Chronic Pain – Time to Adequate Pain Management<sup>3</sup>



### 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, the orthopaedic surgeon, another orthopaedic surgeon - 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

A thirty five year old woman from the Netherlands suffered from severe chronic pain caused by a blockage of the sacroiliac joint. 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 her GP, to a neurologist to exclude a herniated disc, then back to the GP. She was then referred to a rheumatologist and finally 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.

\* Name has been changed

# Living with Chronic Pain

## The Emotional Toll of Chronic Pain

Chronic pain can have a devastating impact on all aspects of an individual's life. It can limit ability to participate in work and social activity, shattering confidence and further impairing quality of life.<sup>1,3</sup> Evidence also shows it is associated with increased risk of depression and suicide.<sup>3,2</sup> Nearly one in six chronic pain sufferers in a European survey said their pain was sometimes so bad they wanted to die.<sup>1</sup>

Despite the documented evidence of the impact of chronic pain, public awareness and understanding are limited. This is well recognised by patients<sup>3</sup> and may act as a barrier to them seeking help or taking appropriate action to manage their condition from the outset.

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 or daily pain.<sup>35</sup>

### A Personal Perspective – Niall's Story

Niall from 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 he 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.

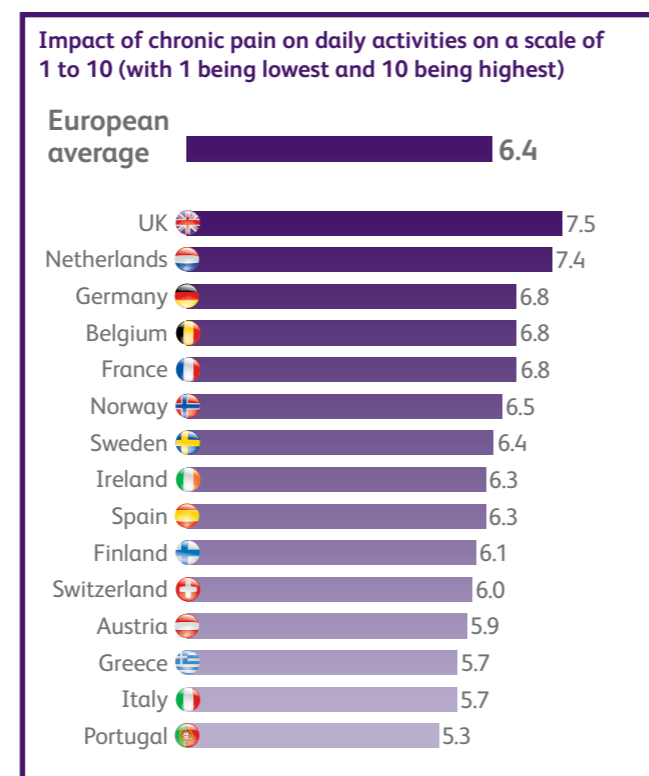
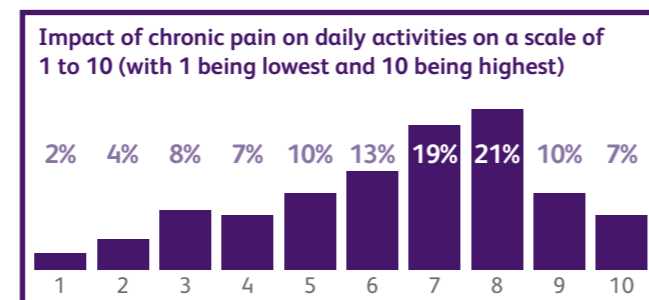
## The Devastating Impact on Quality of Life

The substantial impact that chronic pain has on quality of life is often overlooked. Latest data from the Pain Proposal survey suggest 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.<sup>3</sup>

### Impact on Daily Functioning & Mental Wellbeing

Uncontrolled chronic pain impacts on emotional and physical health, ability to work productively and ability to fully engage in family life.<sup>1</sup> Half of people with chronic pain in one European survey felt tired all the time and 40% felt helpless, or unable to think or function normally. Pain also impacted on everyday activities, with more than two-thirds of people less able to take exercise or even sleep.<sup>1</sup>

### Impact of Chronic Pain on Daily Activities<sup>3</sup>



**The risk of death by suicide has been shown to be at least double in chronic pain patients compared to those without chronic pain.<sup>34</sup>**

### Impact on Relationships

Research shows that a quarter of people with chronic pain feel they can't take as much care of themselves or others as they would like.<sup>1</sup> Twenty seven per cent say they are less able or unable to maintain relationships with friends and family, 30% are less able or unable to maintain an independent lifestyle and 19% no longer feel able to have sexual relations.<sup>1</sup>

