Societal Impact of Pain (SIP) 2017
Valletta, Malta
07 - 09 June, 2017

SIP 2017
Proceedings

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SIP
Societal Impact of Pain

STRUCTURED COOPERATION BETWEEN HEALTH CARE SYSTEMS TACKLING THE SOCIETAL IMPACT OF PAIN!

#SIP2017

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Societal Impact of Pain (SIP) Symposium 2017

STRUCTURED COOPERATION BETWEEN HEALTH CARE SYSTEMS TACKLING THE SOCIETAL IMPACT OF PAIN!

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This booklet is published following the European symposium on the Societal Impact of Pain (SIP 2017) in Valletta (Malta), 07 - 09 June, 2017.

About this booklet

This booklet contains background readings to SIP 2017, providing contextual information on the working groups' discussions and outcomes. You can copy, download or print the content of this booklet for your own use provided that suitable acknowledgement of the Societal Impact of Pain (SIP) platform, as well as to the participating authors as source and copyright owner is given. All requests for public or commercial use and translation rights should be submitted to sip-platform@grunenthal.com. Due to printing deadlines this booklet, however, does not guarantee inclusiveness of each speaker or organisation. The final complete version will be made available electronically at www.sip-platform.eu.

About the “Societal Impact of Pain” and the SIP platform

The burden that pain imposes on individuals and the enormous costs that society has to bear, not only by healthcare systems, but also related social, economic and employment costs, illustrate the urgency for European governments and the EU institutions to act and to put the societal impact of pain on their policy agenda. Basic and clinical sciences have demonstrated the feasibility of care pathways out of pain for many types of acute and chronic pain, but healthcare systems frequently do not guarantee general access for patients to these. In order to address the societal impact of pain, different stakeholder groups joined forces in 2009.

Today the SIP is an international multi-stakeholder platform aiming to:
- Raise awareness of the relevance of the impact that pain has on our societies, health and economic systems
- Exchange information and share best-practices across all member states of the European Union
- Develop and foster European-wide policy strategies & activities for an improved pain care in Europe (Pain Policy)

The scientific framework of the “Societal Impact of Pain” (SIP) platform is under the responsibility of the European Pain Federation EFIC®.
Cooperation partners for SIP 2017 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN).
The SIP 2017 symposium has been co-hosted by the Malta Health Network and the No Pain Foundation.
The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support).The scientific aims of the SIP symposia have been endorsed by more than 300 international and national pain advocacy groups, scientific organisations and authorities.

More information on events and publications by the SIP platform can be found at: www.sip-platform.eu.

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You will find complete background information on the speakers and endorsing organisations in the SIP 2017 background and abstract booklet on our website:
www.SIP-platform.eu

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WHO ELSE SUPPORTED SIP 2017?

Dear Reader,

We are pleased to present the proceedings of the 7th symposium of the "Societal Impact of Pain" (SIP 2017) from June 7-9 in Valletta, Malta. SIP 2017 took place under the auspices of the 2017 Maltese Presidency of the Council of the EU with the title "Structured Cooperation between Health Care Systems tackling the societal impact of pain!" The symposium brought together about 300 international experts in the field of pain care, along with patient representatives, policy makers and other stakeholders in the field of pain policy and representing more than 200 international and national organisations.

Clear policy recommendations were formulated to change pain care in the European Union for the better and alleviate the effect of pain on society. Four working groups at SIP 2017 developed individual suggestions targeting the issues discussed:

1. Establish an EU platform on the societal impact of pain
2. Develop instruments to assess the societal impact of pain
3. Initiate policies addressing the impact of pain on employment
4. Prioritise pain within education for health care professionals, patients and the general public
5. Increase investment in research on the Societal Impact of Pain

As a major highlight at SIP 2017 - Martin Seychell, Deputy Director General in the European Commission responsible for Health and Food Safety', announced in his speech that the European Commission is following SIP's lead and has launched the "Expert Group on Social Impact of Pain" in the framework of the EU Health Policy Platform, to build a bridge between health systems and policy makers on the topic. Ultimately, the expert group that is to be composed will be an instrument that enhances best practice sharing across EU member states, in coordination with the Commission. Once fully functioning, public health groups in all areas, employers' organizations, insurers, economists and even digital stakeholders are expected to be involved. This is a huge step forward for our efforts and for patients throughout Europe.

Further, it has been a great achievement that under the leadership of the Maltese Presidency, EU Health Ministers have agreed that it is time to evaluate access to treatment for patients with chronic pain. This is a substantial step for pain patients throughout the EU, and will hopefully be carried forward as part of the Council of the European Union's continued focus on effective, accessible and resilient healthcare systems. The Societal Impact of Pain (SIP) platform is committed to ensure that these words are transformed into actions.

The scientific framework of the SIP symposium and platform is under the responsibility of the European Pain Federation EFIC®. Cooperation partners for SIP 2017 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The SIP 2017 symposium has been co-hosted by the Malta Health Network and the No Pain Foundation. The pharmaceutical company Grünenthal GmbH has been responsible for funding and non-financial support (e.g. logistical support).

Until now the objectives of the SIP platform have been endorsed by an impressive number of more than 300 pain advocacy and scientific organisations and that number is still increasing. This underlines the increasing awareness on the Societal Impact of Pain Initiative and is a great chance to collaborate together in a structured way involving all the different stakeholder groups.

What is coming next?

In the coming months the partners of the SIP platform will continue to raise the SIP 2017 recommendations with policy makers and influential stakeholder. Further the "Expert Group on Social Impact of Pain" of the EU Health Policy Platform will be established to make this initiative a great success.

HAPPY READING.

On behalf of the Societal Impact of Pain (SIP) EU Platform

Prof. Bart Morlion
European Pain
Federation EFIC®

Joop van Griensven
Pain Alliance Europe

Mariano Votta
Active Citizenship
Network

Norbert Van Rooij
Grünenthal
GmbH

Ad-hoc SIP platform on Malta

Gertrude A. Buttigieg
Malta Health
Network

Silvana Fanalista
No Pain
Foundation

“The Societal Impact of Pain A Road Map for Action”

In 2001, the European Federation of the International Association for the Study of Pain Chapters (EFIC®) published its Declaration on Pain which called on national governments and the EU Institutions to increase the level of awareness of the societal impact of pain. Ten years on from the EFIC Declaration on Pain, national and EU policy action has been very limited. At the same time, basic and clinical science have demonstrated the feasibility of pathways out of pain for many types of acute and chronic pain, but health care systems currently do not guarantee general access to these.

According to the 2007 Eurobarometer survey on “Health in the European Union”, almost one third of respondents experience musculo-skeletal pain which affects their day-to-day life. The burden of suffering that pain imposes on individuals and the enormous costs that society has to bear not only by healthcare systems but also the social, economic and employment sectors only illustrate the urgency for European governments and the EU Institutions to act and to put, as a priority, the societal impact of pain on their policy agenda.

We call on European governments and the EU Institutions to:

1. Acknowledge that pain is an important factor limiting the quality of life and should be a top priority of the national health care system.
2. Activate patients, their family, relatives and care-givers through the availability of information and access to pain diagnosis and management.
3. Raise awareness of the medical, financial and social impact that pain and its management has on the patients, their family, care-givers, employers, and the healthcare system.
4. Raise awareness of the importance of prevention, diagnosis and management of pain amongst all healthcare professionals, notably through further education.
5. Strengthen pain research (basic science, clinical, epidemiological) as a priority in EU framework programme and in equivalent research road maps at national and EU level, addressing the societal impact of pain and the burden of chronic pain on the health, social, and employment sectors.
6. Establish an EU platform for the exchange, comparison and benchmarking of best practices between member states on pain management and its impact on society.
7. Use the EU platform to monitor trends in pain management, services, and outcomes and provide guidelines to harmonize effective levels of pain management to improve the quality of life of European Citizens.

This “Road Map for Action” to address the societal impact of pain in the EU has been endorsed by many organisations and was signed at the Symposium “Societal Impact of Pain 2011”, 3-4 May 2011, Brussels.

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[1] Eurobarometer survey on “Health in the European Union”, Special Eurobarometer 272e, September 2007 http://ec.europa.eu/health/ph_publication/eb_health_en.pdf

The most current version of this document can be found online at www.efic.org

Societal Impact of Pain (SIP) 2016
8 policy recommendations: Time for Action

The organizing partners of the SIP platform formulated the following key recommendations directed at the institutions of the European Union and national governments:

1. **Implementation of article 8.5 of the Cross-border healthcare Directive**

   The institutions of the European Union and national governments should ensure the flawless implementation of article 8.5 of Directive 2011/24/EU in all member states, in order to prevent the refusal of prior authorisation by national health authorities when the patient is entitled to healthcare which cannot be provided on its territory within a time limit which is medically justifiable, based on an objective medical assessment of the patient´s medical condition, the history and probable course of the patient´s illness, the degree of the patient´s pain and/or the nature of the patient´s disability at the time when the request for authorisation was made or renewed.

2. **Establish an EU platform on the societal impact of pain**

   In order to empower pain patients, their family, relatives and care-givers through the availability of information and access to pain diagnosis and management, the institutions of the European Union and national governments should establish an European platform for the exchange, comparison and benchmarking of access, quality and best practices of healthcare services in pain management and its impact on society.

3. **Integrate chronic pain within EU policies on chronic diseases**

   The institutions of the European Union and national governments should acknowledge that pain is a common health state in many chronic diseases and chronic pain itself can be considered a chronic condition in respect to healthcare policy. Therefore the European Commission and member states should integrate pain care within Commission work and Joint Actions (e.g. JA CHRODIS) as well as the expected trio council conclusions on fighting non-communicable diseases.

4. **Ensure that pain care is a part of policies and strategies on cancer**

   Within the framework of the Joint Action on Cancer Control (JA CanCon) and national cancer strategies, the institutions of the European Union and national governments should dedicate adequate attention to the relevance of pain in cancer care, including but not limited to survivorship and rehabilitation.

5. **Initiate policies addressing the impact of pain on employment**

   Within the context of the Europe 2020 Strategy and European Semester framework of economic governance, the institutions of the European Union and national governments should promote policies that reflect the link between pain care and employment, and recognise the interconnection of health, employment and social protection policies and systems.

6. **Implement workplace adjustments for people with chronic pain**

   The institutions of the European Union and national governments should enforce or implement legislation providing for reasonable, flexible workplace adjustments by employers that can help people with chronic pain stay in work or reintegrate into the workforce.

7. **Increase investment in pain research**

   The institutions of the European Commission and national governments should increase investment in research (basic science, clinical, epidemiological) on the societal impact of pain as a priority in future EU framework programs, involving chronic pain patient associations in the development of research priorities, and undertake research on involuntary causes of early retirement and unemployment due to pain across Europe.

8. **Prioritise pain within education for healthcare professionals, patients and the general public**

   The institutions of the European Union and national governments should prioritise and stimulate the prevention of the impact of pain on society by education and providing information on diagnosis, and management of pain amongst all healthcare professionals, patients and the general public through education and training.

Societal Impact of Pain 2017

Policy Recommendations

8-9 June 2017 - Under the motto 'Structured Cooperation of Health Care Systems', over 300 European health care stakeholders from more than 20 countries met in Malta to discuss the "Societal Impact of Pain" (SIP 2017).

SIP 2017 held working groups gathering together policy makers, members of the European Parliament, pain specialists, scientific researchers, patients' associations, advocacy and civic society and other stakeholders to discuss four key issues:

1. Pain as a quality indicator for health systems
2. Building platforms to address the societal Impact of pain
3. Impact of pain on labour and employment
4. Challenges, models and lighthouses in pain policy

Under the auspices of the 2017 Maltese Presidency of the Council of the EU, the scientific framework of the European Pain Federation EFIC (EFIC®) and guided by SIP 2017 partners Pain Alliance Europe (PAE) and Active Citizenship Network (ACN), the faculty of each of the working groups produced specific policy recommendations addressing the societal impact of pain.

Based on these recommendations, the organizing partners of the SIP platform formulated the following key recommendations directed at the institutions of the European Union and national governments:

1. **Establish an EU platform on the societal impact of pain**
   The European Commission should follow up on commitments made by national governments at the informal Council of EU Health Ministers in Milan, 22 September 2014, to establish an EU platform on pain, facilitating comparison and benchmarking of best practices between member states.

2. **Instruments to assess the societal impact of pain**
   National health authorities should define, establish or use instruments and indicators to measure the societal impact of pain. This should be done through the creation of national data registries and a push for this data to be shared at a European level. To do this, national governments and health authorities should establish quality indicators to set criteria for granting access to cross-border healthcare and ensuring that electronic health records take note of pain.

3. **Initiate policies addressing the impact of pain on employment**
   The European Commission and national governments should work together to promote policies that reflect the link between pain care and employment. This should be recognised at both EU and national levels, through a push for greater

interconnection between ministries and services dealing with health, employment, research, and social protection policies and systems. Better understanding of these interconnections would allow for greater efficiencies in pain management, helping patients access the treatment they need to continue being active in the work place.

National plans should also encourage enforcement of existing national legislation requiring reasonable, flexible workplace adjustments by employers that can help people with chronic pain stay in work or reintegrate into the workforce.

4. **Prioritise pain within education for health care professionals, patients and the general public**
   National governments and health authorities should initiate patient education programmes and information campaigns in order to create public awareness of the short and long-term consequences of inadequate access to pain treatment for pain symptoms. The aim of these programmes should be to reduce stigma and increase self-management of pain.

   National governments should also promote wider access to pain education among the healthcare profession, including all those who see and treat pain.

5. **Increase investment in research on the Societal Impact of Pain**
   The European Commission and national governments should increase investment in research (basic science, clinical, epidemiological) on the societal impact of pain as a priority in future EU framework programmes and make funds available via employment and health policy research programmes.

   The OECD and European Commission should also, in their upcoming edition of Health at a Glance: Europe 2018, present pain as a key indicator of health and health systems analysing the links between population health and labour market outcomes.

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PRE-SYMPOSIUM

The Societal Impact of Pain in Malta

Christopher Vella

Introduction

Reporter: VICTORIA MASSALHA

The Malta Pre-Symposium session kicked off the 3-day SIP 2017 Symposium in Valletta with the launch of the "Consensus Statement addressing the Societal Impact of Pain in Malta", as proposed by Malta Health Network (MHN), No Pain Foundation (NPF) and SIP Malta. Christopher Vella, (SIP Malta representative), gave a short preamble on the consensus paper, on behalf of all organizations which contributed to the compilation of the document. The Consensus statement was discussed at length throughout the Pre-Symposium. The scope of the Malta consensus statement was to lay out a roadmap to address accurately the issue of chronic pain. Vella explained that the proposing parties considered it an opportunity to see policy translated effectively into action and, as is the essence of politics and policy-making, "to serve society". He stated, "We are not after some kind of charitable concession or grant, but social justice." He continued saying it was each individual's duty to advance the society we live in. "If we want a just society, we cannot expect rights without duties, and it is our duty to see that everyone has the right tools at their disposal to succeed." Vella defined quality of life as a moral right to wellbeing and to living without pain. This placed the burden of duty on all of us to protect this right and to ensure that it became entrenched in policy infrastructure.

The recommendations set out in the consensus statement were guided by five factors, namely; ease of implementation, cost-effectiveness, urgency, national priorities, and chronic pain having a major impact on patients. Policy makers are being urged to recognize chronic pain as a disease in its own right so as to facilitate access to services. The consensus paper recommends a nationwide chronic pain prevention campaign to be launched targeting all groups at risk of developing persistent pain. There should also be a restructuring of pain management policies and services within the national healthcare system and provision should be made for appropriate funding to conduct effective research. The statement recommends more inter-ministerial collaboration on the matter and "pain" should be included as a key indicator in the outcomes of medical and surgical interventions. Provision of appropriate facilities to allow the specialization of health professionals in the field of pain was also a major recommendation, as was the facilitation of vocational retraining and integration into the workforce for persons suffering from chronic pain. Finally, a National Pain Plan should be formulated and implemented by 2020.

> ***"We are not after some kind of charitable concession or grant, but social justice."***

It was expected that SIP 2017 Symposium would facilitate the adoption of the Maltese Consensus Paper for Chronic Pain launched during the Malta Pre-Symposium. Eight presentations by speakers representing key entities in the field of pain followed this introductory speech.

Boaz Samolsky-Dekel

Pain - Medical perspective

BOAZ SAMOLSKY-DEKEL
No Pain Foundation (NPF), Malta

"...from the age of Hippocrates to the present time, the annals of every civilized people contain abundant evidences of the devotedness of medical men to the relief of their fellow-creatures from pain and disease..." was the opening statement that launched Samolsky-Dekel's presentation at the start of the Maltese Pre-Symposium. Pain was defined both as an unpleasant sensation and as a subjective emotional experience and chronic pain represents a spectrum of disorders that entailed co-morbid, neuro-psycho-sociological manifestations. This highlights the importance for clinicians who treat pain to primarily understand the person in pain and to base pain management interventions on the subjective reality of pain, thus providing a balance of technical and interpersonal approaches.

> ***"Pain physicians should remember that the subjectivity of pain is actually the objectivity of the patient's pain."***

Samolsky-Dekel considered the global adversity of "hurting" to be the fundamental of pain's negative experience. Yet, he claimed that, for many patients, an additional deleterious aspect of the chronic pain experience is the loss of function across multiple dimensions including, but not limited to, activities of daily living, transportation, vocation, work, finances, etc. "Undoubtedly, when an individual has historically been independent the psychological and social consequences of such physical and economical caveats

are likely to be profound." Furthermore, Samolsky-Dekel described how psychological dysfunction and substance misuse elicit increasingly greater suffering that often incur negative stigmatization, which may further affect the clinician/sufferer relationship.

The Scientific Director of NPF described the pain clinician as an agent with intellectual and moral traits of character with a strong allegiance to the obligations of caring for those in pain. The pain clinician is in possession of the knowledge and skills required to manage pain, however, at the same time, he/she should demonstrate sensitivity, dedication and determination to engage each patient as a person and to understand the impact of pain upon the person's life.

This means implementing a more comprehensive paradigm of pain care that entailed recognition of the complexity of chronic pain; accounting for economic factors imposed upon the healthcare system; and enabling articulation of any paradigmatic revision within the contemporary medico-legal environment.

Samolsky-Dekel described the values and relative power of patient and clinician as asymmetrical. And given that pain medicine exists within a social environment, he claimed socio-economic and socio-legal factors frequently become the source and/or instigation of ethical issues and problems within clinical practice. "This has led to the notion of the patient as a consumer", he stated, "and that has created a direct tension between the expert knowledge and actions of the clinician, and the choices and behaviours of the patient."

It is well recognised that the treatment of pain patients can be demanding, but as Samolsky-Dekel concluded on a positive note, "that trust and dignity could be secured when the pain clinician applied knowledge, skills and human sensibility in collaboration with the pain patient."

Chris Wells

Sharing international best practices in pain care

CHRIS WELLS, PRESIDENT

European Pain Federation (EFIC), Brussels

EFIC represents 37 countries in Europe and is one of the main players focused on ensuring that people in pain receive the appropriate attention and care. Chris Wells used his allocated 10-minute slot to give a detailed description of the work undertaken by the federation's members that represent over 20,000 healthcare professionals who study about pain and treat patients in pain across Europe.

EFIC's activities range from the publication of the European Journal of Pain and EFIC newsletter to the organization of symposia and grant schemes for research and to support those studying for the EFIC European Diploma in Pain Medicine (EDPM), which was initiated in 2016. SIP conferences date back to 2010. Other activities involve the running of pain schools in four European cities: Klagenfurt, Bergamo, Maribor and Krakow. The school in Austria focuses on general and acute pain, the Italian set up looks at neuropathic pain, the Slovenian centre focuses on cancer pain and the course in Poland is dedicated to science and research.

> ***"You'll never walk alone."***

A new book titled "European Pain Management" is to be launched at EFIC's Pain Congress 2017 in September in Denmark. Through its activities, the foundation promotes and shares best practices across Europe. Wells described how task forces were in place to submit position papers that collate the evidence to develop best practice for the formulation of guidelines on post-op pain; low back pain and sciatica; cancer pain; use of cannabinoids in chronic pain and complex regional pain syndrome. Appropriate guidelines for opioid use in chronic pain have been completed and published.

Being from Liverpool and a great fan of its football team, the EFIC president concluded his session with an appropriate message directed at all pain sufferers, and which is the title of possibly the most famous song in football, and can be heard before kick-off at every Liverpool match at Anfield, "You'll never walk alone".

Meet the Maltese person in pain: a profile

NEVILLE CALLEJA
Directorate for Health Information and Research - Ministry for Health, Malta


Neville Calleja

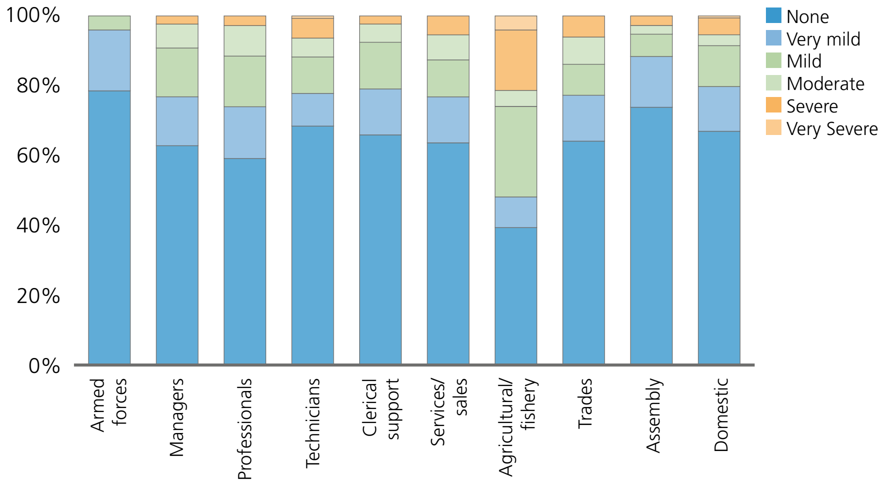
> ***"As in most other chronic conditions, health inequalities have been observed in chronic pain."***

Neville Calleja is a specialist in public health, Director of the Directorate for Health Information and Research (DHIR) in Malta and sits on the Scientific Board of No Pain Foundation (NPF). To give delegates a picture of the full extent of chronic pain across Europe, Calleja began by comparing those living with persistent pain to those with diabetes mellitus, "95 million compared to 60 million", he said "with of course overlap between the two." He went on to describe how around 20% of adults in Europe suffered from chronic pain, which negatively affected their daily, social and working lives. Economically, chronic pain was costing Europe an estimated €300 billion annually due to lost working days because of pain-related, sick leave.

Calleja explained "The European Health Interview Survey", which was conducted in EU states in 2008, and then updated in 2014. Malta's contribution involved face-to-face interviews with four thousand randomly selected citizens aged fifteen years and over. The purpose of this survey was to provide statistics on health status, health determinants and health services for use by government, researchers, academics and the statistical office of the European Union (Eurostat). Although not intended to address the issue of pain, one question in the survey looked at the intensity of pain experienced by participants in the four weeks prior to the interview. Calleja described how an interesting profile of Maltese citizens in pain began to emerge. "Males reported being more pain-free than females and participants in pain described themselves as being less active", he told delegates, "and in the over-60s age bracket, the evidence of pain increased with age.

The findings also showed that pain by district adjusted for age, gender and education may indicate the evidence of traditional trades being susceptible to the precipitation of pain by area. The occupations most susceptible to causing severe pain were agriculture and fisheries, skilled trade occupations and domestic workers.

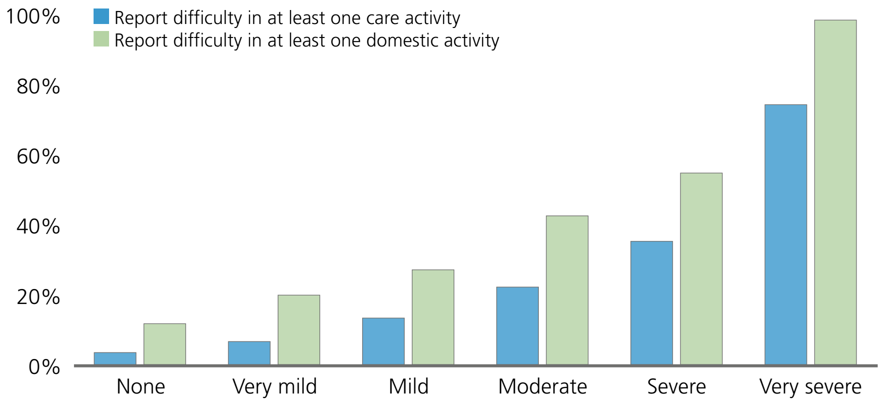
Pain by occupation



Obesity showed a significant trend of reported incidents of pain increasing as individuals put on weight. Twenty five percent of the Maltese adult population self-reported as being obese in this survey. The result of the study referring to the impact on daily life, as the level of pain increased, was particularly relevant and interesting: All (100%) participants reported difficulty in at least one domestic activity when the level of pain increased to "very severe", a jump of more than 40% from the previous "severe" level.

One of the final statistics presented at the Maltese Pre-Symposium, which was equally concerning, showed that more than 90% of those that had visited a GP in the two weeks prior to taking part in the survey suffered from severe pain.

Daily life, by inc level of pain



Calleja announced The No Pain Foundation is launching a large-scale study on chronic pain, supported by the Ministry for Health; indeed the Directorate for Health Information and Research is supporting the NPF on this research – its first research collaboration with a Non-Governmental Organisation. The research will look at the prevalence and treatment of chronic pain in Malta, together with its impact on social and daily life. The aim of No Pain Foundation's research is to obtain data regarding the prevalence of persons who suffer from chronic pain, how this pain is affecting their daily life, and whether the pain is being adequately treated.

When asked how this research project would fulfill the expectations of Malta's consensus statement, Neville Calleja welcomed the inclusion of research in the paper, as it was now important to follow-up the findings from the European survey locally. He also praised the authors of the paper for giving cost-effectiveness due consideration, as the demand to access quality healthcare services had often not considered sustainability issues.

Pete Moore

Is Self-management your first choice or last resort?

PETE MOORE
Paintoolkit, UK

As soon as Pete Moore took to the stage, and without much ado, he asked patient groups in the audience "Is self-management your first choice to manage your persistent pain?" He posed the alternative question to health care professionals "Have you offered self-management skills to your patients?" To decision makers he asked 'Was self-management your first choice to develop in your service?" These three questions got everybody thinking.

> ***"Self-management should be your first choice, not your last resort."***

Moore's realistic and down-to-earth approach on how to address the lack of appropriate pain management skills in healthcare services was apparent throughout his presentation. He called for pain management study units to be set up at undergraduate level and accessible to all healthcare professionals, especially doctors who he stated, "only receive nineteen hours on the topic throughout their six years of training." More shocking was the revelation that according to Moore, "A vet received more training in pain management". This certainly provides a serious dichotomy in that our pets cannot tell us when they are in pain, but patients can, and they are not being heard.

Self-management is the most important pillar of treatment for Pete Moore, including holistic care. This entails balancing the demands of your pain condition with what you want out of life. And for Pete Moore this means the patient leads the way. "It involves teamwork where you are the captain of the ship," he said. The patient should point his team in the right direction as to how he should receive individualized support tailored to his needs. "Self-management should be your first choice, not your last resort" was his parting argument and on being queried about accepting immediate pain relief, Moore agreed that medication could get you over an acute episode, however a long-term plan had to be considered.

Collecting good practices on chronic pain: from the EU Civic Prize to the Pain Euro-Mediterranean Coalition

Mariano Votta

MARIANO VOTTA
Active Citizenship Network (ACN), Italy

Mariano Votta is the Director of ACN and is responsible for EU Affairs at 'Cittadinanzattiva', a non-profit organization founded in Italy in 1978 to promote civic participation and to protect citizens' rights. With more than 30 years experience in the protection of citizens' rights in the health sector, it encompasses 200 local areas with over 10,000 volunteers. 84 citizen's advisory centers provide free guidance, information and protection. ACN was founded in 2001 as Cittadinanzattiva's European branch and forms a flexible network of more than one hundred EU civic and patient organizations.

Votta used his designated time at the Maltese Pre-Symposium to showcase some of the existing good practices evident across Europe highlighting the fight against pain. There have been numerous prizes awarded in Italy over the past three decades led by Cittadinanzattiva to celebrate good practice, such as the "Andrea Alesini Award for the Humanization of Care" (1997) and the "National Prize on Chronic Pain Nottola – Mario Luzi" (1997). One of the more recent projects to collect good practices was "Chronic Pain: Making the Invisible Visible". This is a Europe-wide, civic research project, which is ongoing, and was a follow-on from the work started in 2012 by ACN in cooperation with Pain Alliance Europe. Eleven countries have been involved and forty six examples of good practice have been collected from projects dealing with fibromyalgia, back pain/low back pain, dementia and arthritis to name just a few. The most recent and exciting ACN-initiated project to be discussed, especially for delegates attending SIP 2017 Symposium in Malta, was the "EU Civic Prize on Chronic Pain – Collecting Good Practices". The aim of this award is to highlight existing, innovative and pro-active practices in pain services and pain education in Europe. Thirty entries of good practice from 11 different countries including 2 submissions from Malta were considered,. Most of the 30 submissions, related to patient empowerment and about half of them to innovation and professional education. A few looked at clinical practice whilst 4 of them related to headache disorders. Entries were judged using 4 criteria: Reproducibility, Innovativeness, Added Value and Appropriateness. This project was of particular interest to the SIP Symposium delegates because the awards ceremony for the First European Civic Prize on Chronic Pain – Collecting Good Practices was to be held during the symposium.

Mariano Votta concluded his presentation promoting the Pain Euro-Mediterranean Coalition, which is an open, multi-stakeholder platform dealing with pain relief at local and national levels in Europe. The coalition was launched in May 2017 in Menorca during the XII Mediterranean Multidisciplinary Pain Forum and will meet annually on the Ballearic island during the Sine Dolore World Park – an event where the whole island of Menorca is transformed into a theme park against pain and promoting a better quality of life with many cultural, artistic and sporting activities. One of the aims of the coalition is to act as a bridge on pain within the Mediterranean region and beyond EU borders to exploit the geographical impact of chronic pain management in non-EU countries.

Impact of Pain in Maltese Citizens

MARIO GRIXTI
Malta Health Network (MHN), Malta

Mario Grixti

Mario Grixti, presented the outline of a cross-sectional study focusing on the burden of severe chronic pain in the Maltese population which will to be carried out in the coming months. This project is being managed by Malta Health Network and No Pain Foundation as partners with the advice and collaboration of a group of hand-picked advisors and experts based on their professional expertise. This project is funded through the VOPs scheme managed by the MCVS on behalf of the Ministry for Social Dialogue, Consumer Affairs and Civil Liberties. Grixti described how the main aim of this project was to conduct a cross-sectional study by telephone interview on a representative population of adults in Malta using validated tools (health survey SF-36v2) in order to estimate the prevalence of pain in this population at a point in time.

> ***“In Malta we have put pain on a national platform thanks to this symposium.“***

The main objectives and priorities of this study are to obtain an indication of quality of life of people whilst giving the extent of the impact of pain on Maltese citizens; to discern the frequency of diverse pain forms including chronic and severe pain and to assess the subjective quality of pain care management from the patient’s perspective. The end results will be used to compare with published European data and will be presented to local media, healthcare providers, patient groups, employer representatives and unions, as well as used to inform government.

Grixti concluded stating that it was also envisaged that data obtained would help sustain the assumption that Maltese pain sufferers are no different to those from other countries. This was considered important as pain is often linked to health and has a psycho-social impact on peoples' lives that often leads to social isolation, exclusion, employment problems and poverty. The data obtained from this study would provide the basis for planning of services, policies and stimulate other actions necessary to be developed and put in place for people with chronic pain.

Matthew Camilleri

Can pain policy do without physiotherapy?

MATTHEW CAMILLERI
Malta Association of Physiotherapists, Malta

Matthew Camilleri started off his presentation by stating, "Physiotherapy is all about function". He continued explaining that pain management physiotherapy was different to traditional physiotherapy. Whilst manual therapy, electrotherapy, dry needling and traditional exercise methods had a role to play with many patients, the vice-president of the Malta Association of Physiotherapists advised that short-term pain relief should not be the main aim with persistent conditions. Setting realistic expectations and a long-term plan for pain patients was more important.

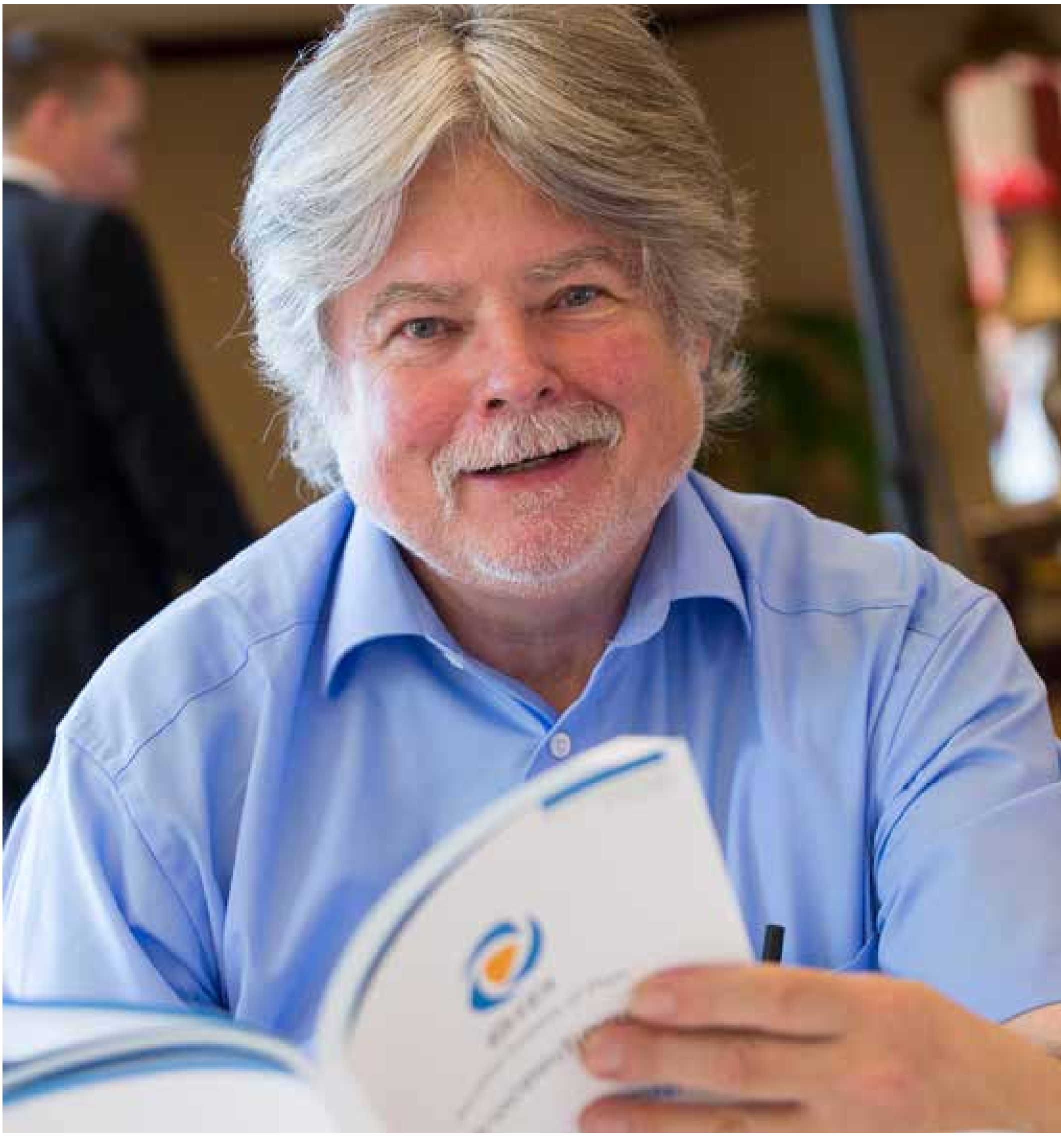
He explained that exercise was more than just movement and not just prescribed simply to strengthen weak muscles or stretch tight ones. Some examples of exercise found to be effective for persistent low back pain were also discussed and included pilates, core stability training, yoga, running and rock climbing. However, Camilleri believes that all exercise is beneficial as long as the suggested fitness regime is realistic and appropriately styled to each patient's needs.

Pain management physiotherapists have their own tool box, which include: motivational interviewing; graded exposure to movement; graded exercise planning; challenging negative / limiting beliefs; moving from fear avoidance to planned movement; activity pacing and tackling iatrogenic disease. Matthew Camilleri described how these tools helped build a therapeutic relationship based on empathy and understanding. The fear avoidance model, using cognitive behaviour, was highlighted because studies suggest that pain-related fear is more disabling than pain itself and can be one of the main causes of pain developing to its chronic state.

> ***"Short-term pain relief should not be the main aim with persistent conditions."***

The patient-centred cognitive functional therapy (CFT) approach was also outlined, as it combines different therapeutic methods into an evidence-based system. CFT has been shown to be effective in non-specific low back pain, lumbar stenosis, non-specific neck pain, lower limb pain and chronic fatigue syndrome.

In conclusion, Camilleri referred back to his original question and the title of his presentation with a lengthy and thorough description as to why a Maltese pain agenda should not exclude physiotherapy. He told delegates it helped restore movement and function and tackled iatrogenic beliefs while promoting self-management, rather than reliance on health care services. In addition, it is cost effective and is a key player in vocational rehabilitation. Matthew Camilleri's closing words advocated an interdisciplinary approach to care and warned delegates not to take the risk of excluding physiotherapy.



Marilyn Casha

The Pain Clinic

MARILYN CASHA

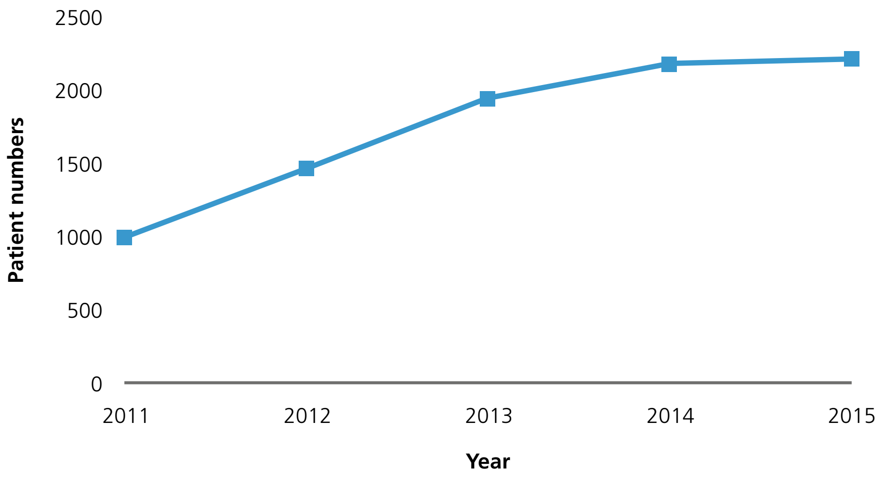
Pain Consultant, Malta

Marilyn Casha described how at the age of twenty five, while studying medicine in the UK, she was diagnosed as suffering from chronic pain. This diagnosis triggered her decision to pursue her professional career in chronic pain management. Her presentation began with a description of pain care services available in Malta's national healthcare system. The Pain Clinic holds five outpatient clinics weekly, four of which are at the Mater Dei Hospital, Malta's acute general teaching hospital. The fifth session, for malignant pain, takes place at the Sir Anthony Mamo Oncology Centre (SAMOC). There are a couple of alternative pain outpatient clinics throughout the week.

> ***"There can never be enough. The moment we say we have done enough, we start walking backwards. Medicine keeps improving, so we can never say we have done enough."***

The concept of establishing a pain clinic in Malta was conceived in 1999. Back in those days the clinic received, on average, five patients a week. Since Casha took over in 2011 numbers have steadily grown and in 2015 more than 2200 patients had been seen at an outpatient clinic.

Outpatient Clinics



However one of her main concerns is that the pain clinic is viewed as a sub-specialty of anaesthetics, whereas in her opinion it should be considered a specialty in its own right. She is also alarmed at the number of patients who are not making it to the pain clinic. For example there are only three of four referrals a month from oncology and patients with gynaecological conditions are also seldom referred. Another concern is the limited amount of drugs she can prescribe through the NHS, namely morphine and pethidine. She called on the suppliers of pharmaceuticals to look beyond the business and the market challenges that small countries like Malta face and to focus on alleviating the pain of all patients. An additional problem was the apparent reluctance by patients to engage in physiotherapy and exercise programmes, a point probably not missed by the previous speaker, Matthew Camilleri. Casha, seeing the benefits of exercise and the interdisciplinary approach, added that she was encouraging a more active and intensive role by physiotherapists in the island’s pain clinics.

Additional comments from representatives of patient groups in the audience

Following a brief video where chronic pain patients and carers spoke of their experience in living a life with pain, patients from the audience were also invited to contribute to the discussion. Mary Vella from the Association for Rheumatoid Arthritis Malta (ARAM) described the importance of involving patients in the discussion about pain. Ms Vella is in control of her pain. She described how in the past her pain controlled her. But now she is managing her pain. She has taken something which made life difficult and turned it into a positive experience. Pain encouraged her to become active and support other patients. She is now President of ARAM and teaches others how to control their pain.

Christine Montague, Secretary of Malta’s Multiple Sclerosis (MS) society described how MS had many hidden disabilities. Pain was just one of them. In her experience, when in pain, she could not go out, so people never witnessed the pain she was experiencing on a daily basis. She put a question to her audience, "Should I have a label on my back saying 'MS patient' or 'chronic pain sufferer'?" Christine was grateful that the symposium was making others see her and other’s pain. In fact, on the very morning of the Malta Pre-Symposium, Christine had stayed in bed in order to be able to attend the session. Focusing on the positive, she concluded saying "At least I'm here'.

Panel Discussion

The session concluded with a panel discussion with representatives from the Maltese delegation who had also been involved in the conception of a Maltese consensus paper on chronic pain. The moderator directed his first question to Antoinette Calleja from the Ministry for Health about whether or not the consensus paper was relevant to policy makers. She told delegates the paper was a "step in the right direction", because it did not only help raise awareness surrounding the issue of chronic pain, but it also provided "valuable information" to enable policy makers to make informed decisions for future actions.

Chris Caruana, who lectures in the Faculty of Theology at the University of Malta, agreed the consensus paper was a step in the right direction, because it introduced "a paradigm shift within the medical and public health policies", especially with the acknowledgement that chronic pain was a condition in itself. This, he continued, "reintroduces the human person at the centre of medicine".

Gertrude Buttigieg, Honorary Secretary of the Malta Health Network, was then asked if it had been difficult during the preparation period to get the working group to agree. She admitted it had been an interesting exercise, but it had been made easier because their work had been based on what had already been achieved on a European level. "So all the fighting had been done before to reach that consensus." she said. The highlight for Gertrude Buttigieg was much more about how well this working group had come together as a united team and once they had established their objectives were patient-centred and they had to convince society and policy makers that these proposals were important for a person's life, she told delegates the process was quite straightforward. "Based on that common ground, it was not so difficult to agree on the reasons to bring out the nine points (in the consensus paper). I think after 3 or 4 meetings and one million emails we had completed it!"

Healthcare professional and bioethicist, Christopher Vella, was particularly pleased that the consensus document was not in any way biased, favouring particular patients. To be taken seriously at policy level he said, they had to remain objective and show they were providing long-term solutions, not a quick fix.

The final speaker, Mario Grixti who specialises in palliative medicine, stated the consensus paper was "the foundation of future good things to come". He was especially pleased that the group had been able to integrate the concerns of chronic pain sufferers, health care workers and service providers.

A Maltese Consensus Paper for Chronic Pain

The Maltese Stakeholders are making the following recommendations, in relation to the Maltese scene:

1. Chronic Pain should be included as an independent condition facilitating the access of chronic pain sufferers to treatment. Chronic pain should be recognized as a disease in its own right and not as a symptom of other diseases.

2. A ‘Chronic Pain Prevention’ Campaign should be run to raise awareness about chronic pain. Such a campaign should be conducted within a wide variety of settings and should target all groups at risk of developing persistent pain.

3. Local Pain Management policies and services within our national hospital should be restructured and streamlined towards European policies and guidelines.

4. Chronic pain should be duly recognized and relative research should be prioritized through appropriate funding.

5. Recognition of the wide-ranging implications of pain should be endorsed through closer inter-ministerial collaboration.

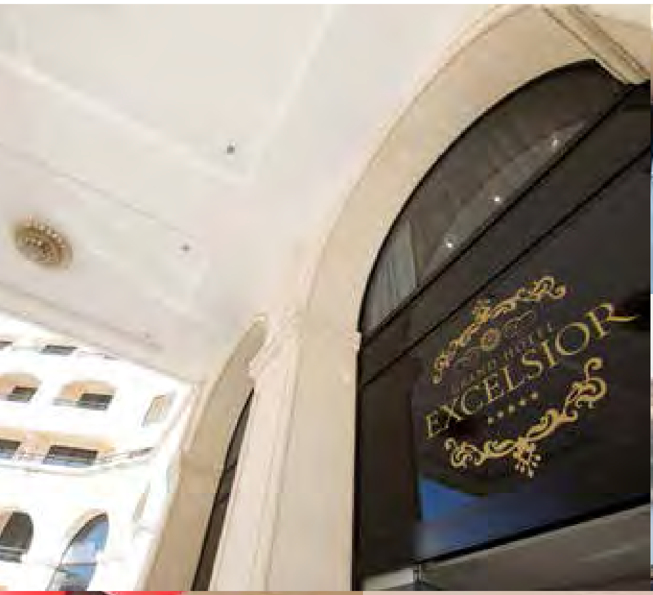
6. Pain should be included as a key indicator in the outcomes of medical and surgical interventions.

7. Appropriate facilities should be established to facilitate specialization of health professionals in the field of pain.

8. The Maltese authorities should enact and facilitate vocational retraining and integration into the workforce of persons suffering from chronic pain.

9. A National Pain Plan should be established and implemented by 2020.


GERTRUDE BUTTIGIEG
MARIA SILVANA FANALISTA


GRAND HOTEL
EXCELSIOR


SIP

WORKING GROUP 1

Pain as a quality indicator for health care systems

WORKING GROUP 1

Pain as a quality indicator for healthcare systems: “If you manage pain, you manage the healthcare system”

Context

Health systems in Europe are a cornerstone of its high level of social protection and the European social market economy. However, problems caused by the economic crisis combined with an ageing population and accompanying chronic diseases have pushed healthcare expenditure to dizzying heights. In the future, healthcare systems in the European Union need to be managed in a smarter way. One way legislators can do this is by focusing on the societal impact of pain: *“If you manage pain, you manage the healthcare system”*.

Why focus on pain?

Pain causes a problem for individuals as well as a challenge for healthcare systems, economies and society: each year, approximately 1 in 5 Europeans or 20% of the adult population in Europe are affected by chronic pain (Breivik, et al., 2006). This includes 153 million people suffering migraine or other disabling headaches, 200 million musculoskeletal disorders and 100 million people experiencing chronic pain (Brain, Mind and Pain, 2015). Four of the top 12 global disabling conditions – low-back and neck pain, migraine, arthritis and other musculoskeletal conditions – are persistent pain conditions (Vos, et al., 2016). Pain related conditions result in an increasing part of the workforce retiring too early. With more than 500 million sick days per year in Europe, musculoskeletal pain causes almost 50% of all absences from work lasting at least three days in the EU and 60% of permanent work incapacity (Bevan, 2013).

Although no pan-European data is available, studies from individual countries sketch a clear picture of the effect on economies: In the UK, back-pain costs the economy 12.3 billion GBP annually, while the socio-economic damage related to chronic pain in Sweden is estimated at 32 billion EUR (Maniadakis & Gray, 2000)(Gustavsson, et al., 2012). The estimated direct and indirect healthcare costs for chronic pain disorders in European Member States vary between 2% and 3% of GDP across the EU (Bevan, 2013)(Breivik, et al., 2013). For 2016 this estimate would result in 294 – 441 billion EUR (EuroStat, 2017). This is an impressive sum. Healthy citizens, on the other hand, reduce the strain on healthcare systems and boost economic growth by staying active for longer.

What is going wrong?

Pain is one of the most significant causes of disability and suffering worldwide and unfortunately is often not addressed in health policies (Lohman, et al., 2010)(Treede & van Rooij, 2011). The problems authorities are facing when it comes to managing pain in their health systems are diverse. One of the foremost is the lack of a 'health system quality indicator' for pain. Health system quality indicators are used to gather data and establish the relative quality of care offered between hospitals or even between countries. As pain is a central element of the patients' experience in many healthcare settings, the quality of pain care should be considered as an indicator for the overall quality of a health system. Measuring and managing the impact of pain on society caused by pain will support the overall functioning of our health care systems by minimising the chance of pain conditions becoming chronic, and reducing the long-term expenditure caused by such conditions.

One of the challenges for policy makers is to allocate a budget for pain management. For policy makers, the different views on the definition of chronic pain held by healthcare professionals can be confusing. The issue of whether chronic pain can be considered a diagnostic entity, or even a condition "in its own right", can lead to consternation. In some cases, the lack of certainty over this issue appears to cause reluctance to address pain in policy measures.

Besides the lack of dedicated policies and budgets, one of the factors contributing to inadequate treatment of persons in pain is the often-inadequate medical training in pain management available (Pergolizzi, et al., 2013). Pain medicine is increasingly recognised as an important field of study, though a weak understanding of chronic pain conditions persists across the wider medical profession. International experts have called for strategic prioritisation and co-ordinated actions to address the unacceptable and unnecessary burden of uncontrolled chronic pain that plagues European communities and economies (Breivik, et al., 2013).

A way forward?

Prioritising pain in policies calls for a whole systems perspective (Phillips, et al., 2008). The UN Universal Declaration of Human Rights (Art. 5) states: "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment."(United Nations, 1948). As most countries have no national pain policy at all, representatives from chapters of the International Association for the Study of Pain (IASP) agreed in 2010 in Montreal that "Pain Management Is a Fundamental Human Right" (Declaration of Montreal, 2010). Although the Montreal declaration was a major achievement, the next step: inserting pain in health policies, is a big challenge.

The recognition of the societal impact of pain has great influence on the development of policies. In Belgium, the health authorities recognized 35 pain centres (Belgian Pain Society, 2013). In Scotland, the conclusions of the report "Getting Relevant Information on Pain Services" (GRIPS) were endorsed by the Scottish Government resulting in a National Lead Clinician for Chronic Pain (NHS Quality Improvement Scotland, 2008) (IASP, 2015). In Germany, pain medicine has been included as a mandatory subject in undergraduate medical studies, generating attention and credibility for the specialty and its providers among medical peers, payers, regulatory and legislative agencies (Dubois & Follett, 2014) (Drießen, 2012) (Kopf, et al., 2014).

Progress is slow, however. Experts have called for changes to policies and resource allocation in pain care; from a biomedical model, dealing with pain as a symptom, to a biopsychosocial model, considering the biological, psychological and social factors affecting the societal impact of pain (Vandenbroeck, et al., 2016) (Behrendt, et al., 2016).

At EU level the societal impact of pain was highlighted under the Italian presidency of the council of the European Union, when ministers from 28 EU member states agreed on the need to create a European network for pain therapy, ensuring training of professionals in the sector and the exchange of information on the effectiveness of therapies for the most vulnerable population groups (Italian presidency of the Council of the EU, 2014). Unfortunately, despite these positive trends, in some EU member states pain centres are hardly available or even being closed (Szilagyi, et al., 2015).

How to use quality indicators to improve pain policies?

Pain is a central element of the patient´s experience in many healthcare settings, but its management is complex and requires a multi-modal approach often involving pain treatment in conjunction with psychological and physical therapy. Two-thirds of adults are reportedly dissatisfied with the care they receive. Therefore, quality, availability and accessibility of pain care can be considered an indicator of the general quality of a healthcare system. Evaluating organizational improvement in pain management performance depends on measurement. The use of standardised quality indicators in pain care will improve society's understanding of the impact pain has on the public. Health system indicators addressing the societal impact of pain could include:

- Availability of data describing the societal impact of pain
- Prevalence of chronic pain
- Accessibility and availability of pain care
- Definition and compliance of quality standards in pain care
- Impact of pain related conditions on early retirement

The definition and classification of chronic pain is one of the crucial first steps in shaping healthcare systems around the needs of chronic pain patients.

The first step in tackling the issue is to find common ground regarding a definition of chronic pain for documentation and policy purposes. It is one of the most significant causes of disability and suffering worldwide and unfortunately often not addressed in health policies (Lohman, et al., 2010) (Treede & van Rooij, 2011). Agreeing on a definition of pain creates a starting point for policies, resource allocation, multi-disciplinary management of the condition, and due consideration of its complexity.

A very promising first step has now been taken, in advance of the ICD 11th Revision due in 2018, to implement a classification of chronic pain in the ICD. The authors of the new ICD proposal have suggested a change of order giving priority to pain etiology (Treede, et al., 2015) (WHO, 2017).

Pain experts and stakeholders have been invited to participate in the ICD revision by making comments or proposals.

Introduction

Reporter: SIMONA GUAGLIARDO

The Working Group was co-chaired by Per Kjærsgaard-Andersen, vice-president at EFORT and an orthopaedic surgeon; Narinder Rawal, Professor of Anaesthesiology and representing No Pain Foundation; and Rhoda Garland, Director at the Commission for the Rights of Persons with Disability in Malta. The attendees, guided by the moderator, Nicola Bedlington (European Patients Forum), actively participated in workshop discussions.

The different presentations highlighted case studies and best practices brought from all over Europe and provided the audience with valuable insights and food for thought on the setting of quality indicators in the field of pain management.