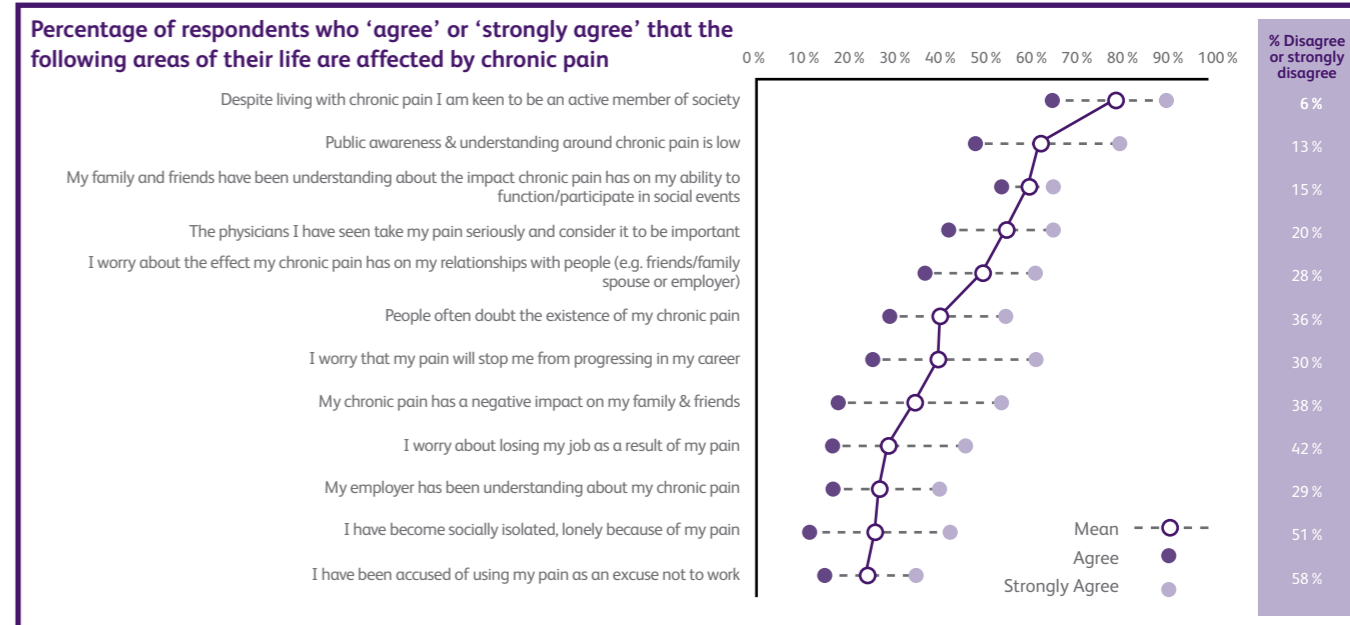
### Impact on Relatives

There is also evidence of a wider impact on those who look after or know someone with chronic pain.<sup>36</sup> Pain Proposal data show that 36% of people with chronic pain agree that their chronic pain has a negative impact on their family and friends.<sup>3</sup>

### A Personal Perspective – Lucy's Story

The first symptom that Lucy, from 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 hospitalised 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 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) and she considers them to be her own family now.

## The Wider Impact of Chronic Pain<sup>3</sup>



# Living with chronic pain

## Perceptions of Pain

The subjective nature of pain can lead others to doubt its severity and public views of people with chronic pain are not always sympathetic. The Pain Proposal survey shows that 41 % of those living with chronic pain feel that people often doubt the existence of their condition.<sup>3</sup>

Despite the fact that 80 % of people living with chronic pain are keen to be active members of society, 25 % 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. Additionally, two-thirds (62 %) of those surveyed feel that public understanding and awareness of chronic pain is low.<sup>3</sup>

There is a need for improved communication between patients and healthcare professionals and for evidence-based resources for people with chronic pain and their families to ensure effective management.<sup>33</sup> 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.<sup>37</sup>

***“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*

It has been shown that people with chronic pain want confirmation that their chronic pain is “real” and want to be empowered through access to consistent and reliable information.<sup>33</sup> 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.

Extending awareness and understanding of chronic pain further, to the general public, could not only help ensure better informed and sympathetic responses to people with chronic pain but could also better enable people to recognise symptoms. With better education and recognition come faster and 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. For example, 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.<sup>38</sup> In addition, 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.<sup>39</sup>



## The “Can You Feel My Pain?” Awareness Raising Initiative<sup>40</sup>

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.<sup>38,41</sup>

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

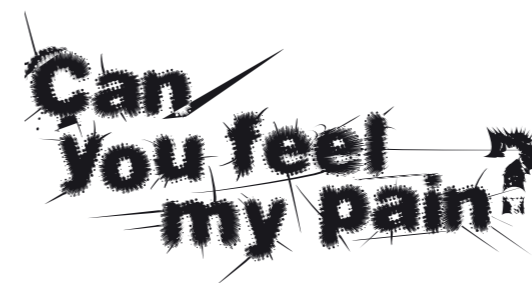
To have access to healthcare professionals who have been adequately trained and fully understand chronic pain; specifically how to diagnose and appropriately manage the condition to limit it worsening

### 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 Vlaamse Pijnliga  
Liisa Mikkonen, Suomen Kipu Ry



# 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*

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, can range from €1.1 billion in Finland to nearly €50 billion in Germany.<sup>46</sup> The total cost of chronic pain across Europe is difficult to calculate due to a lack of comprehensive data. However, available estimates imply an overall burden in the hundreds of billions – perhaps as high as €300 billion at the upper end for the whole of the European Union (extrapolating the results of the German study).<sup>4</sup> This is consistent with estimates of chronic pain costing around 1.5 - 3 % GDP.<sup>56</sup>

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.<sup>8</sup> The scale of these indirect costs greatly exceeds the direct costs of managing pain, and suggests that even incremental increases in the effectiveness of pain management could reap large economic rewards.

The economic case for prioritising pain management is compelling. Tackling inefficiencies in pain management can deliver savings to health budgets and, given the direct relationship between chronic pain and both incapacity and workforce productivity, generate a boost to European economies in the near to medium term. Examples from Europe show that services and patient satisfaction can be improved while cutting expenditure.<sup>13</sup> The scale of the growing challenges facing Europe calls for immediate action to replicate and realise the benefits demonstrated in a number of trailblazing examples around Europe.

## Direct Costs of Chronic Pain

Direct costs of chronic pain include the cost of medications or other treatments and the healthcare staff time needed to administer them. Patients with chronic pain are greater users of health services than those without chronic pain.<sup>11</sup> A Finnish study, where 21 % of patients had experienced pain for 6 months or longer, found that pain accounted for 40 % of consultations with primary care physicians.<sup>42</sup> Additionally, there is a direct relationship between pain severity and health resources consumed.<sup>43</sup>

### Pain Accounts for Significant Healthcare Expenditure

Past estimates have pointed to direct costs of pain of around €187 million for Belgium,<sup>7</sup> \$368 million (€289 million) for the Netherlands<sup>8</sup> and over £1.6 billion (€1.9 billion) for the UK.<sup>9</sup>

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). The vast majority were for non-opioids, 38 million prescriptions at a cost of £150 million (€180 million), and NSAIDs, 16 million prescriptions at a cost of £96 million (€115 million).<sup>44</sup> In addition to prescription drugs, an estimated 23-59 % of people in England take non-prescription drugs for their pain.<sup>35</sup>

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.<sup>6</sup> 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.<sup>45</sup>

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; people with severe pain visited a healthcare professional an average of 13 times in the past six months, double the average number of visits made by the general adult population. 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 – more than double the percentage for the general population in both instances.<sup>10</sup>