Co-Chairs opening remarks

PER KJÆRSGAARD-ANDERSEN

European Federation of National Associations of Orthopaedics and Traumatology (EFORT), Denmark

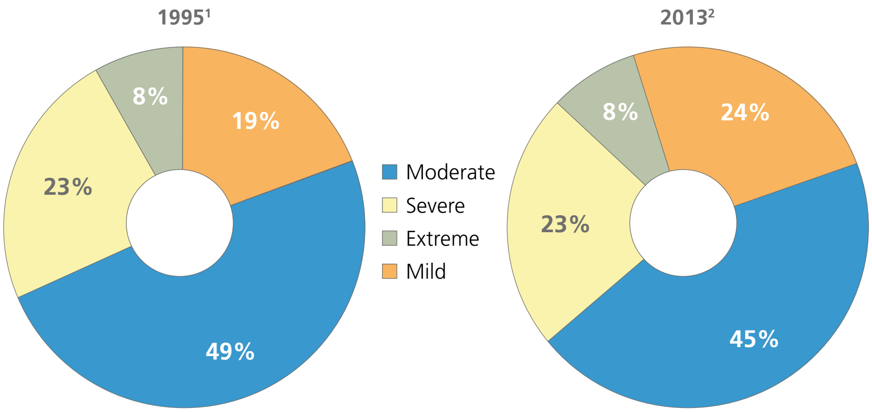
Per Kjærsgaard-Andersen

Per Kjærsgaard-Andersen, co-chair of the working group, kicked off the session offering his professional insight into the management of post-operative acute pain. He argued that pain conditions were often related to surgeries and that "pain related to surgery can increase to become chronic pain". He continued offering figures on surgeries at the global and European level. "It has been calculated that around 234 million surgeries are done annually and each of these patients need pain treatment." he told delegates, "In Europe, more than 6,500 patients are having surgery every year out of 100,000 inhabitants. So, it is a big burden for all of us in the community of pain treatment to make sure that the patients are well treated."

The orthopaedic surgeon also presented the disappointing findings of a survey conducted in the UK, which, despite decades of progress in pain research, showed that 31% of patients reported severe-to-extreme post-operative pain, the same percentage as in 1995. He stated that "we think we have improved over time but we have not. We, as surgeons and pain treaters, are still not very good in treating our patients on the best level and we have to do something about it".

Postoperative Pain continues to be undertreated

Despite nearly decades of progress in pain research, patients reported severe-to-extreme postoperative pain in 2013 remains 31% as it was in 1995



(Smith, et al., 2001)

> *"Most surgeries performed within the speciality of orthopaedic surgery are performed due to pain. Therefore, naturally the patients expect to be either pain-free or have reduced pain after surgery. As this cannot always be obtained, we as surgeons must both learn about types of pain and pain treatment programmes."*

Post-operative pain management can be improved, which would also have a substantial impact on chronic pain conditions. Progress in this area could also benefit patient recovery and satisfaction, by improving clinical outcomes and enabling earlier patient discharge. Kjærsgaard-Andersen highlighted various factors to be taken into account when aiming at effective post-operative pain management.

Team work is key. An effective multidisciplinary team working and communicating between surgeons, nurses, anaesthetists and physiotherapists is a crucial factor, along with simple and well-defined protocols and an active involvement of the patient. He concluded by drawing the audience's attention to the importance of the pre-operative actions towards patients, such as expectations management, clear information and patient education.

RHODA GARLAND

Director at the Commission for the Rights of Persons with Disability, Malta

Rhoda Garland introduced the work done by the Commission for the Rights of Persons with Disability in Malta which, as a regulatory body, makes sure that the UN Convention for the rights of persons with disabilities is complied with. She raised the issue of pain suffered by disabled people.

> ***"As a disabled person myself, I think disabled people suffer more from pain, because often it is a congenital thing."***

"When it comes to pain," she said, "as a disabled person myself, I think disabled people suffer more from pain, because often it is a congenital thing". In these cases, she claimed that often doctors were less inclined to deal with congenital pain suffered by the disabled. The underestimation of pain suffered by disabled people also had important psychological effects on disabled people. She concluded calling for a better understanding of pain conditions and their effects on disabled people, "who deserve the same attention as any other pain patient".

NARINDER RAWAL

No Pain Foundation, Sweden


Narinder Rawal

Narinder Rawal welcomed attendees and drew their attention to the issue of acute pain. He addressed post-operative pain and claimed that the means to treat it were already in place, but more effective measures were needed to alleviate pain issues.

> ***"Acute postoperative pain continues to be a major societal challenge worldwide, there is an urgent need for quality standards in organisation and implementation of pain services."***

Education was paramount in this process, as well as the organisation of acute service models. Healthcare professionals, surgeons, anaesthesiologists, nurses, but also patients and care-givers needed to receive a better and more comprehensive education on pain, its treatment, assessment and management.

Monique Steegers

Pain as healthcare indicator-national survey and secondary data analysis

MONIQUE STEEGERS
Radboud University Nijmegen, Netherlands

Monique Steegers welcomed the presentation by Per Kjærsgaard-Andersen and agreed with him that, despite the many progresses achieved so far, pain management still must be improved.

She presented the findings of a study (Adverse effects and potentially preventable deaths in Dutch hospitals) conducted in 2004 in the Netherlands. When the study was published back in 2004, "it was a shock in the Netherlands", she said. She explained that, using a retrospective record review process, nurses and doctors reviewed nearly 8000 admissions in a random sample of 21 hospitals. When extrapolated at the national level, the data revealed that around 1500-2000 potentially preventable deaths happened in the Netherlands in 2004.

> ***"Improving peri-operative pain management demands 'good' pain assessment."***

Monique Steegers also recalled a more recent research conducted in the United States, according to which medical error represented the third leading cause of death in the US. She then continued, describing the measures taken in the Netherlands to address the issue of pain management. With the overall objective to improve pain management and measurement, quality indicators have been implemented in the Netherlands. On the one side, the Dutch National Patient Safety Programme monitors three different quality indicators: structure, process and outcome. On the other side, Dutch hospitals are required to deliver data on two quality indicators; process and outcome, to the Inspectorate of Health Care. Findings from the analysis of this data showed that post-operative pain had been measured once a day in only 53% of cases, whereas a three times per day measurement was carried out only in 12% of cases.

Monique Steegers concluded her presentation stressing the relevance of compliance to measurement and standardisation. Quality indicators serve an important purpose as they can improve pain care at the hospital level, but they also play a central role for comparative and benchmarking purposes with other hospitals. She eventually called for a European week of uniform pain measurement to be established, taking into account both the short-term perspective of post-operative pain and the long-term perspective of chronic postoperative pain.

Pain, patient reported outcomes and policy

WINFRIED MEISSNER
German Pain Society, Germany

Winfried Meissner

Winfried Meissner presented to the audience the issue of patient-reported outcomes (PRO). In the medical field, normally four dimensions of quality management are taken into consideration: structures, processes, outcomes and quality of medical indications. He emphasised that "taken together, the most important dimension is certainly outcome, you might have good processes and good structures but this does not necessarily translate into good outcomes". He argued that "there is a broad consensus that outcome is the final dimension of quality measurement". This broad consensus should translate in the widespread use of PROs in the area of pain management.

> ***"Patient-reported outcomes have a greater role in quality, quality improvement and might be developed as a quality indicator in pain management in hospitals and outside hospitals."***

"Patient-reported outcome is the only measure that can reveal the subjective experience of pain", Meissner said, and in order to assess this subjective experience, he continued, it was essential to directly engage with the patient in the pain measurement process. He also pointed out that, despite the broad consensus of the usefulness of the PRO, there was no consensus on what methodology should be used and the type of PRO measure that should be implemented.

"In the area of acute pain management", he continued, "there is as yet no real consensus, and sometimes not even a discussion, on what is good quality". Thus, it is essential to discuss and find a consensus on what is good quality in the field of pain management. He suggested a model of PRO that considered at least three fundamental dimensions: pain intensity, side effects and functional interference (e.g. interferences with mobility, sleep, respiration, ability to eat/drink and to communicate). A multi-dimensional model was advisable, as focusing on a single dimension might translate into poor quality pain management. "If we only use pain intensity as our PRO," he stated, "this might trigger over-treatment of chronic pain, and studies have mainly shown that pain intensity is not a good PRO in chronic pain management".

It is also very important to consider functionality, "PROs that do not consider functional interference will not work as well as quality indicators", he argued. Winfried Meissner concluded that PROs are an important tool and they need to be used in clinical practice, as "we cannot judge on pain, both acute and chronic, without this tool". Nonetheless, "we have to critically discuss which type of PRO we should use", he said. In conclusion, Meissner raised some concerns about the possibility of using PROs as formal quality indicators on an institutional and administrative level.

What can be expected from quality indicators in pain?

PAUL CAMERON
University of Dundee, UK

Paul Cameron

Paul Cameron presented the ambitious project that is being conducted in Scotland and that aims at improving the existing quality indicators in the field of chronic pain. It is well known that quality indicators play an important role in measuring healthcare, as they can assist in quantifying the disease condition in communities globally, as well as on a national and local level. They can also be used to "highlight potential quality concerns, identify areas that need further study and investigation, and track changes over time", Paul Cameron explained.

Quality indicators are particularly important in pain management, as the incidence of pain conditions is severely high. "Chronic lower back pain", he said, "is the single greatest cause of disability in the UK, affecting approximately 1 in 5 adults", and its prevalence and severity increases with age. Pain and chronic pain also have important impacts in terms of mortality, productivity and disability. Mortality rates for people suffering from pain and chronic pain are higher. Around 60% of working-age persons with "severe" chronic pain are unable to work, and in Scotland, as across the world, chronic pain is the greatest cause of disability.

> ***"The first thing we have to do is get some sort of standardisation of approaches and things like quality indicators are certainly an initial approach to that to try and have some sort of level of governance."***

The project developed in Scotland, the Scottish Service Model for Chronic Pain, is built on four levels of assistance to pain patients. Level 1 offers information and advice services, which are accessible to the whole community. The next level involves the GP and then beyond that the model moves into the area of specialised assistance and highly specialised help. The team working on the project also produced draft quality indicators that measure patient satisfaction, the existence of a multi-disciplinary approach, patient benefits and outcomes, and regular review programmes.

Johannes Wacker

Pain related patient safety and quality in the peri-operative setting

JOHANNES WACKER
Hirslanden Clinic, Switzerland

Johannes Wacker presented the audience with the important issue of the safety of treatment, as “pain management is often part of the overall treatment, especially in the surgical field”. To do so, he introduced the renowned case of Leah Coufal, the 11-year-old girl from California who died in her hospital bed following surgery. This example, as Johannes Wacker stated, alludes to the problem of safety of patients in the peri-operative setting and helps highlight the basic problems involved in pain management. On her second post-operative day, the young girl was still in pain and was prescribed medicine to alleviate the pain and benzodiazepine. Overnight, Leah died but no one knew because she was not being monitored and no alarm sounded, as her mother reported. Johannes Wacker argued that this example pointed to some of the basic problems that quality and safety management should address. “Taken together”, he said, “this is not just a matter of monitoring, it is mostly about human factors and human resources”.

> ***“Challenges for perioperative pain management include inadequate treatment or severe complications, like opioid-related respiratory depression. Organisation and staffing may be more important to improve quality than individual techniques.”***

Talking about pain scores as quality indicators, he made the point that “looking at pain in isolation can be misleading and even dangerous, looking at pain is very important, but as part of an overall quality and safety assessment. This is very important and it is not happening”. He reinforced his earlier point that human resources were key to an effective quality and safety assessment of the treatment. Many studies show that personnel staffing is crucial, not only in terms of numbering, but also in terms of the relationship between different staff levels and the appropriateness of team work. An adequate staffing is also extremely important to avoid the progression from acute to chronic pain. “Adverse events”, he continued, “can result both from untreated pain and from the pain treatment itself, we should not only focus on one, we need to see both sides”. Johannes Wacker stated that severe pain should be considered as an adverse outcome, but equally the pain treatment itself could have an adverse outcome itself. Thus, an overall assessment of quality and safety in healthcare was needed. He concluded his presentation with a plea to decision makers, asking them to invest more resources on staff, both physicians and nurses, and also in measuring the problem, “because I think insufficient data collection is also part of the problem.”

More Participation, for a better health

ELSA MATEUS

Portuguese League Against Rheumatic Diseases, Portugal

Elsa Mateus

Elsa Mateus started her presentation by introducing the audience to statistics on pain and its prevalence and impact on Portuguese society. "Rheumatic and musculoskeletal diseases (RMDs)", she said, "have a high prevalence in Portugal; around 56% of the Portuguese population complains of RMD. And low back pain is the most prevalent condition in Portugal". The impact of RMD in Portugal is very high, representing over €900 million of costs related to early retirement. Several studies have been conducted in Portugal on chronic pain. They showed that 13% of patients took early retirement as a consequence of chronic pain, 17% had been diagnosed with depression and 35% complained of dissatisfaction with the treatment they had received.

Elsa Mateus also presented more recent studies, which complemented previous work and showed that 3 million adults in Portugal suffered from RMD or a chronic pain problem (3 in 10 citizens) and only about 20% of patients received specialist care.

She explained that the Portuguese League, a patient group addressing pain, was created to share experiences and self-managing strategies, to define priorities and reset beliefs, attitudes and behaviours, and to raise public awareness about the pain issue. "The working group tries to increase social responsibility of patients", she said. In 2014, a photo contest, Chronicles of Pain, was launched to engage with the public and raise awareness of the issue of pain and the socio-economic impact of RMDs and its implication on the patient's everyday life.

> ***"Meaningful involvement of patients' representatives as stakeholders in the decision-making processes, health care assessment and design, is required to improve the quality of chronic pain prevention and management."***

The Portuguese League was also involved in a project aimed at boosting public involvement in health. The final goal was to develop a Charter for Public Participation in Health. The Charter, signed by 82 healthcare-related organisations and 30 individuals, aims at raising public involvement and political commitment around the issue of pain and its impact on the society. Elsa Mateus concluded her presentation affirming that, by promoting public involvement in health, so that patients' perspectives can be taken into account, it is possible to enhance the general quality of healthcare systems.

Anthony Woolf

Musculoskeletal pain: incidence, prevalence and impact on healthy ageing

ANTHONY WOOLF
Global Alliance for Musculoskeletal Health, UK

Anthony Woolf focused on the issue of musculoskeletal conditions and he affirmed that “musculoskeletal conditions are common in all countries and cultures and represent the greatest cause of disability worldwide”. He added that they are a major burden and cost to health and social care and often prevent people being economically independent. Unfortunately, there is a lack of policies and priorities for musculoskeletal conditions and investment in prevention, treatment, education and research. “There is an enormous unmet need”, he emphasised. The reasons behind the lack of policies and priorities are manifold, and Anthony Woolf pointed, among other reasons, to the lack of awareness about the impact of pain and musculoskeletal conditions, the lack of medical education and competency, and the fragmentation of care.

He presented the audience with different studies and surveys reporting the incidence of musculoskeletal pain and its impact. Musculoskeletal conditions and chronic pain have important impacts on society and individuals, “but the bigger cost”, he said, “is around social support and the loss of people’s ability to work.” In many countries this aspect is gaining priority “because everyone is worried about how to cope with extending working life if people are unable to continue working.”

Anthony Woolf also presented the Global Burden of Disease 2010 Study, which was designed to provide policy-makers with data and analyses. The study introduces the concept of Disability Adjusted Life Years, the impact death and disability has on populations.

The studies presented by Anthony Woolf revealed worrying figures on the incidence of musculoskeletal conditions and disabilities, which, he said, “policy-makers have to do something about”. The data also helped debunk the myth that musculoskeletal conditions only affect the elderly, “because data shows that musculoskeletal conditions have an impact across all adult age groups of working life”. The future does not look any brighter, “because we are living longer and these conditions don't go away”, he continued. In many countries the retirement age has been extended “but there is no investment to make us fit for purpose, fit to be able to continue to work”. For this reason, healthy ageing is key, and healthy ageing throughout one’s life course depends on maintaining functional ability. Anthony Woolf concluded by calling on governments, health policy-makers on a regional level and the WHO to deal with the large and growing burden of musculoskeletal conditions faced by individuals and society.

“Musculoskeletal health is commonly impacted by pain and musculoskeletal conditions are the major cause of disability worldwide with a great economic impact through health and social care and work loss. Actions are needed to address this burden.”

Tony O'Brien

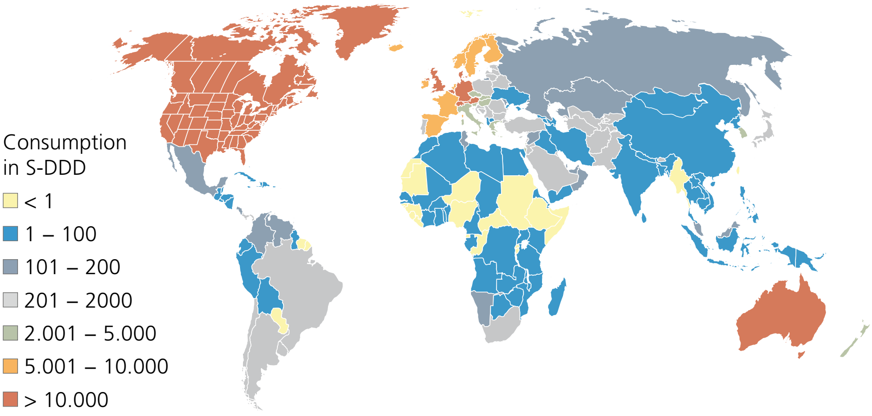
EFIC position paper on appropriate opioid use in chronic pain management

TONY O'BRIEN
European Pain Federation (EFIC®), Republic of Ireland

Tony O'Brien presented the position paper produced by EFIC®, on the appropriate use of opioids in chronic pain. Drafted by a European group of experts convened by EFIC®, the paper was intended "not just to achieve better pain control for patients", he said, "but also to deliver to patients a sustainable and improved quality of life and rehabilitation". Appropriate use of opioids was not an issue that affected one region, or one country, it was a problem relevant to everybody. Tony O'Brien stressed that the reaction to this problem "requires inputs from clinicians, from patient groups, hospitals, regulators, legislators and from the manufacturers". A combined approach harnessing expertise across different areas was needed to address the issue of appropriate use of opioids. "We recognise that opioids are an essential tool, they have a very definite and unique role in the management of pain in selected and supervised patients", but he also recognised the misuse of opioids was dangerous.

INCB data on opioid consumption (2012-2013)

92% of the world's morphine is consumed by 17% of the world's population
Consumption in defined daily doses for statistical purposes (S-DDD) per million inhabitants per day



The boundaries and names shown and the designations used on this map do not imply official endorsement or acceptance by the United Nations. Final boundary between the Republic of Sudan and the Republic of South Sudan has not yet been determined. Dotted line represents approximately the Line of Control in Jammu and Kashmir agreed upon by India and Pakistan. The final status of Jammu and Kashmir has not yet been agreed upon by the parties. A dispute exists between the Governments of Argentina and the United Kingdom of Great Britain and Northern Ireland concerning sovereignty over the Falkland Islands (Malvinas).

> ***"Across Europe there is an enormous variation in opioid use. We see very different regulatory and legislative circumstances. We need to work together to ensure that patients who require opioids for legitimate, medical and scientific purposes can access them without impediment."***

Tony O'Brien also drew the audience's attention to the fact that there is an enormous difference between availability and accessibility of opioid medication. Indeed, such medication may be available nationally, but the bureaucracy associated with the prescription and with the use of opioid medication was such that the patient could not access it. In 2016, the International Narcotics Control Board (INCB) identified a number of reasons why opioids were not available or accessible as they should have been. Among the reasons was the lack of training and awareness amongst healthcare professionals, an inappropriate fear of addiction, as well as cultural attitudes and, in some cases, limited financial resources. Negative perceptions played a relevant role, and "are extremely common even in regions and countries where there are not particular bureaucratic or financial impediments to the use of opioids." he stated.

Against this background, the EFIC® group convened and delivered key principles on the appropriate use of opioids. It stated that the medical use of opioids should be part of a multifaceted, multidisciplinary approach to pain management, which would require adequate patient assessment by clinicians familiar with best practices. Patient and caregiver education on the use of opioids was also crucial, as well as an honest patient/doctor relationship. "We are never treating pain", Tony O'Brien concluded, "we are treating patients and patients are much bigger than their pain"

Audun Stubhaug

Norwegian pain registers

AUDUN STUBHAUG
Oslo University Hospital, Norway

Audun Stubhaug began his presentation pointing out the importance of high quality health registers. Norway has carried out research into the effectiveness of pain registers, which he said was a way to learn more about pain, pain patients, and cost-effectiveness. Many European countries have developed different health registers: from primary care registers to specialist care diagnoses and treatment registers; to sick leave/ pension databases and death registers. "These are all valuable registers that can be used to examine how pain affects the economy" he stated, and continued by saying that such registers had been used in Sweden "to evaluate the impact of chronic pain on the economy". The Swedish example discovered that pain might cost society up to 10% of its GDP. Nonetheless, these registers all presented a weakness, "they are not pain specific", Stubhaug stressed.

He presented the Tromsø Pain Study, which he had been directly involved with, as an example of a population study that, using longitudinal data over time, could be used as a pain specific register. He stated that such a register contained data that "belongs to society, it is a public register. That means everybody can access this data". Stubhaug explained the details of collecting and analysing pain-related data and how such a methodology helped the clinician to deliver a better pain treatment to patients.

> ***"High quality registers are needed both to gain new knowledge about pain and for continuous evaluation of resource allocation and treatment results. Linking epidemiological studies and national health registers is a powerful way to get important information for politicians and health care providers."***

He concluded his presentation by putting forward the idea of combining such a pain-specific register with other existing registers. Using the social security number of a patient, Stubhaug claimed it would be possible to retrieve data from different health registers so as to enhance the pain treatment strategy. However, a comprehensive bringing together of those registers would require the intervention of a legislator. For this reason, Stubhaug called on policy-makers to support and fund the establishment and the maintenance of such registers and to enact legislation to secure both patient integrity and access to data, and to consider the possibility of data sharing across countries.

Prevalence and social burden of active chronic low back pain in the adult Portuguese population: results from a national survey


Nélia Gouveia

NÉLIA GOUVEIA
Portuguese Society of Rheumatology, Portugal

> ***"When it becomes chronic, Low Back Pain causes an enor mous economic burden on individuals and society - it is one of the leading causes of loss of productivity and economic independence through absenteeism, presenteeism and work disability."***

Nélia Gouveia presented a large epidemiological study, EpiReumaPt, conducted in Portugal to estimate the prevalence and social burden of active, chronic, low back pain in the adult population. The study entailed two steps, the first being an estimation of the prevalence of low back pain and the second being an analysis of the prevalence of chronic low back pain. She affirmed that "low back pain is the most prevalent rheumatic condition in developed countries, and the problem is bigger when it becomes chronic". Chronic low back pain, in fact, represents a huge burden not only to the patient, but also to the economy and society. The study also analysed whether anxiety and depressive conditions were to be considered an additional burden to those patients who reported chronic low back pain. Nélia Gouveia went on to explain the details of the methodology and the findings of the epidemiological study. The research showed that 26.4% of the population suffered from low back pain, which was an estimated 2.6 million citizens. The second step of the study focused on the chronification of low back pain, and this data revealed that 10.4% of the adult Portuguese population was affected by chronic low back pain.

Overall, the epidemiological study revealed that the burden of chronic low back pain could be expressed in terms of intangible, direct and indirect costs. Those that suffered from this condition had a poorer quality of life and were significantly more prone to anxiety attacks and depression.The presence of active chronic low back pain was associated with a significantly higher consumption of healthcare resources and with decreased labour performance and early retirement from work. Nélia Gouveia concluded her presentation pointing out some factors that could help reduce the burden of chronic low back pain, such as: patient education programmes; government commitment to promote healthy life style habits; and a multi-disciplinary approach to pain management.

Axel Drews

CHANGE PAIN & My pain feels like

AXEL DREWS
Grünenthal GmbH, Germany

Axel Drews presented some of the initiatives that Grünenthal has been involved with in the field of pain and chronic pain. The "My Pain Feels Like…" campaign was launched in 2013 in collaboration with the Pain School, Italy, to raise awareness of the burden of localised neuropathic pain in patients. The initiative's main purposes was to help improve the communication between patients and physicians, to support patients in their need for information about their unbearable pain, and to help improve the accuracy of a localised neuropathic pain diagnosis leading to early treatment.

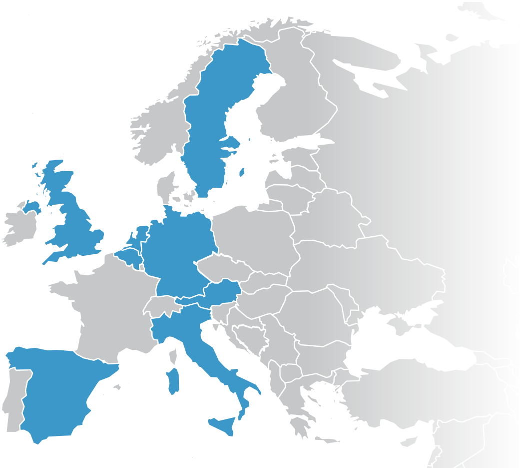
Grünenthal has also been running a campaign since 2009, CHANGE PAIN, with the aim to enhance the understanding of chronic pain patients' needs, and to help improve the management of chronic pain. Since 2015, acute pain has been included in this campaign and the scope has been broadened to include efforts to raise awareness of the unmet needs in post-operative pain management. Axel Drews stressed, as other speakers had been doing

Surgical procedures across Europe

Surgical procedures in selected countries* per 100,000 people:[1]

European average:[1] 6,778

🇳🇱	4,065	🇸🇪	6,919
🇪🇸	4,865	🇬🇧	7,239
🇮🇹	4,951	🇧🇪	8,992
🇩🇪	6,431	🇦🇹	14,333



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[1] European Hospital and Healthcare Federation (HOPE). Healthcare Activities: Inpatients surgical procedures. 2014. Available at: http://www.hope.be/03activities/quality_eu-hospitals/key_figures/11-hospital_activities-inpatient_surgical_procedures.pdf. Accessed 9 September 2015

(HOPE, 2014)

repeatedly during the workshop, that "there is a need to further educate". He explained that the CHANGE PAIN campaign was designed to do just that by producing national and international scientific publications available to the public. The international advisory board of the project also produced a definition of "good quality in post-operative pain management", describing it as: "the early rehabilitation and discharge of a satisfied patient with low pain and few side effects". In 2015, on average, almost 7,000 surgical procedures were performed in Europe, per 100.000 inhabitants.

> ***"To provide the best possible service it is important to understand the needs of pain patients and to develop solutions to improve the management of pain."***

However, the CHANGE PAIN study revealed that 50% of post-operative patients reported moderate to severe pain, while 23% described being in severe pain between half and all the time, so "the issue is there". Axel Drews reaffirmed.

Against this backdrop, Grünenthal , in partnership with EFORT, the European Federation of National Associations of Orthopaedics and Traumatology, launched an awareness campaign to address post-operative pain and to try to educate orthopaedic surgeons to become more involved in the pain management process.

Andreas Kopf

Education: do we still need it?

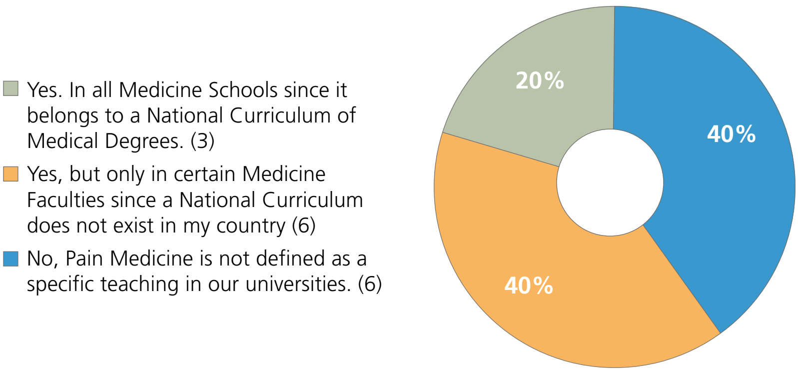
ANDREAS KOPF
Charité-Universitatsmedizin Berlin, Germany

Only two countries in Europe have implemented a mandatory undergraduate pain medicine course and no country has a general pain medicine competency throughout the education path of healthcare professionals. Andreas Kopf started his presentation with a challenging proposal for the audience, "if we are happy with this situation, we do not have to change anything". If, indeed, there is a need for change, as the previous speaker, Axel Drews, had emphasised, then the question should be "Do not we have a deficit in the very different perspective that pain medicine is not recognised as other fields of medicine are?".

Andreas Kopf claimed that the underestimation of pain medicine had its roots in the non-availability of pain medicine in undergraduate studies and in hospital residency programmes. Thus, the key to success in pain management would be to integrate pain medicine in undergraduate and postgraduate education. Pain assessment and management therefore should be an essential part of curricula of medical faculties and of postgraduate residency programmes. A survey conducted across Europe showed that only 20% of countries recognised pain medicine as a specific "materia medica", whereas 40% said pain medicine was not defined as a specific teaching in universities. "Only France and Germany", he said, "have implemented pain medicine as a mandatory cross-sectional field of education in the programmes of all medical faculties".

Situation in Europe: pain as learning objective?

Does your country recognize pain medicine as a specific "materia medica"?



Briggs-E, EFIC Taskforce for Pain Education
in Europe Survey, BMJ 2014 (accepted)

Accordingly, in order to meet this educational challenge, Kopf stressed that programmes had to be put in place to ensure that "every medical school graduate is able to control the most acute peri-operative or post-traumatic pain, treat most cancer pain, initiate first line treatment for most neuropathic pain, and identify most patients with chronic pain."

> ***"We need to acknowledge that pain medication is a serious field of learning within the medical community. For this, pain medicine has to be implemented in both undergraduate and postgraduate teaching."***

He concluded that "the limited spread of pain medicine does not suffer from shortage of money or medications or evidence-based therapeutics and diagnostics. The true shortage is that pain medicine is not a recognised cross-sectional field in the students' and specialists' definition list". It is essential to build on the curricula and examinations provided by private organisations, like EFIC®, and demand national and EU recognition of general and specialised pain medicine.

Closing Remarks

Following the presentations, the floor was handed to the plenary reporters who summarised the intense and constructive discussion over the issue of quality indicators applied to pain management.

The main findings of the working group focused on a number of key points. Both acute and chronic pain are highly prevalent in Europe and have significant economic and social impacts, besides being a huge individual burden on pain patients. The exchange of views within the group emphasised the great importance of quality indicators applied to pain assessment, treatment and management. Also, more work is needed across Europe to build a consensus on what is good quality pain management. The attendees all agreed that adequate pain treatment starts with excellent pain assessment taking into account the dangers of under- and over-treatment, and that specific education programmes were essential, addressing both healthcare professionals and patients. Led by the plenary reporter, consultant pain nurse, Rianne van Boekel, the attendees agreed on a set of policy recommendations for national governments and European institutions to promote quality indicators for healthcare systems, and in the field of pain in particular.

Presentation of findings and recommendations of Working Group 1

Plenary reporters, Marisol Garcia Penalta from PAE and Rianne van Boekel, a pain nurse consultant at the Radboud University Nijmegen, summarised the findings and presented the recommendations from Working Group 1 at Plenary Session II.

Policy Recommendations

1. The European Commission should follow up on commitments made by national governments at the informal Council of EU Health Ministers in Milan, 22 September 2014, by using uniform quality indicators on pain management to facilitate the sharing of best practices.
2. National governments and health authorities should make the organisational changes required to ensure that patients are granted access to all specific and individualized pain treatments, including establishing quality indicators to set criteria for granting access to healthcare, including cross-border healthcare.
3. National governments and health authorities should prioritise pain care within medical training to physicians, the education of nurses and other healthcare professionals to secure the development of pain expertise.
4. National governments and health authorities along with patient organisations should initiate patient education programmes and information campaigns in order to create public awareness of the short and long-term consequences of undertreated pain symptoms, reduce stigma and increase self-management.
5. National governments and health authorities along with patient experts should set clear guidelines on how the regular assessment of pain should be performed and by which means. This would improve direct patient care, facilitate the creation of national high quality health data registries and hence the exchange of information and the creation of international guidelines.
6. National governments and health authorities should be fully aware of the problem of untreated pain and should balance the chance of adverse effects and the misuse of medication against the genuine needs of patients.
7. National governments and health authorities should ensure that health records, including electronic health records take pain into account.
8. A European week of uniform pain assessment should be promoted. It should address both short term and long-term pain assessment, taking into account post-operative pain and chronic post-operative pain in the patients who were operated 12 months before.

Societal Impact of Pain

Documented and accurate data on pain is fundamental to overall care

Societal Impact of Pain

Chronic pain is one of the most common reasons why people seek medical attention, however pain is poorly assessed

MALTA
EU2017

SIP
Societal Impact of Pain

WORKING GROUP 2

European and national platforms addressing the societal impact of pain

WORKING GROUP 2

European and national platforms addressing the societal impact of pain: a paradigm shift towards coordinated, cross-governmental strategies.

Context

Pain, especially chronic pain, is one of the major health problems in Europe (Harstall & Ospina, 2003). The prevalence of pain has a tremendous impact on society and its use of healthcare and social resources (Leadley, et al., 2012). Rough estimates place the cost of chronic pain, as a disease state, in similar cost categories to heart disease, cancer and diabetes (Gaskin & Richard, 2012). The human cost of pain is equally immense in terms of poor quality of life for those suffering, their families and those immediately around them. In daily life, pain can increase the risk of further societal problems, including social exclusion, loss of income and could even result in poverty (Pain Concern, 2016) (Phillips, et al., 2008).

From silo thinking to integrated actions

Policy makers at EU and national government level are realising that pain impacts many areas of their policy-making and spending. In 2012, via a Parliamentary Question, a UK Health Minister answered: "The Department (of Health) recognises chronic pain as a long-term condition, either in its own right or as a component of other long-term conditions" (CPPC, 2012)(Parliamentary UK, 2012). Not only health ministers, but finance and social welfare departments need to realise quickly that tackling the societal impact of pain is of cross-governmental relevance.

To steer policy-making away from a silo approach, wherein each ministry only looks at what is immediately relevant to their department, governments and EU officials need to be given advice on cross-cutting issues such as pain. Establishing "platforms" or structures, where communities of like-minded individuals or organisations unify as a single voice to achieve their goals, would be a useful tool to help policy-makers join up the dots and tackle challenges that they would otherwise struggle to cope with on their own (DG Sante, 2017).

A whole systems approach to improve pain policies in Europe

The Expert group on the Social Impact of Pain is the most recent and, possibly, most ground breaking pain-related platform to date. This expert group aims to contribute to improve EU policy-making via the creation of a stakeholder network which can share best practices and available data on the societal impact of pain, and develop policy recommendations (DG Sante, 2017).

There are still huge qualitative differences throughout Europe in policies addressing the societal impact of pain. Prioritising pain in policies calls for a whole systems perspective (Phillips, et al., 2008). Therefore, it is vital that pain management is moved higher up the political agenda. The will to interact for stakeholders involved in pain policy sparked the initiation of the platform "Societal Impact of Pain" (SIP) in 2009. The SIP platform is driven by the continuous advocacy of the European Pain Federation EFIC®, supported by Grünenthal and, since 2016, including Pain Alliance Europe (PAE) and Active Citizenship Network (ACN) as active partners. Since 2009 the objectives of SIP have been endorsed by over 300 organisations (SIP, 2017).

Platforms empower communities

There are many examples of successful cooperation between organisations. One of those is the public-private partnership, EUPATI or European Patients' Academy, which was launched in February 2012 within the Innovative Medicines Initiative Joint Action. It aimed to trigger a major rethink in the way patients and the public understand the medicines development process and their own involvement therein. This project was coordinated by the European Patients' Forum and included a consortium of more than thirty organisations including: patient organisations, academia, NGOs and industry. (EUPATI, 2012 - 2017)

Local platforms tend to focus more on local issues and can empower local organisations by amplifying what can be achieved on a micro level. In 2016, the Malta Health Network introduced the notion of creating a Maltese platform, dedicated to addressing the societal impact of pain and bringing together patient organisations, healthcare professionals, academics and policy makers. Interest in SIP Malta was very strong, and before long there were enough participants to prove this Maltese platform could make a real difference on a National level, when it came to tackling pain and policy (SIP, 2017).

Introduction

Reporter: PALOMA TEMIÑO DE DIOS, SIMONA GUAGLIARDO

The Working Group was co-chaired by David B. Vodušek, European Academy of Neurology and Anthony Serracino Inglott, Malta Medicines Authority. The attendees, guided by two moderators, Joop van Griensven from Pain Alliance Europe and Silvana Finalista, President of the No Pain Foundation, actively participated in the workshop. The different presentations highlighted case studies and best practices on existing national and European platforms.

Pain and Age-related public expenditure

BORIANA GORANOVA
Directorate-General for Economic and Financial Affairs (DGECFIN), Belgium

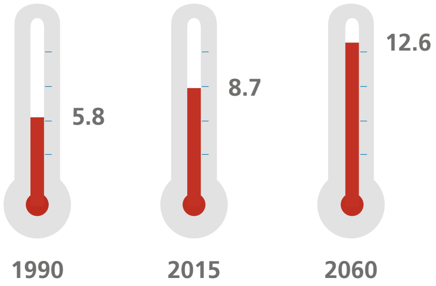
Boriana Goranova

Boriana Goranova, a policy analyst at European Commission DG ECFIN presented the findings from the "Joint Report on Health Care and Long-term Care Systems & Fiscal Sustainability" from October 2016. The Economic Policy Committee (EPC), an advisory body to the European Commission and the Council, published the report prepared jointly with the EU Member States. The report is divided into two volumes: the first presents policy challenges and reform options on how to contain spending pressures through efficiency gains, and the second volume presents specific chapters on each Member State's health care and long-term care systems. Boriana Goranova confirmed that health-related expenditure took up a significant share of resources in the EU and that this was projected to increase in the coming decades, as life expectancy increased and the share of elderly population grows. In 1990, public expenditures in health and long-term care represented 5.8% of the GDP, in 2015 8.7% and by 2060 it is projected to reach 12.6% of GDP.

Goranova presented the policy challenges represented by the cost of hospital and pharmaceutical care, investing in primary care, budget overruns, quality of information, ministerial silos and the threats embodied by fraud and corruption. She then moved on to explain the policy options: governance and sustainability. In order to improve the governance of health care systems the Commission report found alternatives to the following measures: strengthening the cooperation between fiscal and health policy authorities and employing a wide range of budgetary planning tools; adjusting the regulatory framework to support

Health systems and fiscal sustainability

Public expenditure in health and long-term care (% GDP)



Health related expenditure takes up a significant share of resources in the EU. This is projected to greatly increase in the coming decades.

and strengthen efficiency, transparency and accountability; setting up of information technology and data management strategies to support monitoring and governance; assessing health-policy reforms ex-ante and ex-post in a systematic and formalised manner based on evidence; and using workforce planning tools to actively manage the health of the workforce.

> ***"Finding and implementing innovative and cost-effective measures to improve the situation of chronic pain patients can have numerous and wide-ranging positive effects."***

As a second policy option the Commission considered enhancing the sustainability and efficiency of health care financing and spending by: improving the financing mix (benefits packages need to be based on cost-effectiveness criteria and cost-sharing schemes should support the containment of public spending, while preserving access); moving away from hospital-centric models; and strengthening the cost-effective use and the affordability of medicines. The joint report collected information on primary and integrated care, identifying the variation in the overall strength of primary care in Europe.

Goranova concluded highlighting the importance of measuring performance and monitoring progress towards goals and targets at national level to trigger improvements in the health system, increase information to the public, ensure health topics remain high on the political agenda and guide policy making and promote the exchange of best practices to improve efficiency and sustainability at EU level. The Joint report does not make direct reference to treatment of chronic pain patients. The Council's conclusions on the Joint report, however, could be applied to any kind of publicly financed health services. Accordingly, when treating patients with chronic pain conditions, two issues of equal importance emerged: publicly financed chronic pain treatment interventions have to be cost-effective, and the organisation of their delivery has to be well-coordinated and efficient (e.g. a stronger role for primary care and an integrated multidisciplinary approach to manage patients with chronic pain conditions).

Pain Expert Group


Joop van Griensven

JOOP VAN GRIENSVEN
PAE, Belgium

In the context of the current work of the European Commission, Joop van Griensven, President of Pain Alliance Europe (PAE), took to the floor to present the newly launched Pain Expert Group on the Social Impact of Pain that the Commission had published two days before. Joop explained the objective and the value of this group.

> ***"The Expert Group will give us the place to coordinate SIP activities, share best practices, highlight personal stories and underline the need for a greater understanding of pain."***

"The Expert Group will give us the place to coordinate SIP activities, share best practices, highlight personal stories and underline the need for a greater understanding of pain". Joop provided the audience with the details of background and the context of such an achievement. The Expert Group is the result of years of advocacy work by the SIP partners in Brussels to raise the profile of pain and share information with policy makers on its impact on society.

To conclude, Joop provided practical details on how to become a member of the Pain Expert Group and encouraged everyone in the room to participate with all their experience in the newly formed European network.

Doeke Keizer

Transcare-Pain in General Practice

DOEKE KEIZER

Co-founder of Transcare-pain, Netherlands

Doeke Keizer explained how his organisation had developed a method to treat chronic pain patients transdisciplinary. He acknowledged that pain was a serious issue that affected people's personal lives, as well as economic well-being. Transcare believes in evidence-based healthcare with a bio-psycho-social diagnosis and treatment to attend to patients suffering from pain. Keizer, who is a GP in the Netherlands, described how his company promoted cooperation between physicians, therapists, and patients. It also engages in research and promotes education programmes in chronic pain in order to spread awareness.

> ***"The problem with chronic pain is that healthcare is very fragmented. I hope we can work better together to find a way to integrate primary and secondary care to prevent what I call 'pinball medicine' – the patient shooting from one place to another."***

Ultimately, Transcare's aims are to contribute to lowering the societal cost of chronic pain while facilitating access to care for as many people suffering as possible. Keizer developed his company's plan, which aims at stopping patients taking medication that might be harmful, rather than beneficial, and encourage them to start taking Transcare-approved medication that Keizer believes will help treat chronic pain in the long run. The effectiveness of their programme, which combines the powers of different treatment disciplines and allows patients to set their own goals, has resulted in many sufferers leaving traditional health experts to begin treatment with them.

What do we expect from policy makers? The French example in 2017 presidential election

SERGE PERROT
President of French Pain Society, France

Serge Perrot

Serge Perrot presented the successful story of the pain advocacy programme run throughout France in 2017 to raise awareness of the impact of pain in society in the context of the country's presidential election. The programme was implemented in several different steps: an article was published in a national journal from the French pain society; a position paper for policy makers was developed and distributed; meetings were held with Presidential candidates to present the position paper and request endorsement; the White Book on pain was published; and there have been ongoing parliamentary meetings following the election.

> ***"It is the duty of our future leaders to write a new chapter of pain management and ours to accompany them to develop a medicine that is accessible to all, democratic and ethical, and of great quality."***

Perrot, who is a rheumatologist at Cochin University Hospital in Paris, presented the details of the position paper, which embedded seven propositions on pain. Priority number one was to maintain the specialised pain centres, which have been proven to be effective since they were introduced 15 years ago. The continuing education of health professionals in pain management was also seen as a priority, as was the need to improve pain management in emergency and outpatient settings and developing pain prevention campaigns in the workplace, in surgery settings or during care procedures.

Perrot concluded by reflecting on the need to continue pushing policy makers to improve the situation of pain patients. "It is the duty of our future leaders to write a new chapter of pain management".

Louise Skelly

The Patient & Client Council: Who we are & what we do for people in pain

LOUISE SKELLY

Patient & Client Council, UK

Louise Skelly presented the work and functions of the Patient & Client Council within the structure of the Pain Alliance in Northern Ireland (PANI). This arm of Pain Alliance Europe aims at being an independent voice in health and social care for patients and care givers. The role of the Patient & Client Council is to listen to, and act on, people's concerns, encourage citizen involvement, and provide advice and information.

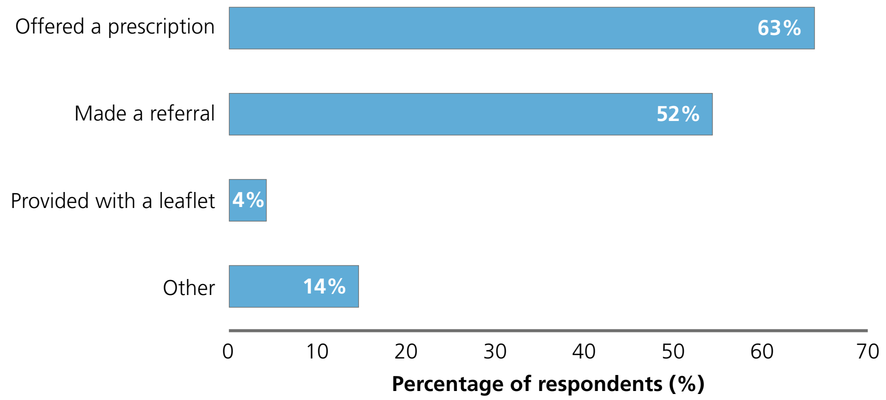
Louise Skelly analysed the current health system in Northern Ireland and stated that it was undergoing a transitional period. In comparison to England, Scotland and Wales, which have published policy documents addressing care pathways, "there was currently no coordinated approach or strategy for the management of long-term pain in Northern Ireland." she said. According to Skelly, there are "gaps and inequalities in access to treatment and pain management".

> ***"Patients working together with decision makers and professionals can come up with really good solutions even in times of austerity. If patients are listened to, it's the first step on the road to recovery for the whole system."***

The Head of Operations at the Patient and Client Council presented the results of the 2014 study "The Painful Truth", which gathered data and personal stories from 2,500 people living with chronic pain. The data, which was collected during consultations between pain patients and their GPs, revealed that a lack of coordinated care pathways might account for the different approaches taken by practitioners. More than 60% of GPs immediately offered patients some form of medication following their initial visit, whereas only slightly more than half of them recommended a referral.

Skelly also explained the key recommendations put forward as a result of the study. Most importantly, there was a need to recognise chronic pain as a condition in its own right. More should be invested in pain education for healthcare professionals, patients and care-givers, and there should be a more integrated approach towards pain management with the focus on multi-disciplinary methods. Alongside pain education, Louise Skelly also stressed the importance of strategies that empowered patients and allowed them

What action did your GP take when you first saw them about ypur pain?



to lead full and active lives. The study was considered a success, especially as most of the recommendations had been well received by the Ministry of Health. "Eight of these recommendations were accepted for implementation by the Ministry for Health of Northern Ireland." she told delegates.

Louise Skelly closed her presentation with a positive and encouraging account of the achievements of the Regional Pain Forum, which included the launch of a 5-year Specialty Development Plan and comprehensive education programmes for medical and pharmacology students at Queens University Belfast, as well as training for GPs in supporting self-management in pain.

Addressing the Societal Impact of Pain in Switzerland

André Ljutow

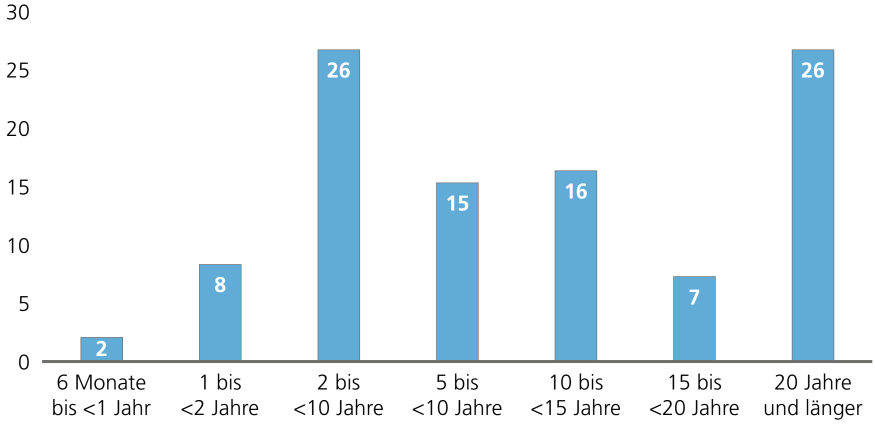
ANDRÉ LJUTOW
Schweizer Paraplegiker Zentrum, Switzerland

André Ljutow introduced to the audience the situation in Switzerland in terms of awareness, medical specialisation, political strategy, and overall treatment. He explained that the level of awareness of chronic pain as a disease in its own right was very small; pain medicine was not a recognised speciality; there was no national structure or strategy, but a broad variety of pain treating units and only interventional pain procedures and inpatient multimodal treatments received special reimbursement. He made the connection between political interest and the realisation of the direct costs of pain in society.

“As the monthly premium for health insurance is rising annually insurance companies and workers’ compensation groups become aware of the problem”. He emphasised the issue of lack of information. He also presented the findings from a survey of chronic pain in Europe: Prevalence, Impact on daily life and Treatment. According to this survey, chronic pain of moderate to severe intensity occured in 19% [Switzerland 16%] of adult

Reported duration of pain

- On average people affected by chronic pain suffer for more than 7.7 years
- Every fourth (26%) has pain for more than 20 years



Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment
Harald Breivik , Beverly Collett, Vittorio Ventafridda, Rob Cohen, Derek Gallacher
European Journal of Pain 10 (2006) 287–333

Europeans, seriously affecting their daily activities, social and working lives.

André Ljutow also presented the findings of three other studies conducted in Switzerland. The first study, organised by Fit for Work, analysed musculoskeletal diseases and the Swiss labour market. The study considered the direct, indirect, and material costs of pain, highlighting that, in Switzerland, the economic burden of job-related musculoskeletal diseases accounted for about 4 billion Swiss francs (CHF), not including direct medical treatment costs.

> ***"The lack of official recognition of chronic pain as a disease in its own right and of official recognition for pain medicine leads to a fast growing number of self-declared pain specialists/special units of unknown quality in Switzerland. Awareness is slowly growing that this situation leads to even more costly and inefficient treatments."***

The second study, initiated by Switzerland's National Prevention Programme at the Federal Office for Public Health , analysed the cost of non-communicable diseases in the country. According to this study in 2011, non-communicable diseases (NCD) created 80% of all health-related expenses, accounting for more than CHF 64 billion. Overall the indirect costs for low back pain in Switzerland were estimated to be around CHF 7 billion, a big portion of which was assigned to presenteeism (CHF 3.294 billion).

André Ljutow used the remaining time for his presentation to reflect on the results of the studies referred to. He called for audience members to join together: "We should claim recognition for chronic pain as a disease in its own right; explain the burden of disease; collaborate for better data on health related costs; propose efficient, interdisciplinary structures based on IASP recommendations; and present our data, which give evidence for effective pain treatment from the point of the patient, as from the point of the economic data."

Alan McGinley

Delivering our strategy, the third sector

ALAN McGINLEY
Arthritis Care Scotland, UK

> *"Patients and patient groups are routinely involved in health and social policy in Scotland, but the understanding of progress is not always shared and fallouts happen. In building a platform around pain we need to engage with the complexity and variability of the third sector, including its own capacity for silo-thinking."*

Alan McGinley aimed to look at the contribution of the third sector, also known as the voluntary or charity sector, and what kind of stakeholder it was. There are a variety of organisations in this sector, from those that conduct research, to others that focus on osteoporosis, for example, demonstrating that many types of third sector organisations contribute to helping solve chronic pain. Unfortunately, the voice of the third sector is not consistent, as the diverse groups have a number of priorities that are "not homogenous".

However, Alan McGinley reassured that there remained a lot of potential for this sector in Scotland, especially in light of the National Advisory Committee on Chronic Pain, which is being convened under the auspices of the Chief Medical Officer for Scotland. This committee intends to improve chronic health services in social care, along with developing data set around chronic pain, increasing the profile of chronic pain in Scotland, and advising the government. Alan McGinley suggested that arthritis, in particular, was not getting the attention it needed and should be given the political and economic resources to battle this issue. He plans to emulate the way other well-financed and better supported illnesses are managed in order to get mainstream recognition to give arthritis the coverage that it deserves. Alan McGinley said this measure was crucial because the number of people affected was rising exponentially and would in turn affect the future workforce of Europe drastically.

Cooperation: Added value or burden?


Souzi Makri

SOUZI MAKRI

European Network for Fibromyalgia Associations (ENFA), Cyprus

> *“Cooperation between all stakeholders is pivotal for the wellbeing of the patient!”*

Souzi Makri introduced workshop participants to Agora, an umbrella platform representing 19 patient organisations for people with rheumatic and musculoskeletal diseases (RMDs) in fifteen southern European nations. It has more than 20,000 registered members. Souzi Makri presented Agora’s main objectives, which are to provide a stronger voice and improve conditions for people with RMDs, so that patients can ultimately live independently and participate fully in society. She went on to share the value of Agora, “through cooperation, Agora has managed to establish and promote a common agenda for health and advocacy for people with RMDs in southern Europe”, she said. However, the president of Agora then reflected on some of the reasons for associations failing to cooperate successfully, which included: a lack of information and experience among the involved partners, competition between the groups and the lack of consistency and clarity on roles and responsibilities. With this in mind, she shared the key elements for successful cooperation, which above all focused on establishing clear and agreed mutual goals, planning and the writing of statements, and constructive discussions on the challenges that might arise from potential conflicts of interest in cooperation with all parties.

She moved on to present examples of successful cooperation between organisations and referred to the public-private partnership EUPATI, which was launched in February 2012 within the Innovative Medicines Initiative Joint Action. The aim of this patient-led project was "to build competencies and expert capacity among patients and the health-interested public". The project was coordinated by the European Patients' Forum and included a consortium of more than thirty organisations, which included patient organisations, academia, NGOs and industry. Souzi Makri also explained the benefits of increased patient input. "Cooperating with regulators enables voices of patients to be taken into account when developing policies. With the pharmaceutical industry it enables the possibility to improve preventive measures and treatments, and cooperation with physicians ensures that patients are better cared for."