### Ineffective Pain Management is Generating Avoidable Costs

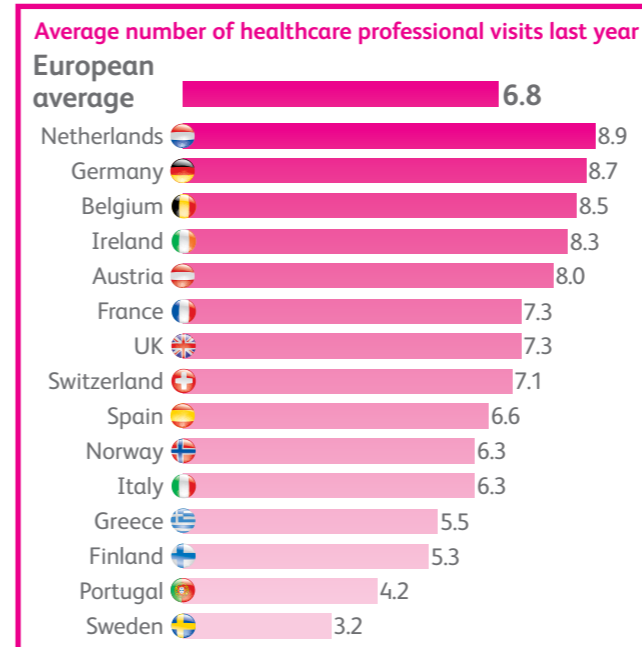
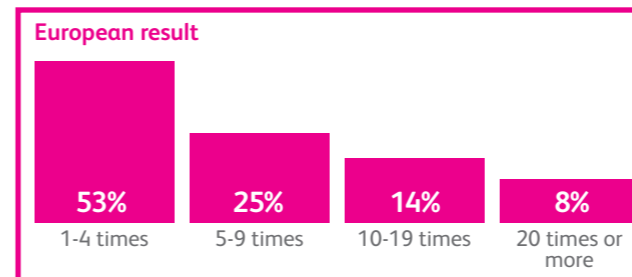
Much of the available evidence on the direct costs of pain indicates that ineffective or inefficient management of pain is responsible for a significant proportion of costs. A UK study in 2002 estimated there were 4.6 million primary care consultations per year involving chronic pain. This consultation time amounted to employment of 793 full-time Primary Care Physicians at a cost of approximately £69 million (€82 million). The study highlighted inadequate management with use of ineffective or poorly tolerated medications as a major factor in the number of consultations.<sup>46</sup>

The lack of clear pathways for those with chronic pain also plays a significant role in the accumulation of costs. The care of people with chronic pain can involve a wide range of medical specialisms, resulting in a fragmented approach to management, where no one group is accountable for improvements or outcomes.

The Pain Proposal survey 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 and to whom.<sup>16</sup> 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.<sup>16</sup> The findings suggest that inappropriate referrals to specialists, a key driver of healthcare costs, may be happening around Europe. As a result of this, direct costs could be 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 primary care professionals indicates that education has a 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.<sup>16</sup>

### Number of Times a Healthcare Professional was Visited Last Year<sup>3</sup>

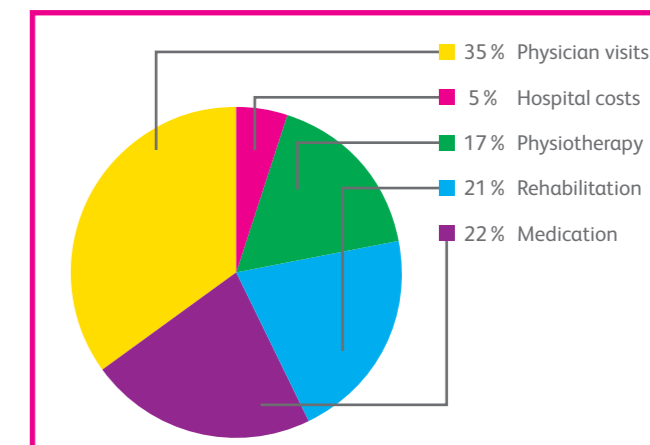


## Summary of Direct Costs of Pain and Pain Management

- Costs of interventions and therapies for treating pain (e.g. drug and costs of therapists)
- Costs related to ineffective interventions (e.g. additional GP 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. The real cost of pain management. Anesthesia.56; 1031-1033 (2001).

## Direct Costs of Backache in Germany



From Phillips CJ. Economic burden of chronic pain. Expert Rev. Pharmacoeconomics Outcomes Res 2006.

# 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 care for a relative suffering disabling chronic pain.

Taking back pain as an example, a UK study reports indirect costs (attributed to informal care and production losses) to be £10,688 million (€12,725.12 million), ten times the direct healthcare costs at £1,632 million (€1,947 million).<sup>9</sup> It has been estimated that as much as 90% of the burden of chronic pain can be attributed to indirect costs.<sup>8</sup>

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.<sup>47</sup>

## Summary of Indirect Costs of Pain Management

- Costs of disability claims 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

Adapted from Phillips CJ. The real costs of pain management. *Anesthesia*. 56; 1031-1033 (2001).

Despite the clear and significant impact of chronic pain on European economies, evidence on indirect costs is variable, as are methods of calculating which vary markedly 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 focusing on the UK, Ireland, Germany, Belgium, the Netherlands and Scandinavia are far more visible in the literature than analyses of Southern or Eastern European countries. Additionally, funding sources for these indirect costs is fragmented making the task of estimating the total burden difficult. The relative scarcity of consistent data on the indirect cost of pain highlights a need for more systematic research to gain a more accurate picture of the current impact of chronic pain on a national and Europe-wide basis.

It is nonetheless evident that the indirect costs of pain are a major drain 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.<sup>6</sup> Societal cost estimates reach figures as high as €50 billion a year in Germany for back pain alone.<sup>4</sup> Extrapolated to the 500 million population of the EU, this finding would point to a total cost approaching €300 billion, even without taking into account other causes of chronic pain. The following map 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. What cost chronic pain? *Ir Med J* 1996;89:218-219<sup>48</sup>  
**Year** – Not given  
**Country** – Ireland  
**Type of Pain** – Chronic 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 then totalled over the life of the 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 **£31,755** for patients with chronic non-malignant pain

**Reference** – Mantyselka PT et al. Direct and indirect costs of managing patients with musculo-skeletal pain – challenge for healthcare. *Eur J Pain* 2002;6:141-148<sup>6</sup>  
**Year** – 1996  
**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**  
 Median cost per patient visit **€74**  
 Range **€42 to €6952**  
 10% of visits generated 64% of total costs.  
 Implied total annual national cost (Finland): **€1.1 billion**, or 3% GNP