Concluding, Souzi Makri made a call for more cooperation among all stakeholders. "Experience shows that the involvement of patient organisations has resulted in increased transparency, trust and mutual respect between (the groups) and other stakeholders."

SIP Malta

Christoph Vella

CHRISTOPH VELLA

SIP Malta, Malta

Christoph Vella concluded the round of presentations providing the audience with an overview of SIP 2017. Preparations for the Malta Pre-Symposium session, which kicked off the 3-day SIP 2017 Symposium in Valletta, had begun more than a year earlier. Much of the success of the event was due to the drive of different stakeholders who had expressed a strong interest in creating a local platform addressing the issue of the societal impact of pain. This cooperative approach was key to the development of SIP Malta, as Christoph Vella explained. "When you are talking about societal impact, it is not something that can be tackled by a single entity, you need a multi-stakeholder approach." SIP Malta brings together patients' organisations, healthcare professionals' organisations, along with academic experts, decision-makers and political bodies.

"Hopefully the momentum of SIP Malta will continue in the years to come with our current projects laying out a solid basis upon which to continue expanding our understanding of the current local situations regarding pain"

Christoph Vella went on to explain the benefits of establishing a local platform, stressing that local platforms were naturally more focused on local issues and empowered local organisations by amplifying their ability to achieve. To be effective, SIP Malta committed to be transparent, objective and unbiased in providing policy recommendations to decision-makers. To do so, SIP Malta set up a key priority: to provide an accurate description of the local scenario of the societal impact of pain. This entailed comprehensive research work on available data and statistics, which proved to be difficult due to the scarcity of such data and statistics related to the societal impact of pain in Malta.

He continued, explaining that patient centricity represented the primary focus of SIP Malta. Indeed, SIP Malta aimed at becoming a liaising point of reference for all stakeholders. It provided a useful platform tool that enabled patients to communicate, share experiences and receive feedback from organisations and policy-makers. Christoph Vella concluded his inspired presentation reinforcing the vision of SIP Malta to put in place the most appropriate tools and resources to alleviate the suffering of citizens with chronic pain.

Conclusion

Following the presentations, the floor was handed to Joop van Griensven (PAE) who presented the draft recommendations of the workshop and opened the floor for discussion and contributions. The main findings of the working group focused on a number of key points. All participants discussed the need for coordinated cooperation and agreed on the usefulness of having a unique European platform to share best practices on pain management.

Led by the plenary reporters, the attendees agreed on a set of policy recommendations and discussed the establishment of the European Commission's Pain Expert Group. Such a platform would represent a key tool for cooperation among the various stakeholders involved. It would eventually enable the exchange, comparison and benchmarking of data, best practices, and information between member states on pain management and its impact on society, and serve as a useful tool for policy makers to support the necessary changes to improve the conditions of those living with pain.

Presentation of findings and recommendations of Working Group 2

Plenary reporters, Frédéric Destrebecq from European Brain Council, Robert Launois from the French Society for Health Economics and Pamela Bell from Pain Alliance of Northern Ireland summarised the findings and presented the recommendations from Working Group 2 at Plenary Session II.

Policy Recommendations

1. The European Commission should establish, implement and support a multi-stakeholder EU platform for the exchange, comparison and benchmarking of data, best practices and information between member states on pain management and its impact on society.
2. The European Platform should compile and disseminate national and local data, best practices and information on the management of pain.
3. The European platform should collect and make available reliable data on quality of life and patient satisfaction with services, resource utilisation, clinical guidelines, workplace impact related to pain (such as absenteeism, presenteeism, lost productivity and/or early retirement) as well as relevant local experiences. Similar initiatives at national or local level should be supported, and should filter into the work of the European platform.
4. The European platform should highlight the interdependence between the key clinical, economic and quality of life end points.
5. The European platform should make it possible for policy makers to access best practices and relevant data to support the necessary changes to improve the conditions of people living with pain. Those changes should ideally contribute to making significant financial savings, improving employment rates and increasing wellbeing throughout society.
6. The European platform should strengthen the dialogue on pain between patients, medical professionals, decision and policy makers, insurance companies and other stakeholders. Such a mechanism is necessary for healthcare providers to co-operate on a structural basis, with the support of European institutions, national governments, healthcare authorities, patient organisations and patients individually.

Societal Impact of Pain

We need ……

ACCURATE DATA ON PAIN IN INDIVIDUALS

OUTCOME AND QUALITY CRITERIA ON PAIN SERVICES

EU-WIDE COMPARABLE, CROSS BORDER DATA


AL T
20
FREDERIC DESTREBECQ
PAMELA BELL
ROBERT LAUNOIS

MALTA
EU2017

SIP
Societal Impact of Pain

WORKING GROUP 3

Impact of Pain on Labour and Employment

WORKING GROUP 3

Impact of Pain on Labour and Employment: a need for more preventive measures

Context

The European Union and its member states are facing a huge challenge in terms of ageing population and the need to increase productivity and prevent involuntary early retirement. Reduced productivity at work or early retirement from the labour market caused by chronic illness and chronic pain has a high societal and personal cost. A European Commission funded report, published at the beginning of 2016 on 'Health-related constraints to raising Retirement Ages in the EU' found that decreasing the incidence of diseases and disabilities resulted in increases in the total number of years active in the labour force, which in turn would lead to less public expenditure on health and social care systems (Gheorghe, et al., 2016). Improving workers' health is therefore crucial as, according to the Commission's 2015 Ageing Report, the total labour supply in the EU (age group 20-64) is projected to stabilise by 2023 and to decline by 8.2% between 2023 and 2060, which is the equivalent to roughly 19 million people (DG ECFIN, 2015).

Health status: a major predictor of labour supply

Pain disorders are amongst the most prevalent, costly, disabling and commonly researched conditions in the workplace (Schultz, et al., 2007). Several literature reviews and database analysis indicate that chronic pain has a substantial negative impact on work-related outcomes (Patel, et al., 2012).While including 46,934 respondents in the United Kingdom, France, Spain, Germany and Italy researchers analysed population, prevalence and attributes of pain experience utilising a large-scale internet-based study (Langley, 2011). As they focused on the impact of pain on labour force participation, the analysis demonstrated that the experience of pain, severe daily pain, had a substantial negative association with labour force, as well as reported absence from work (absenteeism) and attending work while sick (presenteeism) (Langley, et al., 2010). As a health status measure, severe daily pain outweighed many other health status measures (Langley, et al., 2011)(Sternbach, et al., 2013).

A massive challenge for the EU

Nearly half of all absences from work in the EU, lasting more than three days, and 60% of permanent work incapacity are caused in Europe by musculoskeletal disorders (Bevan, 2013). Of the estimated 14 million people living with chronic pain in England alone, in 2011, 31% of men and 37% of women reported persistent pain. One in four said that their pain had kept them from usual activities, including work, on at least 14 days in the previous three months (Bridges, 2012). A 2001 survey conducted by the Belgium health care insurances estimated 50% of chronic pain patients between 25 and 64 to be not able to work due to their health condition. This incapacity has major consequences for the income of people with chronic pain (Berquin, et al., 2011). Among the workers, who are required to take sick leave because of their chronic pain, 22% are absent from work for longer than ten days per year (Reid, et al., 2011). Moreover, the study "Fit for Work Europe" conducted by the Work Foundation across 23 European countries, demonstrated half of all EU citizens suffered from back pain at some stage during their lives. Approximately 15% of these people with back pain will stay off work for over one month (Bevan, et al., 2009).

In the UK, more days are lost to back, neck and muscle pain than any other cause (Jenkins, 2014). A Norwegian Health Interview Survey showed that chronic pain explained 54 per cent of disability cases (Hougen, 2005). While lower back pain causes more global disability than any other condition, chronic pain conditions are by far the greatest cause of disability (Vos, et al., 2016)(Newton, et al., 2015). Chronic pain showed clear associations with healthcare-seeking and occupational activity, indicating considerable socioeconomic costs (Gerdle, et al., 2004). The 2008 UK Chief Medical Officer report stated that 25% of pain sufferers lose their jobs (Donaldson, 2008).

Age-related pain

The highest prevalence of severe and moderate pain is experienced between 40 to 59 years of age, or in the last twenty years of working life (Murray, et al., 2012). An analysis of the 2013 data on the burden of disease and injury in England found the leading cause of disability-adjusted life years (DALYs) to be low back and neck pain (Newton, et al., 2015). For persons with chronic pain its impact is highest for daily activities and work (Bekkering, et al., 2011). Unsurprisingly chronic pain is one of the major reasons why people exit the labour market prematurely and contributes to disability retirement (Phillips, et al., 2008) (Saastamoinen, et al., 2012). In the working population, chronic pain poses a substantial burden on individuals, employers, healthcare systems and society. In fact, the risk of pain patients having to give up their occupation has been calculated to be seven times greater than for the healthy population (SBU, 2000).

Rehabilitation and reintegration of workers

People with chronic pain often are either unable to work or have to cut their hours (Raftery, 2011) Given the very poor quality of life that people in pain report, especially its impact upon their ability to work, there needs to be a greater focus on the needs of people with pain seeking to return to employment (British Pain Society and Dr Foster, 2012). Early and appropriate clinical interventions, including rehabilitation aimed at and organised to support staying at work or return to work, can be cost-effective and have a significant impact on workforce productivity and quality of life (Bevan, 2013). Multimodal rehabilitation programmes and even less intense interventions (rehabilitation plan) can have long-term positive effects on sick leave (Merrick, 2013). Chronic pain has a dramatic impact on European society (Reid, et al., 2011). Pain, rehabilitation and reintegration of workers in the workforce can be addressed in policy making. In 2015 the Swedish Minister for Social Security, started a seven-point action programme for improved health and reduced sick leave, including support for people with chronic pain (Gustafsson, 2016)(Gov. Offices of Sweden, 2015)

Introduction

Reporter: SOPHIA V. M. WAGNER, ALBRECHT KLOEPFER, CINDY RIA BECKER,

Chronic pain is not only a major burden for those suffering and their relatives, but the economies of European countries are also massively affected by non-productive work time caused by chronic pain. Economists estimate that about a quarter of all sick days are caused by back pain alone. If one were to add direct health expenditures to economic costs due to loss of earnings, it would soon become clear that chronic pain is possibly the most expensive medical care condition in all European health systems. It is all the more astonishing because it only seems to be health politicians who take this issue seriously. Those responsible for economic policy-making do not seem to recognise this phenomenon. The aim of Working Group 3, "Impact of pain on labour and employment", was to promote a strong argument to bring the problem of chronic pain onto the politico-economic agenda in future. The 5-hour session included personal stories, a description of local political activities, as well as examples of prevention and reintegration strategies in the workplace. These personal accounts and best practice examples should be taken into account when making health, social, and economic policy decisions for Europe, in order to effectively reduce the economic burden of chronic pain.

From rehabilitation to work participation: System barriers during a patient journey

MICHIEL RENEMAN
UMCG Centre for Rehab, Netherlands

Michiel Reneman

Appropriate clinical interventions supporting employees who suffer from chronic pain to stay at work, or those preparing to return to work, are not only cost-effective, but have a significant impact on workforce productivity and quality of life. During his presentation, Michiel Reneman, a clinician and a researcher, pointed out the current obstacles to a broad implementation of evidence-based and cost-effective services for EU citizens. According to Reneman, one major barrier is the missing financial incentive for an appropriate clinical intervention, "If the medical doctor owns the MRI scanner, he has of course financial incentives to take MRIs." According to Reneman, the difference is the physical therapist is symptom-oriented and he is paid for services, not for outcomes.

> *"Because good work is good for health and well-being, work contributes to good patient care."*

From the employer's point of view: "First get better, then come back to work" was a typical example of poor work-related health care. Modified work opportunities are seldom offered by the employer, even though there is strong evidence to show that work is good for one's health and well-being. Reneman pointed out that "healthcare practitioners have to realize that helping the worker to return to work is often the best for the patient". The solution would be a patient-centred, multi-modal approach where the patient's goals are paramount. Interestingly, Reneman, along with many of his fellow delegates at SIP 2017, believes healthcare providers should financially benefit from the employee returning to work.

He went on to describe how vocational rehabilitation programmes would lead to better work participation, fewer disabilities and less pain, and it would be cost-effective from a societal perspective. The problem is that there are silos between the health and the employment sector. The health insurer is paying for vocational rehab, yet the benefits go towards the work system. Thus, it is necessary that these two departments collaborate.
Michiel Reneman concluded his talk underlining three policy recommendations. "Vocational rehab works." he said. "We need interventions, which have work participation as an outcome." The clinician repeated the need for bridges between healthcare, employment, social protection and finance policies and systems. And finally, as modified work has been proven to work, there should be legislation requiring reasonable and flexible workplace adjustments by employers.

Stephen Bevan

Policy and pain: Progress?

STEPHEN BEVAN
Institute for Employment Studies (IES), UK

Stephen Bevan focused on two questions: how well policy currently helps working age citizens who live with chronic pain and how opportunities could be unlocked through policy innovation. His main argument was that policies did not emphasize the impact of high quality work on health, nor consider the relationship between health quality and job outcomes. Even though the link between healthy and active ageing is well known, it is mostly excluded from discussions about healthy work. Bevan said there was a need for improvement of self-management and to invest in work ability.

Another main argument was that better prevention strategies could greatly reduce the burden of chronic diseases. Bevan estimated that a meagre 4% was the limit of budget outgoings across Europe when it came to prevention. "Most of our healthcare systems feel more comfortable if they are treating people when they are ill, rather than preventing them getting ill in the first place." he said. "And therefore, early interventions are not properly prioritised."

Furthermore, the risk of chronic illness has to be better assessed, as there are conditions where chronification can be prevented. Public health and prevention strategies should play a bigger part. Obesity, for example, increases the risk of osteoarthritis and type 2 diabetes. Bevan agreed that health policies focused on diabetes for good reasons, but he was disappointed that other conditions, which are linked to chronic diseases e.g. obesity, have been ignored so far.

Bevan suggested ways in which a more innovative approach might help bring about policy change. Firstly, there has to be more joined-up thinking. Following on from Michiel Reneman's talk, Bevan agreed that silos, which are hindering any progress between the health and employment sectors, should be eroded. A further issue, from the medical perspective, is that healthcare professionals, especially those in primary care, do not see job retention, return to work or vocational rehabilitation as a clinical priority. Until now, none of these initiatives have focused on the question,

"How can healthcare strategies support people suffering from chronic pain remain at work while recovering?" he claimed. Policies have to focus on job retention. "Make work a clinical outcome." he announced. And again in tune with Michiel Reneman, Bevan suggested including "societal benefits" in the equation. "Allow reimbursement of specific therapies or medical devices which support staying at work." Most importantly, Bevan called for a healthy work policy to prioritise high levels of worker involvement, as well as support self-management & peer-support initiatives.

"Policy could be more joined-up. We have too many silos between policy areas, such as health, education and employment. So if we try to join up these policy issues, it is possible that better outcomes could happen for people with chronic pain in the labour market across the EU."

Antony Chuter

A voice for people in pain

ANTONY CHUTER

Pain UK, UK

Antony Chuter gave a very personal account of a man who has lived with chronic pain for almost twenty five years. At the age of 21 and with everything to live for he suddenly fell ill and within months his previously active and happy life had come crashing down. So much so, that within a year he had lost his lover, his home and his job. His days were now spent going from doctor to doctor for tests, waiting for results and then moving on to more outpatient clinics in the hope of being given a proper diagnosis for the excruciating pain he was experiencing. This all took its toll. “I lost all my hopes and dreams. I stopped going out. I just wanted my old life back. I felt devastated to the bone and sometimes even suicidal.” It soon became clear for Chuter that society did not know how to react or interact with someone suffering from chronic pain. “Awareness and reflection on the topic of chronic pain is needed in societal discussions.” he stressed.

“People, who are newly diagnosed with long term pain, need to be offered a multi-disciplinary-specialist network or at least a pain support group with a psychotherapist.”

Then one day and by chance a decade later, Antony came across an Expert Patient Programme course and became much better at being a “self-manager” of his long-term condition. “My confidence started to rise again, I was being less negative. Some of my doubts and some fears slowly started leaving.” It was around this time he met a doctor who told him, “Sometimes we just don't know what causes pain, a diagnosis would be lovely, but not everyone gets one.” This simple explanation from a physician marked a turning point for Chuter. This was the first time he felt believed.

Eventually Antony began to volunteer, actually running Expert Patient Programme courses. This started a series of requests to help, represent, explain and get involved with different organizations to the point where he was asked to chair the patient group at the Royal College of General Practitioners - a huge leap, from being agoraphobic to chairman. Finally, after 15 years of volunteering, Antony went back into paid work and by this time a “somewhat” normal life. He was elected chair of Pain UK in 2014.

Concluding, Antony proposed a range of solutions that might prevent others falling into the same twenty year trap he found himself in. “People, who are newly diagnosed with long term pain, need to be offered a multi-disciplinary-specialist network, or at least a pain support group with a psychotherapist.” he told delegates. In addition, healthcare providers would benefit from giving people in pain time to process the situation they now found themselves in. “When someone has accepted living with their pain, offer them a self-management programme.” Antony believes this way the patient will get the most out of the multi-disciplinary team’s pain management programme. Finally he recommended encouraging pain patients to take on voluntary work, as this “may lead to paid work”, and, as with Antony, a “somewhat” normal life.

Sarah Copsey

Pain in the work place, the role of the European Union

SARAH COPSEY
European Agency for Safety and Health at Work (EU-OSHA), Spain

Sarah Copsey told her audience that safe and healthy working conditions were key components of retaining an ageing workforce, retaining workers with chronic diseases and making work sustainable. During her presentation, Copsey presented relevant EU-OSHA policy and addressed the question of how occupational safety and health (OSH) could assist in pain management at work. She also presented some relevant findings from the European parliament's pilot project on older workers, which her agency carried out.

OSH practices ensure pain does not worsen due to poor working conditions and promotes health and wellbeing. The OSH framework directive provides a management system for this, based on risk assessment by employers, including collective measures, which will make work safer, healthier and easier for the whole workforce.

Sarah presented an EU-OSHA project on health and safety strategies in the context of an ageing workforce. One of the modules looked at "return to work" and concluded that early intervention should be a priority when health problems arose and the focus should be on "staying in existing work". Furthermore, it was pointed out that multidisciplinary programmes were necessary to provide coordinated support to companies and employees, tailored according to, and based on, assessment. And in line with the previous speakers, return to work should be considered a clinical outcome or treatment goal for general health physicians. Sarah stated that the focus should be on public health for non-life threatening chronic diseases – including musculoskeletal disorders (MSDs).

> ***"Pain sufferers can continue to work with the support of the public health system, the right attitude of employers and often very simple measures in the workplace. But it needs a flexible attitude and a willingness to work with the employee."***

To achieve this, joined-up policy, interventions and budgets were needed. One example from the OSHA report came from Sweden, where there is a system of joint budgeting across the disciplines that are involved in an individual's return to work following illness.

Sarah commented that the Swedish example had shown improvements in return to work rates for MSD sufferers. But, she stressed, such measures should be in conjunction with access to occupational health services, work health surveillance and workplace health promotion for the whole working population and she repeated, “The focus should be on early detection and prevention”.

However, one major problem is that not everybody can easily access occupational health services e.g. small businesses, casual labour and the self-employed. According to Copsey, further important conclusions to the project carried out for the European parliament was that OSH policies, strategies and actions should be sensitive to diversity: gender, age and disability. And small businesses needed guidance and support, because many were not aware of the business benefits of OSH. Sarah Copsey concluded, with the positive message that although chronic pain too often led to an early exit from the workplace, "with the right employer, attitudes and workplace adjustments, combined with support from the public health system, many pain sufferers could continue working.”

John Cachia

Pain, mental health & work

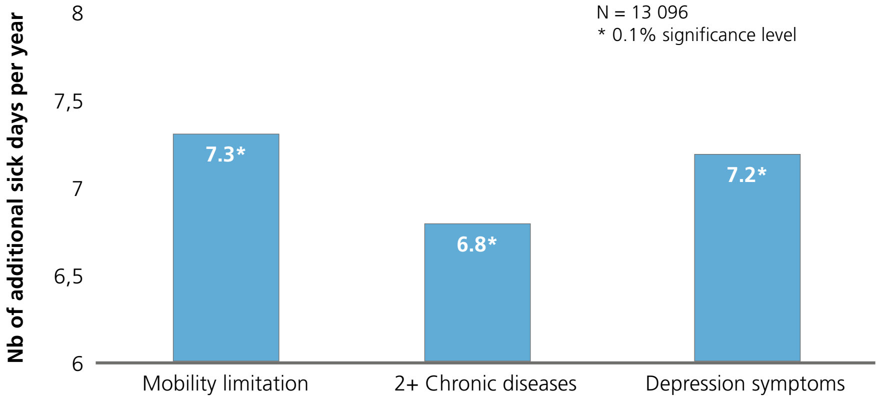
JOHN CACHIA
Ministry for Health, Malta

John Cachia began by pointing out his vision of a more holistic approach to care, based on integrated bio-psychosocial measures. Most importantly action was needed, he said. "Let's move on! Let's create policies based on what we know, instead of just pitching more and more studies." His vision is one of an "all-inclusive society, in which persons with mental disorders are fully empowered to maximize their health." "This," he continued, "would enhance their contribution to the community, their contribution to the labour market, their contribution to society at large".

Cachia gave examples of the link between pain and mental health in a person's work life, as well as to the economic labour market. For example, the significance of additional days in annual sickness absence among workers aged 50–59 in European countries due to depression symptoms was alarming. On first glance, 7 additional days may not seem a lot, but when taking into account the number of workers absent due to illness the numbers "add up" and create quite an impact on an economic level (not to mention a personal level).

Sickness Absence (OECD 2013)

Additional days in annual sickness absence among workers aged 50-59 due to depression symptoms, European countries



He continued showing that pain and depression, or other mental disorders, often went hand in hand leading patients to go to medical services much more frequently, thus creating high healthcare costs. Further studies have shown that for patients suffering from chronic pain and/or mental disorders there was a greater threat of increased alcoholism and medication abuse, creating a vicious cycle for those suffering.

Ideally, sufferers would be treated with an integrated bio-psychosocial care approach, which took physical well-being, mental health, and social issues into account. Cachia pointed out that there was a "great deal of evidence showing the effectiveness of this treatment model for musculoskeletal pain, temporomandibular disorder (TMD), headaches, and widespread pain and fibromyalgia"

> ***"The vision of CMH-Malta is an all-inclusive society, wherein persons with a mental disorder are fully empowered to maximize their health."***

He described how integrated bio-psychosocial care was based on two pillars: Functional restoration is an interdisciplinary application which offers an exercise-focused programme based on the sports medicine principle of working through pain, rather than avoiding it; a disability management programme addressing the psychosocial issues of the patient with chronic pain; and a case management session assisting the patient in navigating workers' compensation and disability insurance systems and also assisting with vocational reintegration so that patients can successfully return to employment after treatment. The 2nd pillar concerns pharmacotherapy. Cachia explained that psychotropic medication was essential in chronic pain management. It was an effective adjuvant analgesic, and further reduced dependency. Cachia is convinced that "pharmacotherapy without functional restoration programmes deprives patients of their rights to holistic care of chronic pain and any co-morbid conditions."

According to Cachia, pain treatment models that incorporate the assessment and treatment of mental disorders were necessary for optimal outcomes. On the basis of past research conducted in patients with co-morbid chronic pain and psychiatric disorders, co-morbidity may be treated with equal success during early intervention programmes. A holistic approach was essential, and at its best, if early interventions were integrated into it. Cachia concluded calling for a careful patient assessment to be carried out before moving on to develop a comprehensive pain management intervention strategy. "An assessment should proceed from a global bio-psychosocial diagnosis of pain to a more detailed evaluation of the most important interactive factors of this diagnosis. Once the comprehensive assessment is completed, it can be used to develop a treatment programme individually tailored for each patient." Thus it is imperative to integrate functional restoration with pharmacotherapy to give integrated and holistic support to sufferers.

David Tjong

Pain policy, why should an employer care?

DAVID TJONG

Ideal Standard International, Belgium

David Tjong stated it was the moral and ethical duty of an employer to ensure a safe and healthy work environment. The global director of HS&E at Ideal Standard International began by presenting different risk factors in the workplace that organisations should take into account. These risk factors, for example, time pressure and lifting or moving heavy loads, have been analysed within the Second European Survey of Enterprises on New and Emerging Risks (EU-Report from EU-OSHA, ESENER-2).

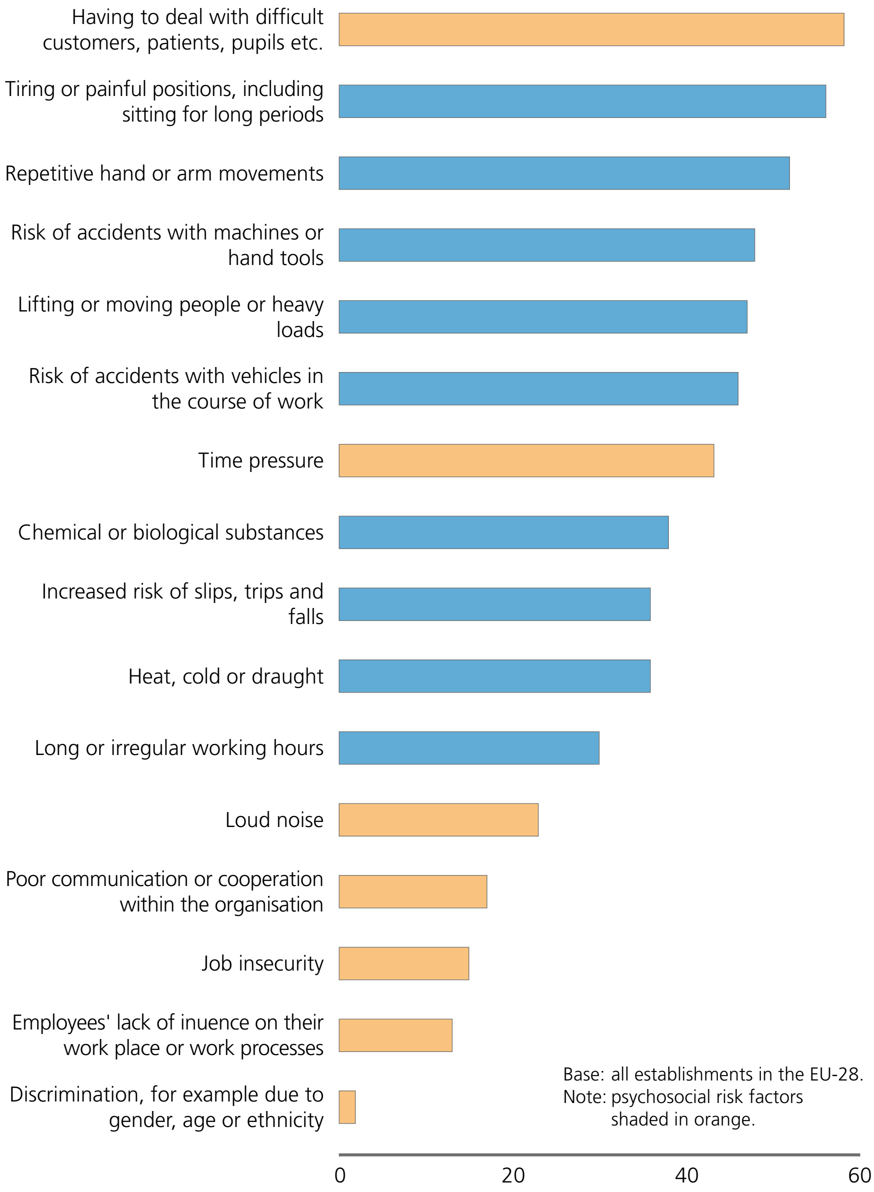
Tjong presented the measures taken by Ideal Standard International since 2002 to ensure their employees work in a safe environment. These measures include ergonomic training, a lifting device manual, and participation in various different campaigns promoting work and health safety (such as the EU-OSHA campaign or the campaign "Health workplace for all ages")

Tjong emphasised the importance of ergonomics, which he described as being "the science of improving employee performance and well-being, in relation to job tasks, equipment, and the environment". Here, the age difference of workers had to be taken into account. One of Ideal Standard International's principles is to continually improve their efforts to design the workplace for what people do well, and design against "what people don't do well". The company provides a catalogue with guidelines of how best to operate all handling devices used at various different stages in the manufacture of their products. Most importantly, this gives employees the opportunity to give feedback or express any remarks or concerns. This allows the company to collect all best practices, which "are not given a top-down approach", Tjong stressed, but have been developed by the employees. In using and promoting the handling device manual, Tjong concluded "a continuous improvement of health and safety performances can then be ensured."

> ***"Care for Our Wellbeing' is one of Ideal Standard Shared Values. We are committed in building a process focused on prevention of injuries and illnesses."***

Second European Survey of Enterprises on New and Emerging Risks (ESENER-2)

Risk factors present in the establishment (% establishments, EU-28)



Base: all establishments in the EU-28.
Note: psychosocial risk factors shaded in orange.

Peter Van Wambeke

Workable work for patients with chronic pain: a randomized trial

PETER VAN WAMBEKE
University of Leuven, Belgium

Peter Van Wambeke was in Malta to present the findings of his current project "Workable work for patients with chronic pain: a randomised trial". Starting off with some facts, he reminded the audience that the prevalence of chronic pain in Europe was 19%. 80% of those people are, according to Wambeke, within the working age. "When we look at all these patients with chronic pain," he continued, "we see that 44% of them are still able to continue working, full or part time." Looking at this portion of patients, one quarter of them is clearly affected by pain, yet they remain in the workplace.

> ***"It is our social obligation to guide patients with chronic pain towards realistic participation and professional reintegration. Successful RTW needs facilitating measures: tailor-made support, intensive coaching (also in the workplace) and communication between all involved parties."***

Peter Wambeke and his team carried out their own study with 200 patients at their pain centre in Leuven. 15% of their clients were still in work. More than 70% had been on sick leave for up to 3 years and the research showed that the chance of a client returning to work after one year was less than 20%. Taking all these points into account, it was clear Europe faced a major challenge, namely the huge impact on, and cost for, society driven by chronic pain. "So we really have to change something!" Wambeke emphasized.

He then put to his audience, "What can we learn from patients with chronic pain who stay at work? What motivates patients with chronic pain to stay at work?"Wambeke identified four motivators: "Work as value" (job satisfaction, recognition, social status), "Work as income" (financial needs), "Work as therapy"(distraction from pain, structure, social contacts), "Work as responsibility" (feeling indispensable, loyalty). He highlighted "Work as income" because this was one of the major aspects of going to work, which, as Peter explained, can be a problem "if the difference between income by working and benefits from the state is almost negligible, especially if the patient is doing part-time or adjusted work."

On the other hand, Wambeke presented success characteristics and factors that could help the employee stay in work; for example, the personality of the person, his coping strategies, having access to healthcare services and what his concept of pain was. Wambeke pointed out that one of the more important success factors was “adjustment latitude”, which includes realistically increasing the capacity of the patient, while at the same time trying to lower the workload. “You have to get your patient back into balance.” he said.

Continuing, Wambeke raised the question of unemployed patients with chronic pain. What were their barriers to return to work? He described how uncertainty about their medical condition, difficulty in making plans because of the unpredictable character of the condition and physical limitations, the lack of flexibility in the workplace, and more importantly for this group, the risk of giving up the security of benefits for paid work that may not be sustained, all had a negative impact and were recognized as barriers to this group returning to work. Additional issues related to too little job coaching and too little control over their own condition, which could lead to depression, anxiety and loss of confidence. Nevertheless, Wambeke told the group, returning to work was possible, but three important measures had to be taken: “a tailor-made support programme for each patient, intensive coaching, and communication between all involved parties - the patient, the treatment team, the employer, the occupational physician, and the advising physician - which is really not that easy,” he continued, “but not impossible!”

Raul Marques Pereira

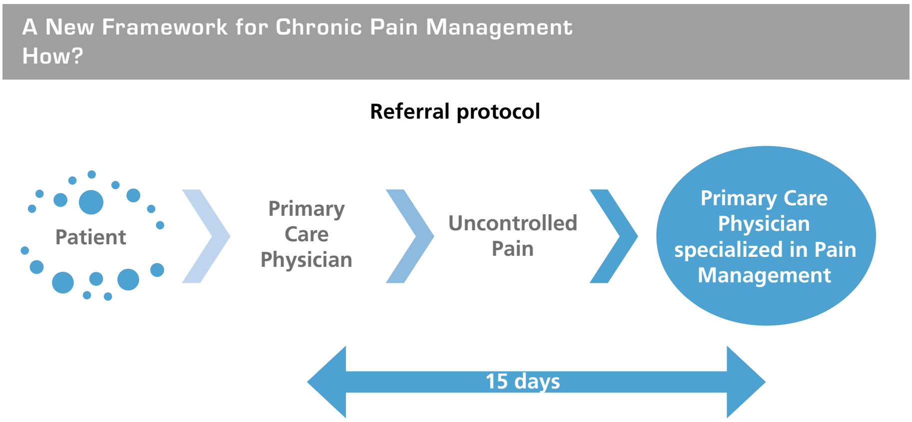
Chronic pain management in primary care – An innovative approach

RAUL MARQUES PEREIRA
Unidade de Saude Familiar, Portugal

Raul Marques Pereira began his presentation setting out three questions he wanted to address, "Why is it important to manage chronic pain in a primary care setting? How can we have a new framework for the management of chronic pain in a primary care unit? And what more can we do to improve the quality of life of our patients?" Pereira introduced some details from his home country, Portugal, where in a population of about 10 million people, the prevalence of chronic pain was about 37%. Unfortunately, only 1% of those patients had access to chronic pain units. Raul described how he worked in a small city practice with 8 other family doctors and 16,000 chronic pain patients. Pain consultations began in 2015 and the team has developed a new framework, namely a fast track procedure for patients with chronic pain.

First, a patient sees a primary care physician. If this doctor is not able to manage the patient's pain, it is considered "uncontrolled pain" and Pereira and his team receive the referral to provide the fast track consultation. A specialized consultation should happen within 15 days of the initial doctor's visit. The chronic pain consultations include a thorough assessment of the patient's needs, they define the patient's goals of care, adjust the treatment plan (by medication, physiotherapy and other resources), and provide a further follow-up consultation, usually one month after the initial referral. "Patients

A New Framework for Chronic Pain Management
How?



have different needs and goals." Raul explained, "Maybe they have not been working for months and they are very worried. Maybe they are 80 years old, maybe they are only 10."

Pereira and his team see more than 150 patients each year and they claim to have witnessed clinical improvements in more than 80% of their clients. The team is now in the process of expanding and is training a number of family medicine residents and medical students "This means we can show them how to replicate this model." he said, "It is a simple model and a low cost model."

> ***"We present an innovative and replicable model on the implementation of a chronic pain consult in a primary care setting. This model allows a rapid first observation and follow-up of the patient and potentiates an improvement in the quality-adjusted life years of our patients."***

In conclusion, Raul told delegates he hoped this model would be replicated in chronic pain consultations in Primary Care Health Units. It is especially important in Portugal that primary care providers play a bigger role in offering adequate medical care for chronic pain patients. Pereira and his team aim to improve patient access to their programme and are in the process of measuring the impact of their type of consultation on quality of life and a reduction of disability days. They hope to publish their findings in the future.

Closing remarks

Following the presentations, participants identified the areas they considered a priority for the rehabilitation and reintegration of workers into the workforce in order to soften the impact of chronic pain on a personal level, as well as on a societal level. It became clear throughout the afternoon that it is often the legislative framework that hinders management from creating better support. It was agreed that discussing these issues with like-minded people was not enough, as you are already preaching to the converted. The challenge now is to convince and involve politicians, but equally to persuade company managers that their employees matter.

Integrated bio-psychosocial care remains underfunded and is seldom implemented. The workshop group agreed that a holistic approach including education, functional restoration, psychological and social support would be most effective. At the same time, especially for healthcare professionals, but also for all others involved, it needed to be clear that "care does not equal cure". Thus, a holistic approach also needed to include working with the patients on acceptance and coping with the status quo, as there were limits to the medical care. The group agreed that early intervention was very important to tackle co-morbidities.

Unfortunately, there are still silos between health and work policies, which hinder the inclusion of chronic pain patients into the workforce. The education of all stakeholder groups and patients was also deemed vitally important to reduce the burden of pain. There is a strong need to raise awareness of chronic pain and its impact. Participants agreed that they had a social obligation to guide patients to a realistic participation and work-related reintegration level. But this also required intensive coaching for patients, for healthcare physicians, for politicians; basically, for all stakeholders. Over and above this, the real challenge was to get employers and health professionals working together. The group agreed that one of the near future goals should be to harmonize the different best practices across Europe. All of these ideas should not just be considered "nice to have" as they would be urgently needed in practice over the next 30 years, as the workforce ages and more and more people develop chronic conditions.

A number of recommendations designed to encourage politicians to prioritise pain policy discussions at a European and national level were discussed. These concrete policy suggestions were presented the following day during the plenary session and would be forwarded to MEPs and national governments to keep the topic of pain high on the political agenda.

Presentation of findings and recommendations of Working Group 3

Plenary reporters, Britta Lambers from Schmerzlos e.V., Saskia Decuman from the National Institute for Health and Disability Insurance and Julien Nizard from the University Hospital Nantes, summarised the findings and presented the recommendations from Working Group 3 at Plenary Session III.

Policy Recommendations

1. The European Commission should increase investment in pain research (basic science, clinical, epidemiological) as a priority in future EU framework programmes, and undertake or promote research on presenteeism and involuntary causes of early retirement across Europe, while stimulating collaboration in this field between all stakeholders.
2. The European Commission should promote and facilitate the exchange of good practices on pain and workability among all relevant stakeholders in Member States to facilitate the reduction of health inequalities (eg. business cases: good examples from employers).
3. The European Commission should promote national information campaigns.
4. National governments should invest in technologies to prevent involuntary early retirement and allow workers, who wish to, to continue participating in the workplace.
5. National governments should appoint relevant national institutions (e.g. cross-ministerial working groups) to build bridges between healthcare, employment, occupational safety, social protection and finance policy systems, to improve the work participation of people with health-related challenges. With the right employer attitudes and workplace adjustments, combined with support from public health systems, many people living with pain could continue working.
6. National governments should invest in interventions which have (work) participation as an outcome in line with patients’ goals; including early intervention.
7. National governments should prioritise vocational rehabilitation (starting point: primary care) promoting focus on work capacity, instead of on disability.

8. National governments should promote taking into account mental co-morbidities e.g. through the promotion of health and wellbeing in the workforce.
9. National plans should encourage enforcement of existing national legislation requiring reasonable, flexible workplace adjustments by employers that can help people with chronic diseases stay in work or reintegrate the workforce.
10. National governments should develop chronic disease cost-of-illness studies and cost-effectiveness evaluations of interventions (including societal aspects beyond the direct costs on the health system) to support rational decision-making and cost-effective resource allocation.
11. Intensive coaching for patients, politicians, HCPs, employers, and for all stakeholders. Employers also need efficient communication, including communication with private insurance companies, if applicable.

Societal Impact of Pain

With the right treatment, chronic pain patients are more productive and can stay in the workforce longer

Societal Impact of Pain

Chronic pain has a major impact on workforce participation and productivity

WORKING GROUP 4

Challenges, lighthouses and best practices in pain policy

WORKING GROUP 4

Challenges, lighthouses and best practices in pain policy

Context

Pain treatment is likely to be as old as humans. Already Neanderthalers searched for pain relief as they tried to treat tooth pain (Frayer, 2017). In our modern society pain is a common element of numerous chronic health conditions, such as cancer and musculoskeletal diseases, and often persists past normal healing time (Bonica, 1953). Usually pain is regarded as chronic when it lasts or recurs for more than 3 to 6 months (Merskey & Bogduk, 1994). Although acute pain may reasonably be considered a symptom of disease or injury, chronic and recurrent pain is a specific healthcare problem, leading to typical co-morbidities, such as sleep disturbances, anxiety, depression and low self-esteem among others. Thus, chronic pain develops into a typical syndrome and could, for policy purposes, even be considered a "disease in its own right". While acute pain is a brief and self-limiting process, chronic pain comes to dominate the life of the people concerned and often also family, friends and caregivers.

What are we talking about?

Pain and chronic pain affects a large proportion of the population. In fact, one in five Europeans suffers from chronic pain, which translates into millions of patients facing pain every day (100 million people in the 28 European Union countries alone). The distress of individual patients is coupled with the financial burdens caused by the condition and a general burden on society: impacting caregivers and families, the workplace and causing changes in relationships with other people. Governments and individual payers, pay high costs for pain-related care and disability support. However, the costs of care are often hidden in budgets across all ministries, not only in the Ministry of Health and Social Affairs.

Unfortunately, throughout the EU, chronic pain patients report insufficient pain control and dissatisfaction with treatments (Breivik, et al., 2006). Overall, individuals reporting chronic pain have a significantly higher health care system utilisation than individuals without chronic pain complaints (Eriksen, et al., 2004). People with chronic pain consult their general practitioner five times more frequently than those without chronic pain complaints (Von Korff, et al., 1990).

The most widespread chronic pain conditions, such as low back pain, arthritis, and recurrent headache (including migraine) are so common that they are often seen as a normal and unavoidable part of life. Chronic pain is often not only under-diagnosed but also under-, over- or just wrongly-treated (Dietl & Korczak, 2011). In some indications, elderly persons get less access to pain treatment than the general population as pain is often overlooked by health professionals (Booker, et al., 2016)(WHO, 2015). In addition to the erosion in quality of life and financial burdens caused, chronic pain often sets the stage for the emergence of a complex set of physical and psychosocial changes that are an integral part of the chronic pain problem, greatly adding to the burden upon individual patients.

Challenges, lighthouses and best practices

As pain is a problem across Europe, policy makers, patient advocates, campaigners, academics and administrators have approached the subject of pain in a multitude of ways (Federanziani, SIHA, AGE, PAE, 2016). While in each country there are negative examples, in each country there are also inspiring and eye-opening best practices setting the benchmarks for the future.

The Societal Impact of Pain platform benefits from its wide variety of partners and allies sharing these experiences and best practices. As such, the SIP platform allows policy makers access to important insights that not only lead them to implementing changes improving the lives of pain patients, but also achieve significant financial savings, improve employment rates and increase wellbeing throughout society.

Introduction

Reporter: ANDREW LITTLEJOHN

Bart Morlion, President-elect of EFIC, moderated Working Group 4's seminar about "Challenges, lighthouses and best practice in pain policy". It is well established that chronic pain is demanding and difficult to treat. It is estimated that around 100 million people in Europe suffer from chronic pain. In other words, 19% of European adults are suffering from a condition that is negatively affecting their daily, social, and working lives and according to research most of them do not receive pain treatment. Studies have also shown that for those that do receive treatment 40 % of it has been described as inadequate. For this reason, a workshop focusing on lighthouse projects and best practices was vitally important to show that progress has been made. However, as research has shown, there are still many challenges to overcome and some of those were also touched on during the 5-hour workshop. For the occasion, twelve speakers from Germany, Spain, France, Portugal, Slovenia, Austria and the UK had come together to share information, some reminding participants there was still a lot to be done and others to offer a detailed account of their most recent and, in some cases, most successful initiatives, which were aimed at inspiring and offering guidance for follow-up projects to the workshop participants.

The opening words were given to the two Maltese co-chairs, Antoinette Calleja from the Ministry for Health and Mary Vella from the National Rheumatoid Arthritis Society (NRAS):

"As you may know this symposium is being organised under the auspices of the Maltese Presidency of the Council, and as presidency it is a real pleasure and honour to have amongst us such highly esteemed experts. Since January 2017 Malta has been at the helm, as we had taken on the role of the Maltese presidency and by the end of this month (June) we will be handing over to Estonia. As a presidency, we have worked by building on the previous

> ***"There are many good initiatives around the management of pain, about societal structures around pain, but it's quite disseminated in many countries, so we should learn from each other and bring it together in an integrated way."***
>
> *Bart Morlion*

work of our previous presidencies and as priorities we have focused on areas where we found that there was clear added value for action at EU level. And as case in point, one of our priorities we focused on was voluntary structured cooperation between healthcare systems. And as you can imagine SIP's symposium has also taken on this concept, as this symposium is also being headed under the caption of "Structured cooperation between health systems tackling the societal impact of pain", which allows me to move on to today's programme. As you know the programme is highly intense with speakers of a high calibre. I would also like to take this opportunity to make you aware of the fact that a set of draft recommendations have been prepared. These recommendations are SIP's draft proposals and SIP is inviting you to pass any comments or suggestions for further review by SIP."

> ***"The Maltese government does not underestimate the case to manage correctly and highlight the need to manage chronic pain better."***
>
> *Antoinette Calleja*

Boaz Samolsky Dekel

Why is stratified-based referral selection in pain patients relevant for policymakers?

BOAZ SAMOLSKY DEKEL
No Pain Foundation, Malta

Boaz Samolsky Dekel opened the workshop setting the scene by reminding participants that chronic pain conditions and their undertreatment had a substantial socio-economic burden on society. The management of chronic pain is complex, usually requiring specific pain treatment and simultaneous psychological and physical therapy. Samolsky Dekel believes one of the reasons for inadequate chronic pain management is the lack of guidelines on who, when and where to refer the patients for appropriate care. This has a negative effect on costs, he said.

With too much time and money being spent on poor chronic pain management, the scientific director of No Pain Foundation Malta introduced the concept of "stratified medicine", which seeks to target therapy and make the best clinical decisions for groups of similar patients. "A stratified-based referral-selection of patients, based on prognosis can target the appropriate treatments to the "right" patient." he said. Samolsky Dekel continued saying that stratified medicine was regarded as central to the progress of healthcare according to the leaders of the National Institutes of Health, and the Food and Drug Administration in the US.

He explained the difference between the standard approach to pain patient care and using stratified medicine. "Our normal attitude towards patients is we take a group that has something in common, and we apply a treatment, which may be successful. But many times this is not the case. So we repeat this loop again and again and we lose time and money. A stratified medicine approach seeks out those in the group with similar characteristics and who we know will respond to the treatment that we are about to give them. This is stratified medicine. "

Samolsky Dekel stated it was about knowing which person to send to the right physician to provide the right treatment. "When we give lipid lowering therapy to people above a certain threshold for cardiovascular risk this is exactly what we do. We are doing this stratified medicine for this person, so why can't we do it for lower back pain patients?" Samolsky Dekel believes this approach holds real promise, as pain patients will receive the most appropriate treatment to suit their needs and this in turn should decrease the socio-economic burden of chronic pain.

He continued by referring to the Italian state law (38/2010), where all citizens in need should have free access to palliative care or pain therapy facilities. "This law foresees the design of a nationwide network of three types of pain therapy facilities from the primary care physician to intermediate ("spoke" or 1st level) and high ("hub" or 2nd level) proficiency pain centres. This approach coincides with the concept of stratified medicine," he continued, "which seeks to target therapy and make the best clinical decisions for groups of similar patients."

According to Samolsky Dekel, the problem with this particular law is that, as in other countries, there are no specific guidelines as to which patients should be sent to which facility. "So we don't know if the patient should remain with the GP, should he be sent to the 1st level or the 2nd level." Key to this, he continued was "an adequate screening tool that can stratify chronic pain patients according to their risk for a specific outcome". They would then be referred to the most appropriate treatment programme in order to minimise the risk of a negative outcome.

> ***"It is important to have the right referrals to the right pain physician, because it derives from stratified medicine an extremely novel and important new target for pain medicine."***

The Mainz Pain-Staging-System (MPSS) was recommended as the most appropriate tool to carry out this screening process. MPSS is a ten-item interview-administered, multi-dimensional measure of pain chronicity. Samolsky Dekel explained how this tool was widely used in Germany. It grades chronic pain in terms of four pain related axes: persistence, spreading, medication, and health care utilization. The resulting score classifies patients at three chronicity stages: mild, moderate, and severe chronic pain. Samolsky Dekel explained that these stages were assumed to represent different phases in the process of chronification. "The higher class requires a more extensive intervention and is less likely to result in a full recovery from chronic pain."

Samolsky Dekel and his team adapted this tool and referring to patients who came to their "spoke" level, he noted that on the initial visit around 30% of the patients could have been treated by their GP, about 40% had found themselves in the right treatment category, which meant "more than a quarter of patients should actually have been sent to the "hub" for a more sophisticated care programme." The second visit showed a high percentage of patients could switch from "spoke" level care to be further managed by their GP as "the treatment they received initially was appropriate to and improved their situation." It seemed apparent this measuring tool had a positive result in stratifying patients. The scientific director of No Pain Foundation Malta concluded his presentation reinforcing his message that stratification was the way forward, as it could lead to a more efficient and effective healthcare approach when dealing with chronic pain.

Laura Fernandez Maldonado

Act against Chronic Pain (MOOC)

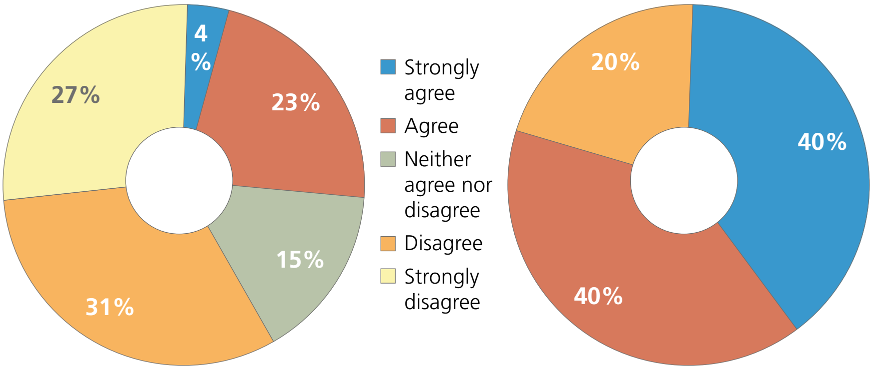
LAURA FERNANDEZ MALDONADO
Fundació Salut i Envelliment UAB, Spain

Laura Fernandez Maldonado had come to Malta to share information about her organisation's most recent initiative in pain self-management using an e-learning approach. Fernandez was representing the Fundació Salut i Envelliment (FSIE) UAB Expert Centre (or People's University) in Barcelona. The foundation carries out research on all aspects of health promotion and active ageing, both clinical and social, and has a long history in the study of chronic diseases and dementia.

She described how during the last five years the foundation had developed four chronic pain self-management training programmes with primary care centres in Spain. Due to the need to offer resources to those patients who, for example, lived in geographical areas where it was difficult to organise face-to-face activities, the research team devised a massive open, online course (MOOC) to reach those poorly serviced individuals and their carers.

As this was a pilot project the team worked with a relatively small cohort. 44 individuals were recruited; 27 of them became active participants. Those eligible to take part were chronic pain patients and their relatives, especially care givers, who were already seeking help from two hospital pain units linked with the foundation.

Preliminary results



At the beginning of the MOOC

Agreement with "I'm satisfied with the way I'm managing my pain daily" (Both sex)

At the end of the MOOC

Agreement with "I have improved my quality of life perception" (Both sex)

The multi-dimensional, 6-week course was split into four areas. Users were first provided with tools to help them navigate easily on this new-style, online format. There then followed 3 specific sections concerning pain: understanding pain, living with pain and confronting pain. As Fernandez explained the course was designed as a "learning by doing" process. "We also tried to create a space where participants could share their own experiences and evaluate their progress."

The foundation is in the primary phase of evaluating the results. A questionnaire was sent out at the beginning of the course focusing on expectations. Most participants responded with "to improve how I manage pain", but the overwhelming majority wrote, "to improve my quality of life." Interestingly, 58% of this cohort claimed to be satisfied with the way they managed their pain. The post-course survey went on to show that 80% were satisfied with the self-care education programme. And 80% of respondents agreed they had improved their quality of life perception. The majority of participants were also confident they would continue with their health aims for the next 3 months.

"We believe absolutely that self-management is one of the tools that could be useful to arrive at pain relief."

However, the research team was most pleased with the data concerning the participants' perception of the health aims. "60% were satisfied with their achievement." she added. "This complements the trend regarding their motivation to continue to be in control of their health outcomes in future."

In conclusion, the self-care education course using an e-Health (MOOC) approach to improve pain management was considered effective. Fernandez described how potential changes to a second phase were already being considered, "the platform needs to be more intuitive and easier to use". And she concluded praising the MOOC approach due to its ability to promote healthy behaviours, lifestyle changes and pain management strategies to such large swathes of the chronic pain community.

Kristin Kieselbach

Networking in pain therapy and health care policy – future options to go

KRISTIN KIESELBACH
University of Freiburg, Germany

Krisitin Kieselbach described the experiences and achievements of the close cooperation between pain medicine and social care politics in the southwest of Germany. Kieselbach is a pain specialist and neurosurgeon, but she had been invited to SIP 2017 to talk about the successful work of the Advisory Board for Pain Care working under the Ministry of Social Affairs in Baden–Württemberg (BW), the third largest of Germany's 16 federal states.

"The board was able to produce an important relationship between social politics and healthcare in a regional setting and I aim to show you that this manner of federal approach can be considered as a paradigm for national strategies." she told delegates.

The Pain Forum BW was founded in 1999. This was the first time a diverse group of representatives of pain healthcare had been brought together with the Ministry of Social Affairs playing a decisive role in health promotion. It was vital to determine a strategy for the future and one of the forum's proudest achievements was the implementation of the "Concept of improving Pain Care 2000". One of the highlights of this strategy was the introduction of supra-regional and regional pain centres. The former was set up in BW's five university teaching hospitals and the latter in approved district hospitals throughout the region. There are currently 13 regional pain centres with close links to local GPs, healthcare and pain specialists.