**Reference** – Van Tulder MW, Koes BW, Bouter LM A cost-of-illness study of back pain in the Netherlands. *Pain* 1995; 62:233-240.<sup>8</sup>  
**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 billion**  
 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

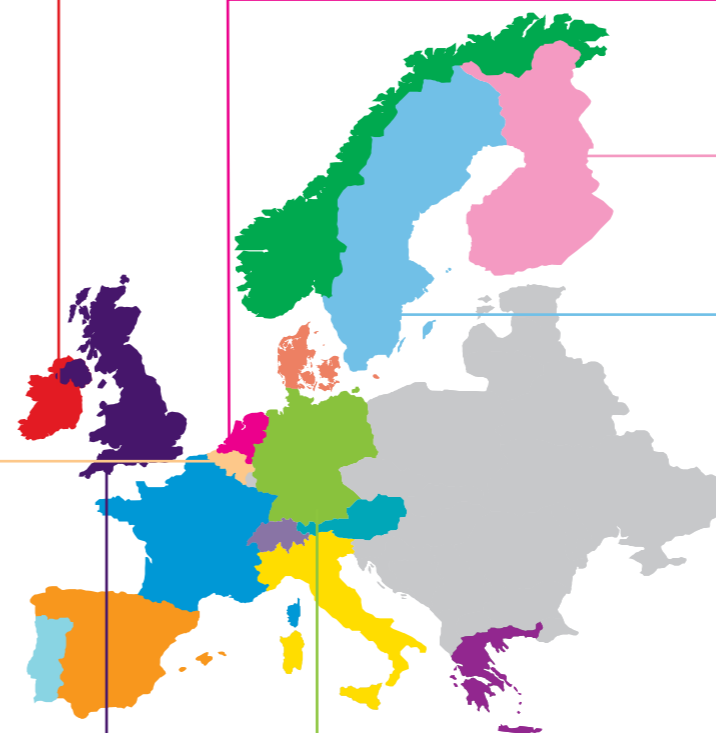
**Reference** – Ekman, F. Johnell, O. Lidgren, L. The economic cost of low back pain in Sweden in 2001. *Acta Orthopaedica* 2005;76(2):275-284.<sup>50</sup>  
**Year** – 2001  
**Country** – Sweden  
**Type of Pain** – Lower back pain  
**Scope of study** – Measured direct treatment costs and indirect 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: **€1.86 billion**  
 Indirect costs: **€1.56 billion**

**Reference** – Wenig CM, Schmidt CO, Kohlmann T, Schweikert B. Costs of back pain in Germany. *Eur J Pain* 2009;13:280-286<sup>4</sup>  
**Year** – 2007  
**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 billion**

**Reference** – Van Zundert J, Van Kleef M. Low Back Pain: From Algorithm to Cost Effectiveness. *Pain Practice* 2005; 5(3)179-189<sup>7</sup>  
**Year** – 1999  
**Country** – Belgium  
**Type of Pain** – Back pain  
**Scope of study** – Measures of the cost of 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: **€1.18 billion**  
 Direct costs of back pain treatment = **€187.0 million**  
 Costs of absenteeism = **€992.6 million**

**Reference** – Slead C, Eccleston C, Beecham J et al. The economic impact of Chronic Pain in adolescence: methodological considerations and a preliminary cost of illness study. *Pain* 2005;119:183-190<sup>49</sup>  
**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: **£3.84 million**  
 Mean cost per individual per year: **£8,000**

**Reference** – Maniadakis N, Gray A. The economic burden of back pain in the UK. *Pain* 2000;84:95-103<sup>9</sup>  
**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: **£6.65 billion** (friction cost method) – **£12.3 billion** (production loss cost)  
 Direct Cost: **£1.632 billion**



# 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. Pain Proposal data suggest that, on average, 21 % of Europeans with chronic pain are unable to work at all as a result of their chronic pain. Of those that are able to work, 61 % state their employment status is directly affected by their condition.<sup>3</sup> Another European survey found that almost a fifth (19 %) of those with chronic pain have lost their jobs as a result of their condition.<sup>1</sup>

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.<sup>51</sup> New data from five countries in Europe shows that people with severe pain had been absent for 27 % of work time in the last seven days, compared with 5 % for the general population.<sup>10</sup> Even when people do manage to attend work, loss of productivity or 'presenteeism' is a problem. Of those questioned in the 2010 survey, people with severe pain reported 54 % overall work impairment due to health compared with nearly 20 % for the general population, impacting the individuals themselves, employers and the wider economy.<sup>10</sup>

This is supported by Pain Proposal data showing that, on average, people with chronic pain are likely to take around 14 days off work a year due to their condition.<sup>3</sup> In addition, people with chronic pain feel so impaired by their pain that it impacts on their ability to do their job for more than a quarter (28 %) of the time they are in work.<sup>3</sup>

***“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 Pablo Vázquez, Executive Director, FEDEA*

## Welfare Budgets Bear the Cost of Incapacity

The negative economic impact of chronic pain on capacity to work falls not only on those with pain and on employers but also on government welfare budgets. A Danish study shows that people with chronic pain are seven times more likely than other individuals to leave a job because of ill health.<sup>11</sup> In the UK musculoskeletal conditions are the most common reason for people to receive incapacity benefit. As many as 3,000 UK citizens are added to the number receiving incapacity benefit each week; of these only 10 % ever return to work.<sup>12</sup> Leaving paid employment to be dependent on welfare payments or family members also has obvious repercussions on household incomes and standards of living.

As European populations age, we expect people to remain productive and work longer and so the likelihood is that the proportion of the workforce with chronic pain will continue to increase significantly.<sup>52</sup> This will put an even greater strain on those affected, their families, society, healthcare resources and the European economy.

Most people affected by chronic pain (80 % in the pain proposal survey) want to contribute to the economy and be active members of society.<sup>3</sup> 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. The Patient and Primary Care Physician Surveys 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.<sup>3</sup> 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 to which specialist.<sup>16</sup>

Well-managed patients with chronic pain consume fewer healthcare resources - the practical example of the Southampton Pain Clinic in the UK appears to illustrate this, with per patient cost savings of 35 %, largely driven by lower expenditure on GP visits and physiotherapy.<sup>14</sup> These savings 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 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.

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.

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. Strong communication between primary and secondary care has been critical to the success of the service.

The service has improved patient care with patient satisfaction at 75 %, <sup>14</sup> reduced waiting times to consistently around six to eight weeks and reduced drug spending within the Trust.<sup>13</sup> It has also been cost effective with cost savings per patient averaging £204.<sup>14</sup>

### 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 2008<sup>14</sup>

# Chronic Pain: A High Cost to Europe

## Joined-up Government Approach Needed to Tackle 'Hidden' Costs

As demonstrated, the costs of chronic pain to the public do not fall solely within the healthcare budget. Welfare expenditure in particular bears a heavy burden as a result of pain, through incapacity and unemployment benefit and the provision of local support services. Health budgets themselves are 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 both in the short as well as the longer term. However, coordination 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 (health and welfare) - are likely to be critical in 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. 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 primary care physician, 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 six to eight 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 six to eight 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 1 billion SEK 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 more than 84% 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***

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 primary care doctor first, only around half (53%) of these physicians 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.<sup>16</sup>

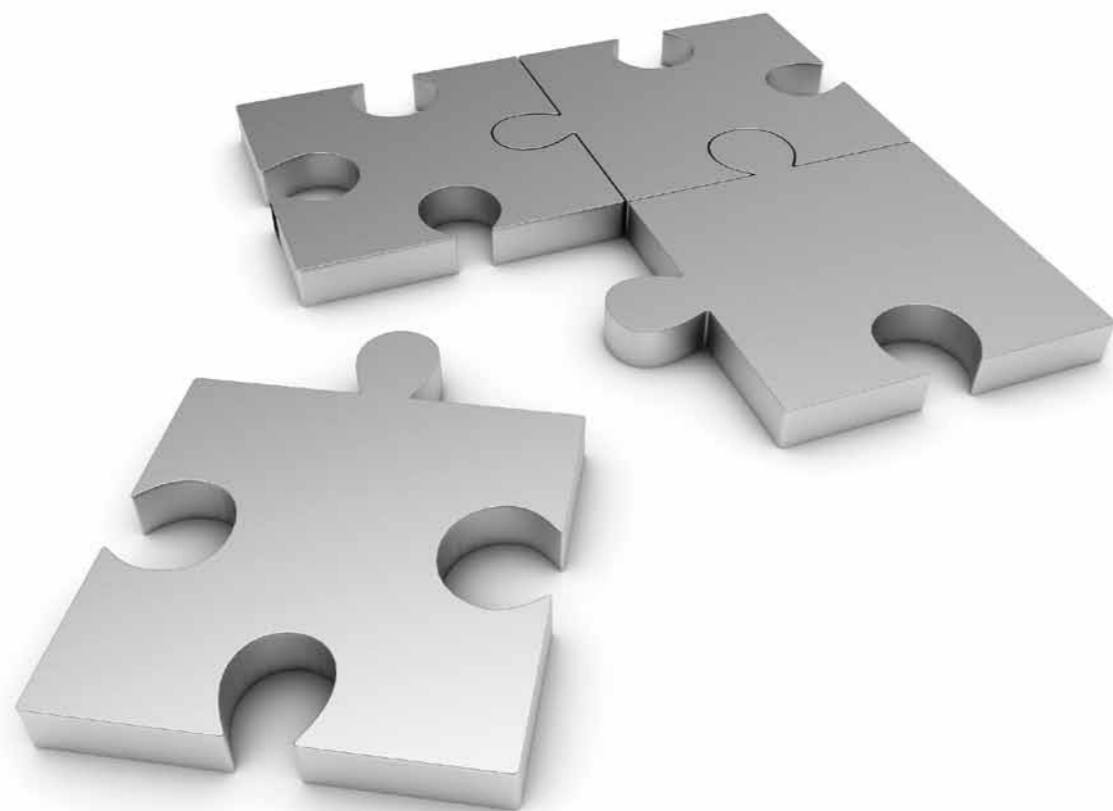
Pain is subjective and difficult for patients to describe and, in the absence of further training, primary care physicians may find it challenging to understand patients' experiences. This could result in communication problems between physicians and their patients,<sup>53</sup> making it difficult to 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.<sup>33</sup> Most available treatment modalities offer modest improvements and full recovery of function is rarely achieved. Supporting healthcare professionals in setting appropriate pain management objectives with their patients could help to achieve better outcomes.<sup>37</sup>

Current levels of training and education do not always leave medical practitioners equipped to employ best practice in pain management. 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.<sup>16</sup>

***“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 Giustino Varrassi, EFIC President, L'Aquila University***



## Undergraduate Training

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 serve as a flexible model to be used as a guideline.<sup>54</sup> 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 imparting interpersonal skills and knowledge of the human aspects of care. Some patients report that their doctors failed even to ask about their pain.<sup>1</sup>

In 2009, the UK's Pain Society proposed 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.<sup>15</sup> 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 use of pain educational resources and models of good practice in undergraduate pain education should be identified and shared. A number of resources have been developed and this report supports the use of the IASP pain curriculum in Europe.<sup>15</sup> EFIC has also issued a call for specialist training in Europe.<sup>55</sup>

## Spotlight On... Certification of Pain Specialists

### Competence in Pain Management - Portugal

The Portuguese Medical Association is the entity responsible for attributing specialisation certificates to medical doctors in Portugal. These fall into three categories: specialty, subspecialty and competence. Following a proposal endorsed by eight national scientific societies, the Portuguese Medical Association created a Competence in Pain Medicine in 2006. In order to get such a certificate, any medical specialist, including family doctors, must fulfil the following conditions: (1) completion of 120 hours of theoretical courses; (2) completion of practical work equivalent to 12 hours per week for two years in a Multidisciplinary Pain Clinic; (3) participation in at least one basic or clinical research project on pain; (4) presentation or publication at national or international level of at least three papers on pain. Currently, approximately 120 Portuguese MDs hold the Competence in Pain Medicine.

There are examples 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. The Pain Proposal survey found that 85% of primary care physicians supported this stance.<sup>16</sup>

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.

## 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 management 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.”