The Ministry of Social Affairs is responsible for the certification process, which indicates quality assurance as well as a high standard of pain treatment in such centres. The process of

certification itself is done upon application and is based on the structural and organizational data of the particular institution.

Kieselbach described how these supraregional and regional pain centres worked closely together. “The (easy) proximity of university teaching hospitals to the regional centres are essential factors for this close collaboration.” she said. “Further, there are several annual symposia and congresses organised locally.“ In addition to new insights into pain therapy, Kieselbach said that the face-to-face contact between the relevant players supported a “corporate identity-attitude“, which benefits all involved parties and patients. “Overall, there is close cooperation between pain centres, residential pain specialists, psychotherapists and centres for rehabilitation.“

> ***“A comprehensive and high–quality medical care for all patients suffering from chronic pain should be centred in healthcare policy and pain therapy. Federal social policy can facilitate the interaction of different healthcare structures.”***

Ten years on, in 2009, the Pain Forum BW was disbanded to create the Federal Advisory Board for Pain Care and one for Palliative Care. Kieselbach described how the pain care strategy from 2000 had been updated to optimize networking and encourage more cooperation between different sectors in healthcare, as well as health professionals themselves, to financially achieve solutions tailored to the needs of the region. “The expertise of pain specialists serves as the guiding force for political action.” she said. “And the collaboration between federal pain politics and pain health care on all levels represents the basis for the previous and future pain health care in Baden Württemberg.” Finally Kieselbach described how this close cooperation between pain management and health care politics was already recognized by other federal states and could easily be rolled out as a template nationwide, and picked up by other nations.

Stefan Wirz

Cancer, pain, policy

STEFAN WIRZ
CURA Hospital, Germany

> *"In cancer pain we have a big problem. The management of chronic cancer pain has been omitted and there are about 20% of cancer survivors who still suffer from pain, which is persistent and ongoing and deprives them of their social life."*

Stefan Wirz started off on a positive note describing the marked improvement in cancer survival rates over the past forty years, "In 1975 for instance around half of cancer patients survived 5 years after diagnosis." he stated. "In 2012, the 5-year survival rates were almost 70%." You could not disagree that these figures truly demonstrated the progress that had been made. And yet all was not as rosy as first described, and Wirz spent the rest of his time passionately expounding the details of where the cancer treatment process was going wrong. His main concern was the way in which cancer pain was being managed, especially in those that were considered "survivors". He even went as far as to claim controversially, "We don't care about the high rate of cured cancer patients!"

Looking at the general picture of pain management in cancer care, Wirz made clear that in his opinion there was still an undertreatment of cancer pain in Europe. "It's still 50%." he

said despondently, "And there are a lot of obstacles that lead to this bad condition."

And yet, as Wirz went on to explain, Germany especially has made much progress in setting up a good guidelines programme in oncology, which also includes a section on palliative medicine. Wirz explained how creating a guideline was an expensive process, "as much as €1 million in some cases." he said. Here again Germany was in a strong position with 3 charitable institutions: The Association of Scientific Medical Societies in Germany (AWMF), the German Cancer Society (DKG) and German Cancer Aid (Deutsche Krebshilfe) mainly footing the bill. "These 3 societies jointly launched the German Guideline Programme in Oncology in 2008." he said (Follmann et al., 2014). Germany also has a law on the specialized ambulatory care of palliative patients. Workshop participants agreed these were admirable achievements in Germany.

However, despite the positive progress that had been made, Wirz described how one major aspect had been disregarded: the high rate of cured cancer patients, so-called cancer survivors that suffered from pain. "We have nearly 20% of those patients." he said, "Where do they go? Do they go to their oncologist? No they're cured. Do they go to a GP? Sometimes, but these GPs are often not trained in pain therapy." He went on to describe the numerous cancer survivors he meets who still suffer pain sometimes up to 10 years after being cured.

To conclude, Wirz summarised what still had to be achieved to deal with this relatively new entity of cancer care. "We need to identify and address the needs of those 20% of long-term survivors with chronic pain. Pain specialists need to be integrated early in the process. Adjustments need to be made to non-palliative and palliative or stages of cancer. And finally, we need more efforts in epidemiology, diagnosis, and treatment of chronic cancer pain beside acute cancer pain". His final words were reserved for the 20% of patients cured from cancer, yet still suffering from cancer pain or cancer-initiated pain, "We have to address this clientele!"

Tit Albreht

The role of pain in future cancer policy

TIT ALBREHT
National Institute of Public Health, Slovenia

Tit Albreht's presentation was very timely as CanCon, the Joint Action on Cancer Control, which Albreht and his National Institute of Public Health (NUZ) in Slovenia was responsible for coordinating, had held its final conference a few months earlier, also on Malta and as with SIP 2017, under the auspices of the Maltese tenure of the Presidency of the EU Council. The aim of the 3-year project, which had started in 2014, was to advise policymakers on some of the key aspects of cancer care which needed: improvement; more attention; and/or more structuring across Europe.The project was split into four core work packages: Comprehensive Cancer Control Networks, Role of Community care in cancer after-care, Survivorship and Screening for Cancer.

Workshop participants were told that the role of pain management had been included in the work package on Survivorship. "Pain management should be, or is, a part of the comprehensive recommendations that need to be set up in what we called a Survivorship Care Plan (SCP) for every cancer patient since the diagnosis onwards."

Albreht described how a SCP should be available to all patients following a multidimensional needs' assessment and should be tailored and updated regularly according to a patient's health condition.

“It is important that pain management becomes an integral part of the comprehensive management of cancerous diseases and that patients have equal and ensured access to pain management throughout the course of their disease.”

“There should be baseline information on the personal and medical profile of the patient. Also a summary of the treatment received, with additional data on possible late and long-term effects and medical history.” he said.

The CanCon coordinator also recommended a minimum set of tailored supportive care services consisting of pain management and psychological help. “According to the results of our work,” he explained, “pain management and psychological support for patients and their relatives against anxiety and depression are the common grounds for supportive care.” Albreht reminded his audience that pain was especially problematic in cancer care because it could occur at various stages of cancer management. “Addressing pain is therefore essential and needs to become both a part of clinical protocols and pathways, as well as a special topic in the Survivorship Care Plan.” he said, “Irrespective of how the course of the disease is going to develop.“

Work continues on the development of future cancer policy and Albreht described two topics in the proposed new structure where pain would enter into discussion. “One is the comprehensive care work package and the other, of course, the continuation of the survivorship work package, where the Quality of Life (QoL), rehabilitation and reintegration into pre-morbid life issues will involve dealing with pain.

The future partners of the next Joint Action have already set up initial meetings in the autumn 2017, so Albreht encouraged workshop participants to use this opportunity to help steer how the management of chronic pain could feature in the next phase of CanCon.

Jordi Miró

The treatment of youths with chronic pain: An unmet challenge

JORDI MIRÓ
Universitat Rovira i Virgili, Spain

Jordi Miró opened his presentation with a stark warning that too little was being done to prevent young people from suffering with chronic pain. This was the first of two presentations dealing with niche areas when it comes to pain treatment, and as became clear this was an area under-resourced and under-researched. According to Miró, one of the last studies in 2008, which appeared in the Journal of Pain, revealed 37% of young people between 8 and 16 years suffered some sort of pain.

"So we are really facing a huge worldwide problem" he told his attentive audience. "It's not just a widespread problem it is also a problem that has an enormous impact on the lives of these young people."

> ***"Chronic pain in youths is a neglected, highly misunderstood problem and undertreated. But this can be changed, and must be changed."***

Miró went on to describe how research had shown that pain-affected youngsters had more cognitive and emotional problems than their healthier counterparts. And there was mounting evidence they also had sleep problems, suffered from fatigue and had issues forming relationships with their peers. One of the main challenges facing society is that we do not know enough about the problem. "There are 10 times fewer studies about chronic pain in youth than in adults" he said, "But if we look into the papers published on treatment of chronic pain in youths it's even worse– almost 15 times fewer papers."

A second issue was even more problematic for Miró, "Even though we don't know enough, what we do know, we don't use. We know the best treatment possible is a multi-disciplinary approach." he continued, "That's not how we are working with these children." According to Miró there are no multi-disciplinary chronic pain treatment programmes for young people. And he stressed this was not unique to Spain, "It is essentially the same throughout Europe."

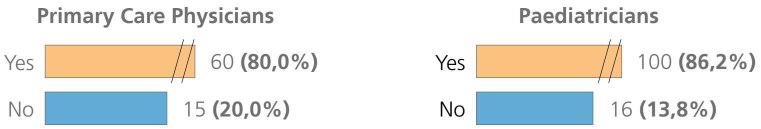
Miró and his team decided to face this challenge by looking more closely at the situation. Their quantitative research targeted GPs, paediatricians, parents and teachers. Lack of education was the main factor preventing young people from receiving appropriate chronic pain care treatment. The research results showed less than 50% of those participating received specialised training in the management of children with chronic pain. "And we are talking about paediatricians!" he exclaimed. Of those that received training, as many as 90% of the respondents felt they did not receive enough training and probably most disappointingly, training had mainly taken place after their undergraduate studies.

In the home, parents felt children with chronic pain were more likely to suffer from depression, anxiety and sadness. They were less likely to take part in recreational activities and sports and showed signs of easily becoming irritable and angry.

Training of healthcare professionals

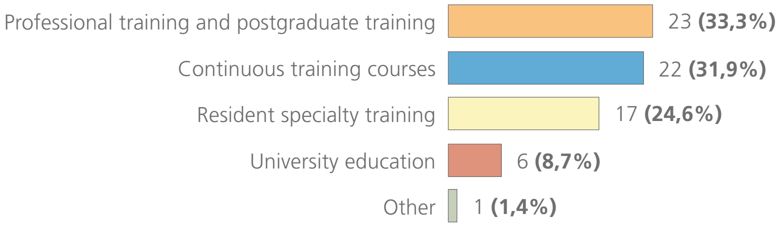
1. Have been trained in the management of youth with chronic pain?

2. Report a lack of training in the management of youth with chronic pain?



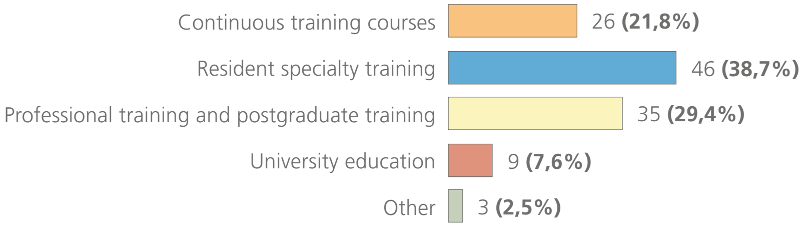
3. Where did they get the training?

Primary Care Physicians



* The question reflects the answers of the respondents who have been trained in chronic pain (n = 39)

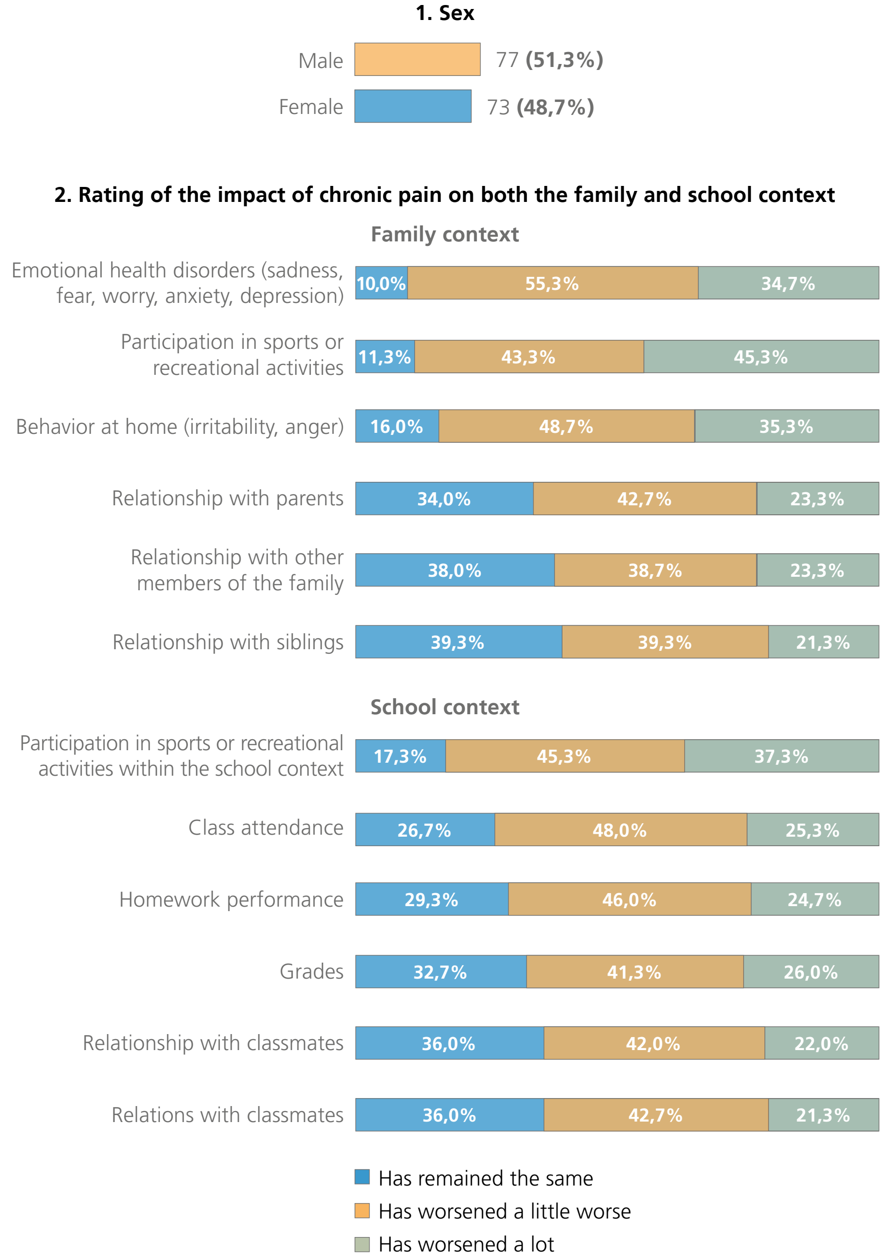
Paediatricians



* The question reflects the answers of the respondents who have been trained in chronic pain (n = 53)

Teachers had also noticed deterioration in class attendance and a lack of participation in lessons. The youth specialist is confident we can reduce the impact of chronic pain in young people, but he believes it requires a joint action of experts; clinicians, pain advocates, patient groups working closely with the general population. Jordi Miró ended the presentation with his own call for action, "It's time to get this agenda on government agendas." he concluded.

Impact of chronic pain in youths as perceived by the parents



Policy requirement on psycho education

FRANCOISE LAROCHE
Saint-Antoine University Hospital, France

Francoise Laroche

Françoise Laroche is a rheumatologist with a special interest in pain management. She currently heads the pain clinic of the Saint-Antoine Hospital in Paris and is an expert and therapist in cognitive behavioural therapy (CBT). Laroche agrees a multi-disciplinary programme is the most effective way to deal with chronic pain, especially when CBT, a psycho education, is incorporated. CBT has become one of the leading approaches to psychotherapy due to its strong research support and quick treatment timeline.

> ***"Chronic pain is not only an acute pain with long duration. It is a multidimensional illness, which requires a biopsycho-social approach. Developed countries have to deal with this major issue because of an ageing population and the heavy socio-economic burden of chronic pain."***

Laroche focused her presentation on chronic lower back pain because of the amount of data gathered to show how effective CBT has been. As she said, the big question was "what works for whom?" First, patients have to be treated early in the disease to get best results, she explained, but most importantly the form the therapy takes is dependent on the personality of the pain patient. Laroche went on to describe how the therapy programmes at the Saint-Antoine University Hospital in Paris focus on understanding the patient using a structured education in order to restore function, decrease a person's limitations, catastrophyzing and fear, but also to increase health behaviour. Outpatients referred to the clinic may also be included in this kind of programme. Laroche described how the programme has been running for almost twenty years.

"We decided many years ago to provide 8 weekly sessions each of 2 and a half hours for a small group of 5 to 8 patients," she said, "to help them in a collective, but also individual, way to improve their coping strategies when faced with pain." The team in Paris provides a pain targeting therapy using rehabilitation, but also coping skills, cognitive tools, relaxation and graded exposure to activities. "For example, we use the operant side of behaviour therapy and graded activity to decrease fear and avoidance," Laroche explained, "while in order to decrease hyper vigilance and anxiety we use sharing experience and relaxation." The aim of graded activity is to improve functional ability by positively reinforcing health behaviours and activity levels. "Our results showed a statistically significant decrease of fear-avoidance beliefs related to physical activities," she revealed.

Pat Schofield

Do we need policies addressing pain in the elderly?

PAT SCHOFIELD
Anglia Ruskin University, UK

Similar to Jordi Miró and his concerns about youth and chronic pain, Pat Schofield addressed the issues concerning another special interest group – pain in the elderly. Her remit for today's workshop was to discuss whether policies specifically addressing this group of patient's needs were necessary. "A group that is actually growing in numbers in Europe." she reminded her audience.

Pat has worked with older people to develop strategies for self-management of chronic pain for many years and has been involved in developing national guidelines in the UK. And yet chronic pain in the elderly still seemed to be one of the most under-reported areas of concern in this field. Pat shared some of the work she has been involved with over the years.

"People assume pain in older people is part of getting older, so older people should just live with it. We need to raise the awareness that it is not something you are expected to live with. We can do something about it."

There is a general consensus that the ageing demographic is becoming a problem. Studies have repeatedly shown that significant chronic pain affects 20% of adults. But this number rises to 62% for those over the age of 75. The older generation is also more prone to diseases causing chronic pain e.g. arthritis, diabetes and dementia. And as Pat warned, many risk factors for chronic pain are associated with ageing. "The older person is more likely to be socially isolated, lose their independence and therefore be in need of more long-term care."

Pat referred to an interesting piece of work carried out in 2011 by Tai-Seale et al which focused on chronic pain in the elderly inside a primary care setting in the US. The study found that pain was discussed on 48% of the visits and yet physicians only spent on average two and a half minutes per consultation addressing pain. In the UK, GPs allow a 7-minute consultation patient window per visit, but from experience Pat knew this wasn't enough. "How can the older person expect to discuss chronic pain as a problem in such a short time." she put to her audience of mainly health professionals, "They often feel flustered and rushed and don't actually raise the real issues that are of concern to them. They don't feel they want to be seen as a burden or complain a lot."

Pat and her team at Anglia Ruskin University in England recently completed a project looking specifically at pain in adults with dementia, “another issue we have with our growing numbers of older people,” she reminded us. The working group looked specifically at how pain was being managed in 9 countries across Europe and if care workers were using pain assessment and measurement guidelines.

“Only 25% of the sample that we surveyed actually used guidelines” she remarked, “even though some of the countries, like the UK had guidelines in place. They were just not being used.” The study also showed there was limited education specifically regarding this group.

During her years as a researcher Pat has come to realize that those in the healthcare profession should not automatically assume they know best about what the older generation wants. “Older people are not a homogenous group, but the impact on the older person is significant.” she concluded. “We should be adaptable and flexible, but most of all we have to listen to this growing sector of the population”. And referring back to her initial question about whether or not we needed policies specifically addressing pain in the elderly, Pat gave a resounding “Yes, we do!”


Wolfgang Jaksch

Advocating Pain Policy

WOLFGANG JAKSCH
Austrian Pain Society, Austria

Wolfgang Jaksch knew he had a massive job ahead of him when he took on the presidency of the Austrian Pain Society in 2015. He also had a very clear idea as to how he would carry out his duties as president. “My focus was on quality and quality assurance in pain care, as only then did I feel we could approach the health authorities for support.” he said.

One goal was to set a clear quality criteria and classification of pain management facilities. Another was to ensure a high standard of education for healthcare providers and finally, as the Global Year Against Pain After Surgery (2017) fell during his presidency, Wolfgang Jaksch wanted to monitor the quality of peri-operative pain management in hospitals.

Under the patronage of the Austrian Pain Society, various national specialist societies worked together to define the structure and quality criteria for pain management centres in Austria. They agreed on four different types of facilities and created 22 quality criteria for each facility.

“At the highest level we wanted to establish interdisciplinary Centers of Excellence” Jaksch told the workshop participants. “Next on the list was an ambulatorium for specialized pain therapy and in addition to this, we wanted to establish regional facilities outside of the hospital environment, which offered pain therapy and which would collaborate with similar organizations in the same area.” The fourth suggested facility was a new structure for Austria - the psychotherapeutic pain centre.

In addition, and as part of the 22 quality criteria agreed upon, the facilities should prove they offered ongoing training programmes, set a minimum number of registered new patients per year and show that they could function in an interdisciplinary team setting.

Education has always been high on the agenda of the Austrian Pain Society. In 2005, the society worked closely with the Austrian Chamber of Physicians to create a pain diploma to certify further training in pain therapy. However, Jaksch felt it was now time to take the qualification level a step higher and establish a post-graduate certificate in pain therapy. "With the help of different medical associations involved in pain therapy, we defined a curriculum for this specialized course and we submitted a suggested curriculum to the Austrian Chamber of Physicians in April 2017."

Finally, to mark the Global Year Against Pain after Surgery (2017), the Austrian Pain Society in conjunction with the Austrian Society for Anaesthesiology and Intensive Care came up with the idea for a multi-disciplinary paper on pain after surgery. Together with 12 different surgical societies dealing with the subject, including nursing staff, the paper was designed to support the organization of peri-operative pain management structures and to make best use of proven practices.

In conjunction with this, the group of societies initiated a survey focusing on the quality of post-operative pain management of Austrian patients on their first post-operative day. More than 1600 patients took part in the survey on two separate days in April 2017.

> ***"We have to pool all our forces and act in concert to reach our objective: a nationwide coverage of high quality pain management, which meets international criteria."***

It has certainly been a busy couple of years for the president of the Austrian Pain Society, but Wolfgang Jaksch concluded that the time had been well-used and it had been necessary to gather evidence to recognise and accurately define Austria's shortcomings in pain management. "If we are to be listened to as advocates of pain policy," he told his audience, "we have to prove our professional competence. We have to communicate precisely the deficits and show the healthcare authorities we are committed to improving the situation."


Pete Moore

Self-management: first choice, or last resort

PETE MOORE
Pain Toolkit, UK

Pete Moore is on a mission. He wants to help people all over the world self-manage their persistent pain. First though he says, “we need to change the conversation”. Pete asks direct questions and to the doctors in the audience he put, “Is self-management your first choice, or last resort?” There was a slight mumbling from the workshop participants. Moore wants the option for patients to self-manage discussed at the beginning of a consultation, not half way through or at the end of the process when despairingly the physician says, “I can’t help you any more, you need to learn to look after yourself”.

> ***“The number of people with pain in Europe is not on the decrease, it’s on the increase. It’s important to work as a team. We need to become problem solvers, not problem makers.”***

Pete’s story is very typical of that of a pain patient; he was, like many, looking for the magic bullet to take away his pain. That was more than twenty years ago. Managing pain was like playing a game of snakes and ladders – a game of luck. Most days melted into the next and he became a very poor pain self-manager. He did not exercise or generally look after his body and when something went wrong with it, he expected the doctor to fix him.

Then in July 1996 his life changed. Moore attended the INPUT Pain Management Programme (PMP) in London, which helped him increase his confidence and mobility and provided him with life-long skills to self-manage his pain. Pete hasn't looked back. He proudly turned to his audience and told them he had been off medication for twenty years. He described how he had got stuck in the medical model of care and because of that he had "lost seven years of my life!" And to the doctors: "You were treating me, you were not helping me to manage." Pete estimates he has cost the UK taxpayer €350,000 over the years due to what he sees as medical mismanagement. He reinforced his point, "We need to change the conversation."

Pete continued using the analogy of driving a car. "When we visit the healthcare professional we are taken out of the driving seat. If you see people struggling to keep their pain under control, they have become the passenger. We are doing nothing as passengers. You have to guide us to become the driver." One of the biggest problems is the lack of education. Pete wants pain management study units to be set up at undergraduate level and accessible to all healthcare professionals, especially doctors. According to Pete, newly trained doctors only receive nineteen hours on the topic throughout their six years of training.

It is clear Pete is on a mission. In 2002, he authored the Pain Toolkit; a user-friendly, easy to read patient booklet based on 12 self-management tools. Almost one million copies of the booklet are in circulation in the UK and it has been translated into 10 languages and adapted for Australia, Canada, Ireland and New Zealand. Nowadays, Pete holds workshops for patients and healthcare providers, has his own pain toolkit channel on YouTube and records regular podcasts for his thousands of followers. It looks as though Pete is starting to change that conversation.


Robert Johnstone

Patient involvement in healthcare

ROBERT JOHNSTONE
European Patients' Forum, UK

Robert Johnstone's presentation followed on perfectly from Pete Moore's call for more pain sufferers to take back control of their lives and become self-managing patients. Johnstone, representing the European Patients' Forum (EPF), took the discussion to the next level. "What happens if you become a self-managing patient is you then have the confidence and hopefully the skills to become an advocate." The leitmotiv that resounded throughout Robert's presentation and was directed at healthcare providers in the audience was "Working with us will give the best results."

EPF represents 74 patient groups and its focus is a co-operative approach in access and quality for healthcare. "We say that as patients we want to be involved." he said, "We want to be round the table. We don't want to be in charge, we want a partnership. We want the skills, the confidence and the ability to be part of the process."

> ***"As patients we want to be involved. We want to be round the table. We don't want to be in charge, we want a partnership. We want the skills, the confidence and the ability to be part of the pain process."***

Johnstone called on the workshop participants to think beyond simply asking patients for their comments, "Involve patients in assessing, designing, implementing and continuous evaluation and improvement." he said, "Only the patient sees the whole journey and knows her or his levels of pain." This new, forward-looking approach was described as "experience-based co-design".

However, EPF is realistic about the future and recognises there would have to be a culture change before such a radical approach could become the norm. "We understand empowered patients can be seen as a threat by some professionals. We don't want it to be that way. But we want to work as equals in planning and implementing a better health care system for everybody."

Another of the forum's aims is to move healthcare teams from "doing things to the patient", to "doing things with the patient". This was described as being hugely relevant in terms of pain control. "It's working with the patient to get a sense of control, a sense of ownership, that even if you (healthcare professionals) are not there, the patient can do things for themselves."

Access is a longstanding priority for EPF. At the beginning of 2017 the forum launched its flagship campaign on Access to Healthcare, which will contribute to making universal access (and pain management) a reality for EU patients by 2030. The message is simple and clear and focuses on 5 As. Is the service Available? Is it Affordable? Is it Accessible? Is it Adequate? Is it Appropriate?

Johnstone hoped that if participants took away just one point from his talk it would be the 5As, "because then you can start thinking about what you are planning, and your ideas and work with your local patient community can consider availability, affordability, accessibility, adequacy and appropriateness."