**Professor Burkhard Gustorff,  
Head of Anaesthesiology and Intensive Care,  
Vienna Medical University**

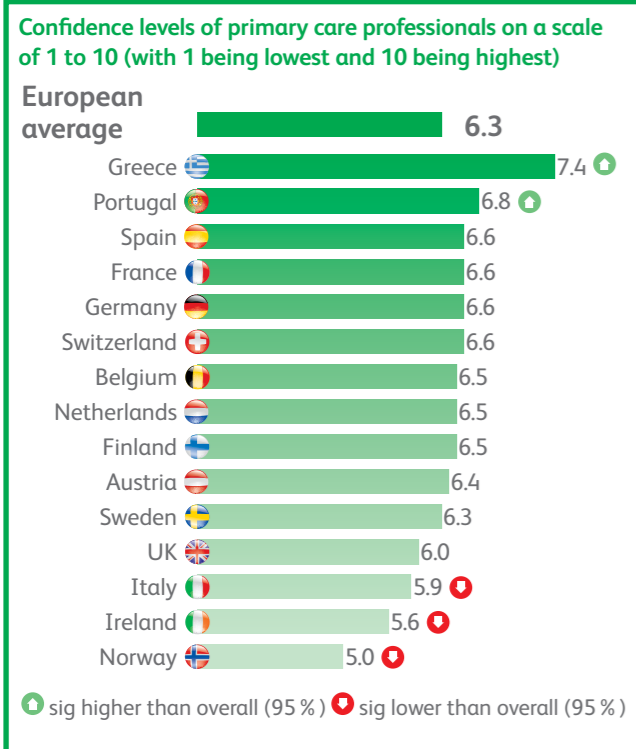
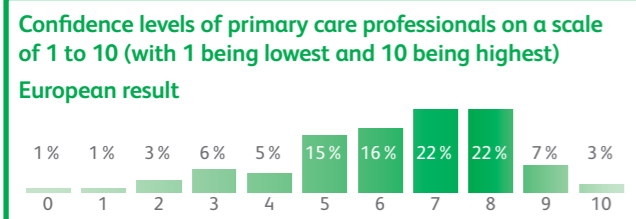
# Physician Training is Paramount

## Improved Clarity Around Guidelines is Needed

Specific clinical guidelines for managing chronic pain are sporadic. At the macro level, a World Health Organisation (WHO) Steering Committee published a scoping document for WHO treatment guidelines for chronic non-malignant pain in adults in 2008.<sup>56</sup> At a national level, not all European countries have devised their own guidelines. Usually, where advice on chronic 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. The Pain Proposal Primary Care Physician survey shows that some doctors (39%) may lack confidence in consulting with people in chronic pain and many do not know when to make a referral (36%) or change treatment (47%).<sup>16</sup> This would seem to indicate a need for assistance in navigating the guidelines that are currently available.

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 of Primary Care Professionals in Using and Understanding Existing Guidelines for the Management of Chronic Pain<sup>16</sup>



## 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 change is delivered.

### 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 ensure the law reaches 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 revolutionised.

### 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 are as follows:

- 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 Plan – The Portuguese Perspective

#### Portuguese National Strategy for Pain

In 2001, the Portuguese government approved a National Plan Against Pain, with the main goal of creating Chronic Pain Clinics and establishing Acute Post-operative Pain Services in 75% of the Portuguese public hospitals. Since then, the number of Chronic Pain Clinics has grown by 65 but, unfortunately, the percentage of public hospitals having organised post-operative pain services has remained low at 25%. In 2008, a new National Programme for Pain Control was approved, with the following main objectives: (1) reducing the prevalence of non-managed pain in the Portuguese population; (2) improving the quality of life of patients living with pain; (3) rationalising resources and controlling the costs necessary for pain management. In order to achieve these main objectives and several other specific goals, three types of strategies were designed: (a) intervention strategies, focused on the reinforcement of the organisational capacity and the development of good practice models for pain management; (b) training strategies, aimed at healthcare professionals, and within the scope of communication, to the general population; (c) strategies for gathering and analysing information, with an emphasis on the epidemiological characteristics of pain and its distribution amongst the Portuguese population, as well as measuring the health benefits arising from pain treatment. The programme is currently being implemented under the guidance of a national steering committee.

### 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.

# Access to Appropriate Services 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.”**

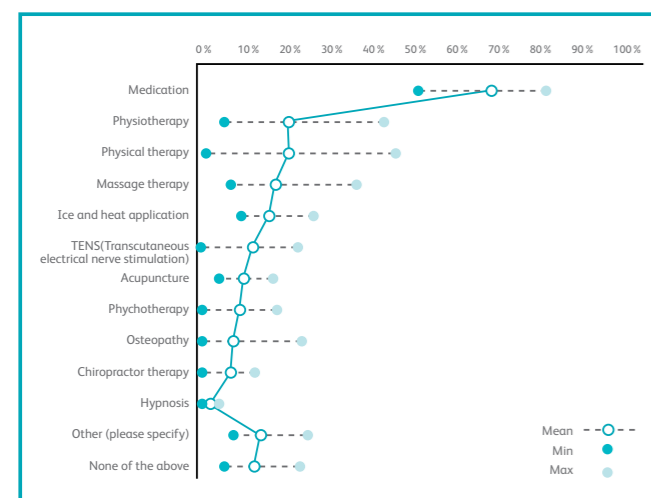
**Professor Giustino Varrassi, EFIC President, L’Aquila University**

According to international human rights law, governments must take steps to ensure that people have adequate access to treatment for their pain. Failure to do so may result in the violation of a person’s right to health.<sup>31</sup>

The most appropriate treatment for chronic pain will depend on the pain type and the needs of the individual; for example, pain with a neuropathic component will require a different approach to purely nociceptive pain. The needs of patients may require an intergrated, more multidisciplinary approach to pain management involving appropriate behavioural therapy, as well as input from a broad range of healthcare professionals.<sup>57,14</sup> This approach is available at specialist pain clinics but access to them is limited and waiting times for referral can be long.

## Chronic Pain – Treatment Type

Percentage use of treatments currently used by people with chronic pain<sup>3</sup>



People with chronic pain 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, opioids may be used. The WHO (World Health Organization) 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.<sup>32</sup>

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. However, 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.<sup>58</sup>

## 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

Despite advances in the understanding of the pathophysiology of pain, benefits for patients with chronic pain remain limited, indicating a need for further basic and translational research in the field. While a range of treatments for chronic pain are available, we know from the Pain Proposal Patient Survey that over a third (38%) of people say their pain is not adequately managed.<sup>3</sup> This is particularly interesting given that the Pain Proposal Survey shows that less than half of primary care doctors (46%) are confident in knowing what to do if initial treatment is unsuccessful and pain persists.<sup>16</sup>

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 worsening of inadequately managed pain.

## 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, assesses 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 doctor to consider other treatments.

This model has increased the efficiency, 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 model has worked well and reduced the number of telephone calls for reassurance from patients.

## The Role of Specialist Pain Clinics

Specialist pain clinics, with expertise in diagnosing and treating chronic pain, are available in many European countries. 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. While many major hospitals will operate a chronic pain management service, 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. A recent IASP survey found that there are significant problems with waiting times and access to pain services, resulting in worsening of patients’ pain.<sup>59</sup>

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 six months for treatment experience deterioration in quality of life, psychological wellbeing and depression.<sup>17</sup>

# The Pain Proposal Recommendations: What Needs to Change?

## 1. Call to Action 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. Call to Action 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 - identify 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 of 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. Call to Action 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. Call to Action 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. These challenges have 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 'absenteeism' and 'presenteeism' 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 people in Europe who suffer from chronic pain.

*“European economies cannot sustain the current spend on chronic pain – for example welfare costs which may run into millions. There are steps we can take to improve the current system and help people get the recognition, diagnosis and treatment they need for this life-long condition. We believe that by working together to address inefficiencies we can make this goal a reality.”*

*Professor Giustino Varrassi,*

*President of the European Federation of IASP Chapters (EFIC),*

*Professor and Chairman, Department of Anaesthesiology and Pain Medicine, L'Aquila University Medical School, Italy*

*“The perception that people with chronic pain can't or don't want to work is wrong. Many pain sufferers are productive, talented and committed employees with the same aspirations and ambitions as people without chronic pain and shouldn't be limited by their condition. Yet the system is failing many people living with pain – preventing them from playing their full part in the nation's workforce.”*

*Dr. Mary Baker, MBE*

*President, European Federation of the Neurological Associations*



# References

- <sup>1</sup>Breivik H, Collett B, Ventafridda V, Cohen R, Gallagher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *Eur J Pain* 2006;10:287-333.
- <sup>2</sup>Poole H, White S, Blake C et al. Depression in chronic pain patients: prevalence and measurement. *Pain Pract* 2009;9:173-180.
- <sup>3</sup>InSites Consulting. Pain Proposal Patient Survey. July – September 2010.
- <sup>4</sup>Wenig CM, Schmidt CO, Kohlmann T, Schweikert B. Costs of Back Pain in Germany. *Eur J Pain* 2009;13:280-286.
- <sup>5</sup>Phillips CJ Economic burden of chronic pain. *Expert Rev Pharmacoecon Outcomes Res* 2006;6:591-601.
- <sup>6</sup>Mantyselka PT et al. Direct and indirect costs of managing patients with musculo-skeletal pain – challenge for healthcare. *Eur J Pain* 2002;6:141-148.
- <sup>7</sup>Van Zundert J, Van Kleef M. Low Back Pain: From Algorithm to Cost Effectiveness. *Pain Practice* 2005; 5(3)179-289.
- <sup>8</sup>Van Tulder MW, Koes BW, Bouter LM. A cost of illness study of back pain in the Netherlands. *Pain* 1995;62:233-240.
- <sup>9</sup>Maniadakis N, Gray A. The economic burden of back pain in the UK. *Pain* 2000;84:95-103.
- <sup>10</sup>Kantar Health. National Health and Wellness Survey, 2010.
- <sup>11</sup>Eriksen J, Jensen MK, Sjogren P, Ekholm O, Rasmussen NK. Epidemiology of chronic non-malignant pain in Denmark. *Pain* 2003;106:221–228.
- <sup>12</sup>Frank AO, Chamberlain MA. Keeping our patients at work: implications for the management of those with rheumatoid arthritis and musculoskeletal conditions. *Rheumatology* 2001;40:1201–1205.
- <sup>13</sup>Price, C. Managing pain management. Setting up an effective pain service in Southampton. *Bulletin* 36; The Royal College of Anaesthetists. March 2006.
- <sup>14</sup>Welsh Assembly Government. Designed for People with Chronic Conditions: Service Development and Commissioning Directives. June 2008.
- <sup>15</sup>The Pain Education Special Interest Group of the British Pain Society. Survey of undergraduate pain curricula for healthcare professionals in the United Kingdom 2009. Available at: <http://www.britishpainsociety.org> Last accessed 13.09.10.
- <sup>16</sup>InSites Consulting. Pain Proposal PCP Survey. July – September 2010.
- <sup>17</sup>Lynch ME, Campbell FA, Clark AJ et al. A systematic review of the effect of waiting for treatment for chronic pain. *Pain* 2008;136:97-116.
- <sup>18</sup>Sjogren P, Ekholm O, Peuckmann V, Grønbaek M. Epidemiology of chronic pain in Denmark: an update. *Eur J Pain* 2009;13:287-292.
- <sup>19</sup>Bouhassira D, Lantéri-Minet M, Attal N, Laurent B, Touboul C. Prevalence of chronic pain with neuropathic characteristics in the general population. *Pain* 2008;136:380-387.
- <sup>20</sup>Bucker B, Groenewold M, Schoefer Y, Schäfer T. The use of complementary alternative medicine (CAM) in 1001 German adults: results of a population-based telephone survey. *Gesundheitswesen* 2008;70:e29-e36.<sup>21</sup>Perquin CW, Hazebroek-Kampschreur AA, Hunfeld JA et al. Pain in children and adolescents: a common experience. *Pain* 2000;87:51-58.
- <sup>22</sup>Rustoen T, Wahl AK, Hanestad BR et al. Age and the Experience of Chronic Pain: Differences in Health and Quality of Life Among Younger, Middle-Aged, and Older Adults. *Clin J Pain* 2005;21:513-523.
- <sup>23</sup>Catala E, Reig E, Artes M et al. Prevalence of pain in the Spanish population, prevalence in 5000 homes. *Eur J Pain* 2002;6:133-140.
- <sup>24</sup>Gerdle B, Bjork J, Henriksson C, Bengtsson A. Prevalence of current and chronic pain and the influences upon work and healthcare-seeking: a population study *J Rheumatol* 2004;31:1399-1406.
- <sup>25</sup>Torrance N, Smith BH, Watson MC, Bennett MI. Medication and treatment use in primary care patients with chronic pain predominantly of neuropathic origin. *Fam Pract* 2007;24:481-485.
- <sup>26</sup>Parsons S, Breen A, Foster NE et al. Prevalence and comparative troublesomeness by age of musculoskeletal pain in different body locations. *Fam Pract* 2007;24:308-316.
- <sup>27</sup>Smith BH, Elliott AM, Chambers WA et al. The impact of chronic pain in the community. *Fam Pract* 2001;18:292-299.
- <sup>28</sup>Moore A, Edwards J, Barden J, McQuay H. *Bandolier's Little Book of Pain* Oxford: OUP, 2003.
- <sup>29</sup>Merskey H, chairman. Pain terms: a current list with definitions and notes on usage. *Pain* 1986;(Suppl.3):S215-S221.
- <sup>30</sup>EFIC. Declaration on pain as a major health problem, a disease in its own right. Available at: <http://www.efic.org/pain-efic-declaration.php> Last accessed 13.09.10.
- <sup>31</sup>Lohman D, Schleifer R, Amon JJ. Access to pain treatment as a human right. *BMC Med* 2010;8:8.
- <sup>32</sup>National Institute for Health and Clinical Excellence. Neuropathic pain: the pharmacological management of neuropathic pain in adults in non-specialist settings. *Clinical Guideline* 96. London: NICE, 2010.
- <sup>33</sup>Dewar AL, Gregg K, White MI, Lander J. Navigating the health care system: perceptions of patients with chronic pain. *Chronic diseases in Canada* 2009;29:162-168.
- <sup>34</sup>Tang NKY, Crane C. Suicidality in chronic pain: a review of the prevalence, risk factors and psychological links. *Psychol Med* 2006;36:575-586.
- <sup>35</sup>Woolf AD, Zeidler H, Hagland U et al. Musculoskeletal pain in Europe: its impact and a comparison of population and medical perceptions of treatment in eight European countries. *Ann Rheum Dis* 2004;63:342–347.
- <sup>36</sup>Cano A, Miller LR, Loree A. Spouse beliefs about partner chronic pain. *J Pain* 2009;10:486-492.
- <sup>37</sup>Woolf A, Carr A, Frohlich J, et al. Investigating the barriers to effective management of musculoskeletal pain: an international survey. *Clin Rheumatol* 2008;27:1535-1542.
- <sup>38</sup>Chronic Pain Ireland. Charter of Rights for people living with chronic pain 2009. Available at: <http://www.chronicpainireland.org/index.php?q=membership>. Last accessed 13.09.10.
- <sup>39</sup>IASP. Declaration of Montreal 2010. Available at: <http://www.prnewswire.com/news-releases/health-care-professionals-and-advocates-from-84-countries-to-issue-declaration-that-access-to-pain-management-is-a-fundamental-human-right-102137469.html>. Last accessed 13.09.10.
- <sup>40</sup>Can You Feel My Pain? Patient Bill of Rights. Available at: <http://www.action-on-pain.co.uk> Last accessed 13.09.10.
- <sup>41</sup>Active Citizenship Network. European Charter of Patients' Rights. 2002.
- <sup>42</sup>Mantyselka P, Kumpusalo E, Ahonen R, et al. Pain as a reason to visit the doctor: a study in Finnish primary health care. *Pain* 2001; 89:175-180.
- <sup>43</sup>Blyth FM, March LM, Brnabic AJM, Cousins MJ. Chronic pain and frequent use of health care. *Pain* 2004;111:51–58.
- <sup>44</sup>NHS Information Centre. Prescription Cost Analysis for England 2009. Available at: <http://www.ic.nhs.uk> Last accessed 13.09.10.
- <sup>45</sup>Bolton W, Kempel-Waibel A, Pforringer W. Analysis of the cost of illness in backache. *Med Klin* 1998;93:388-393.
- <sup>46</sup>Belsey J. Primary care workload in the management of chronic pain: a retrospective cohort study using a GP database to identify resource implications for UK primary care. *J Med Econ* 2002;5:39–50.
- <sup>47</sup>EFIC. Costs of Chronic Pain 2009. Available at: <http://www.efic.org/costs-of-chronic-pain.php> <<http://www.efic.org/costs-of-chronic-pain.php>> Last accessed 13.09.10.
- <sup>48</sup>Sheehan J, McKay J, Ryan M, Walsh N, O'Keefe D. What cost chronic pain? *Ir Med J* 1996;89:218-219.
- <sup>49</sup>Sleed C, Eccleston C, Beecham J et al. The economic impact of chronic pain in adolescence: methodological considerations and a preliminary cost of illness study. *Pain* 2005;119:183-190.
- <sup>50</sup>Ekman, F, Johnell, O, Lidgren, L. (2005). The Economic cost of low back pain in Sweden in 2001. *Acta Orthopaedica* 2005; 76 (2): 275–284.
- <sup>51</sup>CBI/Pfizer 'On the path to recovery': Absence and workplace health survey, June 2010.
- <sup>52</sup>Brennan F, Carr D, Cousins M. Pain management: a fundamental right. *Anesth Analg* 2007;105:205-221.
- <sup>53</sup>Matthias MS, Bair MJ, Nyland KA et al. Self-management support and communication from nurse care managers compared with primary care physicians: a focus group study of patients with chronic musculoskeletal pain. *Pain Manag Nurs* 2010;11:26-34.
- <sup>54</sup>Pilowsky I. An outline curriculum on pain for medical schools. *Pain* 1988;33:1-2.
- <sup>55</sup>EFIC's call for Specialization and Certification in Pain Medicine. Available at: <http://www.efic.org/edu-call-for-specialization.php>. Last accessed 13.09.10.
- <sup>56</sup>World Health Organisation Steering Group on Pain Guidelines. Scoping Document for WHO Treatment Guidelines on Chronic Non-Malignant Pain in Adults 2008. Available at: [http://www.who.int/medicines/areas/quality\\_safety/Scoping\\_WHOGuide\\_non-malignant\\_pain\\_adults.pdf](http://www.who.int/medicines/areas/quality_safety/Scoping_WHOGuide_non-malignant_pain_adults.pdf) Last accessed 13.09.10.
- <sup>57</sup>Giordano J, Schatman ME. A crisis in chronic pain care: an ethical analysis. Part 3: Towards an integrative multidisciplinary pain medicine built around the needs of the patient. *Pain Physician* 2008;11:775-784.
- <sup>58</sup>Ernst E. How the public is being misled about complementary/alternative medicine. *J R Soc Med* 2008;101:528-30.
- <sup>59</sup>IASP Task Force on Wait-Times: summary and recommendations 2009. Available at: <http://www.iasp-pain.org/AM/AMTemplate.cfm?Section=Home&CONTENTID=11228&TEMPLATE=/CM/ContentDisplay.cfm> Last accessed 13.09.10.