Summing up, participants were reminded of EPF's wish list. "We want access, we want a commitment to sustainable investment in health, we want affordability, we need access to a holistic range of health and social services, preferably with the physician so that everybody can monitor the outcome. And we also want to end discrimination and stigma for patients." he said

And as a final request and in tune with his call for closer co-operation to achieve the best results Johnstone concluded, "talk to the patients, fund the patient organisations, enable people to come forward and share their experiences, because you are missing a huge resource if you don't do that."

Carina Raposo

School for people with pain

CARINA RAPOSO
University of Porto, Portugal

Education was the focus of the final part of the afternoon's workshops, and in particular, the importance of the pain sufferer learning to take control and self-manage their condition. Very often the patient plays a passive role in the process and simply receives information from the healthcare provider. But as long-term pain sufferer Pete Moore had explained earlier in the session, patient empowerment was crucial for the successful management of a long-term health condition. In fact, self-management was, for Pete, the most important pillar of the treatment process. This entailed balancing the demands of his pain condition with what he wanted out of life. And for Pete Moore, this meant he had to take control and create his own pathway supported by a team of healthcare providers. Most importantly, he was in the driver's seat.

Carina Raposo had brought along a similar example, but this time it related to pain sufferers in Portugal and how they had been given the tools to take control of their condition. Whereas Moore was a sole operator working in partnership with his support team, Raposa described a classroom full of pain sufferers ready and willing to take on the responsibility of developing their own health pathways. Students attended the "School for People with Pain" (Escola para Pessoas com Dor) at the University of Porto in northwest Portugal.

Raposo explained why the learning took place in a school environment, “It was called school,” she said, “because the classroom was in the Faculty of Medicine at the university and this was to be a different experience from being in a consultation room or in a hospital.” The curriculum focused on a multidisciplinary approach integrating modules on nursing, anesthesiology, rehabilitation and psychology relating to chronic pain. The programme was delivered over a 6-week period with a single two-and-a-half hour session per week. Patients were over 18 and suffered from chronic, non-cancer pain.

Raposo described how the first session was designed to demystify chronic pain and introduce the possibility of self-management. First though, patients had to understand and accept their condition as it was felt this was the only way they would actively participate in the management of their health. The following sessions covered the body and the importance of physical activity; how to develop adaptable coping strategies; dealing with fears, feelings and learning to communicate those emotions. The latter stages of the course focused on healthy eating, sleep management and the importance of sticking to the therapeutic regime.

“We called our pain school a school because the classroom was in the Faculty of Medicine at the university and this was to be a different experience from being in a consultation room or in a hospital.”

During the final session participants set out their plans for the future discussing how they would approach consultations differently and make use of patient support groups to help them stay on course. As Carina Raposo explained, the students got very emotional at the end of the programme. “Sharing their pain with others was very important for the participants.” she said, “For the first time they could say, “I am not alone and it is possible to live an active life.”

Closing Remarks

For the remainder of the workshop following Carina Raposo's presentation, participants were given the opportunity to pass on any comments or suggestions for further review of SIP's set of draft recommendations that had been prepared in advance of this seminar. After much friendly debate and sharing of ideas, the group agreed that for best results health authorities should regard pain as a multidimensional health condition, which requires a bio-psychosocial approach.

Education was a further topic that recurred throughout the afternoon. Delegates called for more education programmes and ongoing training sessions for healthcare professionals. And equally important, chronic pain patients should be given the tools to learn how to self-manage their condition. It was also agreed that health authorities should take more seriously the issue of chronic pain in young people in society, as this was still a highly misunderstood and undertreated problem.

Presentation of findings and recommendations of Working Group 4

Plenary reporters, Michael Schenk from the German Pain Society and Patrice Forget from the European Pain Federation EFIC®, summarised the findings and presented the recommendations from Working Group 4 at Plenary Session III.

Policy Recommendations

1. Health authorities should regard chronic pain as a multidimensional health condition which requires a biopsychosocial approach.
    a. Health authorities and national governments must come together to address the fact that chronic pain is associated with an increase in somatic morbidity, mortality and higher rates of depression, anxiety and sleep disturbances with significant negative social interference, like loss of work.
    b. Persistent pain and comorbid psychological disorders produce significant disability (as measured by impairment of daily activities)
    c. Chronic pain should be considered as a public health priority and it’s linked with social and economic determinants of health.
2. Health authorities, national governments, patients and professional organizations must pool forces and act in concert to reach coverage of high quality pain management empowered by networks.
3. Pain management should be an integral part of all phases and stages of a comprehensive cancer management. It needs to become both a part of clinical/research protocols.
4. Health authorities and national governments must develop a structured approach to implement screening programs for early detection of patients at risk of chronification , particularly in low back pain and postoperative pain, and a care system with stratified multimodal interdisciplinary programs for in- and outpatients. Self-management programmes and psychoeducation are effective and cost-effective tools to enable patients to autonomously manage their pain.

5. Health authorities should follow up on the common position reached under the 2014 Italian presidency of the council of the European Union by the Ministers from the 28 EU member states on the need to create a European network ensuring training of professionals in the sector and exchange of information on the effectiveness of therapies for the weakest population groups.
    a. Health authorities should recognize that chronic pain in youths is a neglected, highly misunderstood problem, and undertreated. But this can and must be changed.
    b. Health authorities should recognize that as the percentage of older adults increases in our society, that have a high incidence of pain, we need to work with them to develop communication and self-management strategies.

“The people have the right and duty to participate individually & collectively in the planning & implementation of their healthcare”, Alma Ata Declaration – Principle IV, 1978 World Health Organisation. (WHO, 1978)

Societal Impact of Pain

The estimated direct and indirect healthcare costs for chronic pain disorders in European Member states vary between two and three percent of GDP across the EU. For 2016 this estimate would result in 294 to 441 billion Euros.
Healthy citizens, on the other hand, reduce the strain on healthcare systems and boost economic growth by staying active for longer.

Societal Impact of Pain

The impact of pain on society costs the EU up to 441 billion Euros annually

Societal Impact of Pain

1 in 5 adults in Europe are affected by chronic pain


MHN
MALTA HEALTH NETWORK
SIP
MA
EU


CHANGE PAIN
Patient and
Client Coun
Your voice on
health and soc
care issues.
EFIC
EFIC
IPBF

MALTA
EU2017

SIP
Societal Impact of Pain

PLENARY SESSION 1

Evolving concepts in the definition of chronic pain: a dynamic process

Opening remarks

LIISA JUTILA, Pain Alliance Europe
MIROSLAV MIKOLASIK, MEP, Group of the European People's Party (EPP)
RICHARD MUSCAT, University of Malta
ROLF-DETLEF TREEDE, International Association for the Study of Pain
THOMAS TÖLLE, European Pain Federation, EFIC®

Reporter: KARIM ZAGHLOUL, CHRISTEL GEEVELS

Liisa Jutila

Miroslav Mikolasik

Richard Muscat

Liisa Jutila (Pain Alliance Europe) explained that currently visiting a doctor and not being diagnosed with an illness while suffering from chronic pain, might cause one to be labelled as mentally ill. This needed to change, she told delegates.

Miroslav Mikolasik (EPP) encouraged pressure to be placed on the European governments, hence through the Commission, in order to enact chronic pain reforms.

Richard Muscat (University of Malta) referred to the drug action plan (60 actions) emphasising number 8, to do with access to opiate medications, as being critical.

Rolf-Detlef Treede (International Association for the Study of Pain, IASP) said that it was important to have super national policy that could influence policy. He was pleased to see MEPs actively participating in SIP 2017 in Malta.

Thomas Tölle (European Pain Federation, EFIC®) claimed that scientific and clinical advisors were convinced that it was important to define chronic pain in order to tackle it and that chronic pain was always considered a symptom, but is itself an illness.

Introduction

At the first plenary session of SIP 2017, a working group of experts met under the banner of “Evolving concepts in the definition of chronic pain: a dynamic process”. Leading thinkers in the field of chronic pain deliberated the nature of pain and considered that it was not a homogenously monolithic topic, but was a more extensively layered phenomenon.

Participants revealed that chronic pain existed not only as a symptom, but as a disease in its own right. It was made abundantly clear that the way in which chronic pain was discussed within the scientific community was of paramount importance as the way it was regarded by patients and policy makers alike would significantly impact the manner in which it was tackled. Speakers discussed the upcoming revision of the International Classification of Diseases (ICD), and the proposal to include ‘chronic primary pain’ as a disease in its own right for the first time.

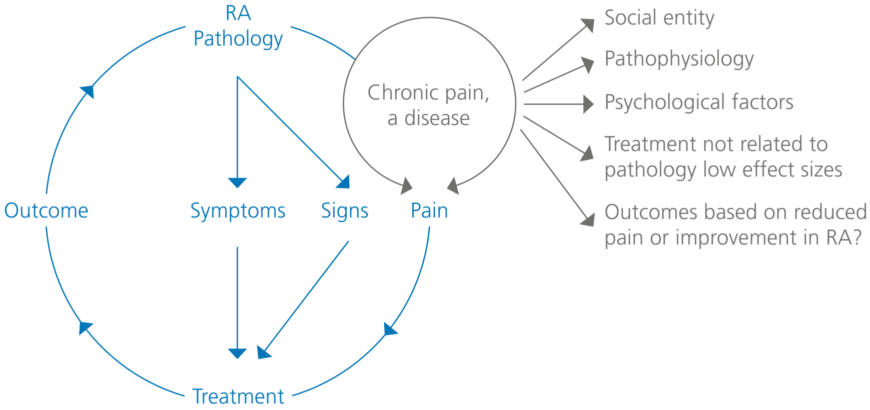
Ann Taylor

What can we learn from the Pre- OMERACT Workshop on Chronic Pain?

ANN TAYLOR
Cardiff University, Wales

Ann Taylor summarized the importance of the lessons learned from the pre- OMERACT workshop on Chronic Pain. The conclusions of this workshop were published in the journal of rheumatology. She emphasized the importance of understanding what chronic pain was, "we had to define what we meant", and how the way it was perceived would affect the way treatment would be conducted. Although there exists extensive debate about what chronic pain is in the medical community, it is even less clear among patients who themselves don't know what chronic pain is or where it derives from. "A large amount of them did not know what it was, which was not a particularly helpful starting point".

Illustrating the problems with trying to fit chronic pain as a disease into the biomedical model approach to rheumatoid arthritis (RA; used as an example)



Neuropathic and cancer pain was not discussed at this workshop. She stated that pathophysiological mechanisms are different (central v peripheral) in acute compared to chronic pain states. This means that there exist varying degrees of neurobiology that are not specific to pain, while some living with pain have very complex central pain changes, others do not. Ann Taylor explained that pain was also processed with a lot of other information such as "visual centres" and "centres that process depression". So, there are many issues of grouping all pain conditions into a disease model given differing assessment needs and outcome measures. She also presented a brief literature review stating that most studies demonstrated recognizable signs and symptoms and as well as unique specific causes. In addition, evidence from neuroimaging studies presents functional, anatomical and neurochemical evidence. What qualifies chronic pain as a disease is the underlying mechanisms or the type of pain, given the nature of the disease, it is hard to confirm an absolute diagnosis.

On the other hand, she posited that uncertainty as to whether it should be classified as a disease stems from the fact that it often remains an acute symptom of other illnesses. Furthermore, chronic pain has an impact on mood, function, and social ability, therefore, holistic assessment and management is required. "If chronic pain is a symptom we need to measure it with a visual analogue score, if it is not if it is a disease, we really need to assess how we are measuring pain."

> ***"There has been a groundswell of opinion that persistent pain needs to be reclassified and if we accept, for instance, that it is more than just a symptom, then the philosophy of care should change from a biomedical model to that of a biopsychosocial one that views persistent pain as a disease or LTC."***

Eva Kosek

Do we need a third mechanistic descriptor for chronic pain states?

EVA KOSEK
Karolinska Institutet, Sweden

> ***"The understanding that chronic pain is not necessarily a symptom but can result from altered nociceptive function and thus constitute a condition in itself is not reflected in the current IASP terminology. Therefore a third mechanistic descriptor is much needed."***

Eva Kosek discussed whether we need a third mechanistic descriptor for chronic pain states because, according to her, pain can be regarded as a symptom or disease. Although "chronic pain can definitely be a symptom […]the current understanding of how our nervous system process pain information in the pain networks would suggest that some types of chronic pain should be regarded as a disease itself". This is "comparable to hyper tension," she continued, "you can have high blood pressure due to kidney disease and then the high blood pressure is a symptom. But you can also, as with a majority of people, have a primary hyper tension, which would then translate to the pain field and the pain, as a disease, would be primary pain." Eva Kosek distinguished between nociceptive pain: pain that arises from actual or threatened damage to non-neural tissue and is due to the activation of nociceptors; and neuropathic pain: pain caused by a lesion or disease of the somatosensory nervous system. Next, she claimed that "we lack a mechanistic descriptor" and as such proposes to add a third: 'Nociplastic/algopathic/nocipathic pain'. Defined as "pain that arises from altered nociception despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain." Moreover, she even posited a fourth, 'pain of unknown origin' which is defined as, quite obviously, pain which originates from an unknown cause or origin. The third definition is needed for large patient groups with altered nociception not full-filling criteria for nociceptive or neuropathic pain. Which are situations where no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors is causing the pain. She then explained when to use the third descriptor. The term is intended for clinical usage for patients presented with pain and hypersensitivity with clinical and psychophysical findings that suggest altered nociceptive function. Typical such patient groups include: Fibromyalgia, complex regional pain syndrome (CRPS) type 1, other instances of 'musculoskeletal' pain (such as 'non-specific' chronic low back pain, and 'functional' visceral pain disorders (such as irritable bowel syndrome, bladder pain syndrome).

What policymakers need to know on the rheumatic and musculoskeletal diseases and their consequences on the working population

Maurizio Cutolo

MAURIZIO CUTOLO
School of Rheumatology, Italy

Maurizio Cutolo talked to the audience about what policy makers need to know about Rheumatic and musculoskeletal diseases, emphasizing the importance of projecting a uniform account of chronic pain to government officials so that they take the issue seriously. Professor Maurizio Cutolo emphasized the importance of understanding "what is behind the pain?" He asserted that in fact there are now scientific approaches that enable us to investigate pain with non-invasive procedures. He claimed that behind the pain is a "tremendously serious situation" but that today we are able to distinguish between the types of pain. He continued to explain that "there is no organ that doesn't send a signal, and the first signal is pain". According to him the majority of pain problems result from acute inflammation or acute pain. While most cases of pain finish at this stage, in some instances this initial pain can develop into chronic pain, "the second level of alarm".

> ***"Pain is an early symptom that signals an inflammatory/ degenerative condition. Early correct diagnosis and treatment of any pathological condition is followed by the disappearance of the pain."***

Unfortunately, at this level, the tissue cells begin to change their structure and the consequences of chronic inflammation are dire, in fact "15% of chronic pain develops into cancer." Additionally, Maurizio Cutolo revealed that pain follows a certain rhythmic pattern, which is highly dependent on time of day and the cycle of lightness and darkness. "Our brain is a central clock" and nocturnal hormones produced at night are responsible for attacking antigens and invasive entities which causes the body to activate inflammation at night. The inevitable consequence of this is a de-inflammatory reaction in the morning, which leads to pain. A classic example of this is rheumatoid arthritis. Since the periphery of the brain receives all the signals and reacts accordingly, with chronic pain the threshold for pain goes down so people suffer a lot more with the possibility of even entering depression. Generally, symptoms of pain are the most intense in the morning and much less during the day.

Next the professor addressed how to manage chronic pain. He suggested that "Circadian pain must be considered in order to optimize the timing of intervention". Finally, he cited that 120,000,000 people experience pain across Europe, emphasizing that this a large burden on the health and social systems, affects individuals' wellbeing, and reduces productivity and economic performance.

Pain a disease, a symptom or a disabling state?

THOMAS TÖLLE
European Pain Federation, EFIC®, Germany


Thomas Tölle

Thomas Tölle posited that chronic pain is one the most prevalent health problems in our modern world, with millions of people debilitated by conditions such as back pain, headache and arthritis. He explained that while acute pain can be considered a symptom, chronic pain is a disease in its own right, a concept which has stimulated a lot of discussion within the scientific community. He elaborated on the recent global initiatives primed at raising awareness of this problem such as the global day of pain. Thomas Tölle asserted that the relief of pain should be considered a human right, and that this belief has always been the intention of the European pain federation. He called on the Maltese government to take this to the European Union and incite change. Although many of these ideas have become ubiquitous in the scientific community some have yet to be translated into substantial policy reforms. Ultimately it is important to consider that chronic pain is now considered a spectrum with a range of varieties not a singularity.

> ***"Chronic pain should be regarded as a disease in its own right."***

Next, he compared the definitions of disease and chronic disease. The former: "A definite pathological process having a characteristic set of signs and symptoms. It may affect the whole body or any of its parts, and its etiology, pathology, and prognosis may be known or unknown". The latter: "A disease that persists over a long period. The symptoms of chronic diseases are sometimes less severe than those of the acute phase of the same disease. Chronic disease may be progressive, result in complete or partial disability, or even lead to death." He explained the importance of understanding that chronic primary pain "is pain in 1 or more anatomic regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or significant functional disability (interference with activities of daily life and participation in social roles) and that cannot be better explained by another chronic pain condition" as defined by Treede et al., 2015. This is important because it reveals that chronic primary pain can co-exist with other conditions or exist on its own.

Next, he elaborated on disability suggesting that it is not just a health problem but a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. "Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers." Given that these characteristics are also faced by those with chronic pain it can even be considered a disability. He also cited a paper which demonstrated that back pain was the top ranking chronic pain among disabled patients all over the world. "So for me, there is no doubt that chronic pain is also a disability". Finally, he presented factors that make people more vulnerable to chronic pain: "Older age, lower level of education, anxiety, depression, unhelpful illness behaviours, and poor social support."

Terminology: able to make or break patient access

WILLEM SCHOLTEN
Consultant – Medicines and Controlled Substances, Netherlands


Willem Scholten

Willem Scholten discussed the importance of ensuring that the correct terminology is used surrounding drugs and medicine. Primarily that there is a difference between psychoactive substances and medicine and as such it is important to respect these differences as confusion surrounding these terms can be detrimental. He also claimed that it is important to always use friendly words when discussing medicine with patients. Words must be precise, neutral and respectful. This is because the language used can maintain existing biases and even worsen political normative biases. Inappropriate terms are likely to negatively influence social and public health policy. He then went on to present an intriguing number of examples where this is most relevant. Words such as "amputee" were reducing the patient to one characteristic and in this example, he recommended personal language to be used, for example "a patient with cancer or substance use disorder".

> ***"Imprecise terminology may result in misunderstanding of the nature of pain treatment and the management of substance use disorder."***

He also stressed that terms need to be defined, for example, the difference between addiction and dependence. Addiction is pejorative because it has Latin roots relating to being a slave to something and does not mean the same thing as dependence. It is critical that words like this be properly defined. The word narcotic is a police term and he says that "I think in a medical context it should absolutely not be used." Additionally, he preferred to use the term controlled medicine as opposed to opioids. Moreover, the terms abused and misused are judgemental and therefore should be avoided. Instead he suggested that non-medical terms be employed. According to Willem Scholten the main culprit of linguistic negligence remains 'physical dependence'. Dependence suggests that the patient is dependent, however the definition includes mental dependence, so he said it was better to say tolerance or withdrawal.

His most striking example was that of 'substitution therapy', the procedure of replacing one drug with another drug. Again, he suggested that this terminology was ineffective and that "opiod agonist therapy" should instead be used as it was more mild and accurate. The effects of this misuse of language have already been apparent. He explained that Thomas E Price – US health and human services secretary has questioned the use of opioid substitution treatments because "they only substitute one opioid for another".

Willem Scholten feared that this might cause the US official to take away this treatment even though it is highly effective highlighting the danger of using the wrong vocabulary. Finally, he said that wording could not be radically changed immediately, because it would lead to confusion.

However, he urged the scientific community to come together and agree to change the words used and slowly begin correcting individuals who wield inappropriate terms. He called for correct language in scientific journals and publications to ensure they were not propagated and pleaded that everyone promote respectful terminology especially when people were reviewing the work of others. He believes this will increase the chances that people get the best treatment and that policy is based on rationale and not emotion. He concluded by saying that medical journals, policy documents and resolutions of international organisations should be free of terms that do not meet this standard.

Can pain classification change clinical practice?

ROLF DETLEF TREEDE
IASP, Germany

Rolf Detlef Treede

Rolf Detlef Treede argued that we need a system of classification for chronic pain. He explained that pain was an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Often, pain serves as a symptom warning of a medical condition or injury. In these cases, treatment of the underlying medical condition is crucial and may resolve the pain. However, pain may persist despite successful management of the condition that initially caused it, or because the underlying medical condition cannot be treated successfully. While chronic pain is pain that persists, or recurs for longer than 3 months, such pain often becomes the sole or predominant clinical problem in some patients. As such, it may warrant specific diagnostic evaluation, therapy and rehabilitation and is a frequent condition, affecting an estimated 20% of people worldwide.

> ***"The introduction of a code for chronic pain with somatic and psychological factors (F45.41) in Germany 2009 made it the major indication for multimodal pain treatment and influenced health care funding since 2013. IASP and WHO have proposed chronic pain diagnoses for ICD-11 that hopefully will have a similar effect worldwide."***

Rolf Detlef Treede further explained that chronic primary pain was chronic pain in one or more anatomical regions that is characterized by significant emotional distress (anxiety, anger/frustration or depressed mood) and functional disability (interference in daily life activities and reduced participation in social roles). Chronic primary pain is multifactorial: biological, psychological and social factors contribute to the pain syndrome. The diagnosis is appropriate independently of identified biological or psychological contributors unless another diagnosis would better account for the presenting symptoms. He also claimed that patients with chronic primary pain often reported increased depressed and anxious moods, as well as anger and frustration. In addition, the pain significantly interfered with daily life activities and participation in social roles. Ultimately, chronic primary pain is a frequent condition, and as such treatment should be geared towards the reduction of pain-related distress and disability. Rolf Detlef Treede explained that classification was required to better treat chronic pain more accurately as opposed to treating it as a singular symptom.

Robert Jakob

Does the ICD 11 impact pain policy?

ROBERT JAKOB
World Health Organization, Switzerland

Robert Jakob discussed the revised International Classification of Diseases (ICD), ICD-11 and what updates have been made relative to ICD-10. ICD is the international standard for reporting and measuring health and health services. Healthcare costs are driven by ICD and the progress to the sustainable development goals are monitored with the ICD. So, ICD is already used across the globe by multiple professionals, this allows data from the ICD to be used to create statistics and inform policy decisions. Robert Jakob also explained that the ICD is also considerate of culture so information is not invasive and respects many groups.

> *" Pain is a relevant aspect in health. The needs and ways of reflecting pain in the international classification of diseases need to be laid out and addressed in discussion with the specialty tags and the reviews."*

Robert Jakob also explained how ICD specifically operates, and that maintenance is done on a permanent online platform and is open to suggestions to improvement. So, if members using it, during the process of data collection identify possible improvements to the classification, the system has an update mechanism that allows for changes to be made in the future. He then explained why a revision of the ICD, ICD-11 was so necessary. ICD-11 will improve usability as it requires less training and provide more clinical detail. It will be modified to modernize its incorporation in the electronic environment. Moreover ICD-11 will update the scientific content, linkage to relevant other classifications and improve the comparability of translations.

Robert finally went through the ICD browser and demonstrated many of the updated capabilities, it became clear that the user interface is extremely accessibly and friendly to use. Also, the information is displayed in a well-organized manner that makes it easy to read. There are many new features that facilitate new users and make the transition from ICD-10 to ICD-11 much more seamless.

Conclusion

This first plenary session demonstrated the crucial importance of understanding the concept of chronic pain and that before any actions towards solving this global health problem are taken, a consensus on what chronic pain is must first be achieved. The way patients and experts think and talk about chronic pain not only shapes the field's understanding of the topic, but will be reflected in the policy measures taken. Experts' knowledge of how various types of chronic pain are classified and their understanding of how to treat this diverse disease/symptom is crucial. It is now that extensive groundwork, on creating a coherent framework from which to analyse chronic pain, must be laid out so that future generations of chronic pain experts can effectively tackle the issue.

Societal Impact of Pain

SIP

Pain that persists for more than 3 months is considered to be chronic pain. In many cases it is present without any underlying physiological causes

PLENARY SESSION 2

MARLENE MIZZI, MEP, Group of the Progressive Alliance of Socialists and Democrats (S&D)
ROBERTA METSOLA, MEP, Group of the European People's Party (EPP)
TAKIS HADJIGEORGIOU, MEP, Confederal Group of the European United Left - Nordic Green Left (GUE-NGL)
JOOP VAN GRIENSVEN, Pain Alliance Europe
CHRIS WELLS, European Pain Federation, EFIC®

Reporter: ANDREW LITTLEJOHN


Bart Morlion

SIP policy recommendations, now what

BART MORLION
President-Elect of the European Pain Federation EFIC, Belgium

Bart Morlion opened the morning plenary session with an update on developments relating to the key policy recommendations from the previous SIP symposium in 2016. But first, Morlion, who takes up his Presidency in September 2017, thanked the current incumbent, Chris Wells, for his commitment to expanding the Federation's education policy over the years. EFIC has been responsible for setting up pain schools in 4 European countries and in 2016 initiated the European Diploma in Pain Medicine (EDPM), which saw 17 graduates successfully pass the examination in 2017.

Morlion made it clear that there were many good initiatives around the management of pain, including within some social systems, but that there was still, in some cases, a lack of joined-up thinking. "The landscape on management of pain is not uniform within Europe. It's quite disparate and can depend on where you live, as to what kind of therapy and treatment you get." he said. "So we should learn from each other and bring best practices together in an integrated way."

This prompted a brief summary of the key policy recommendations that had been agreed at SIP 2016 in Brussels. Morlion admitted that getting a consensus on the implementation of Article 8.5 of the Cross-border Healthcare Directive, which gives citizens the right to treatment in another EU country, had been "a little more complicated", but he reassured delegates "we will stick to this and follow this up." A further key recommendation had been the establishment of an EU platform on the societal impact of pain, and here indeed he said, "We are at the first step of creating this EU platform." (Half an hour following Bart Morlion's presentation, Martin Seychell, Deputy Director-General of DG Sante, stood on stage to formally announce the launch of a new 'Social Impact of Pain' Expert Group under the EU Health Policy Platform.) Participation on this platform is expected to integrate further chronic pain within EU policies on chronic diseases.

With only a few months until Chris Wells stands down as president of EFIC and Morlion picks up that mantle, the President-Elect concluded with a strong message of "together we can conquer" making it clear there was no room on this journey for silo mentality. "There is no ownership on the topic of pain. The only owner of pain is the patient who is suffering from it." Collaboration with all pain organisations was Morlion's priority.

> ***"There is no ownership on the topic of pain. The only owner of pain is the patient who is suffering from it."***

Statements from MEPs

Following Bart Morlion's presentation the moderators, Michael von Fisenne (Grünenthal) and Donna Walsh (European Federation of Neurological Associations) invited 4 Members of the European Parliament, and strong advocates of the pain agenda, to join them on the stage to give their political perspective on pain.

> **_"Politicians need to be aware of the importance of research and development to promote the problems of pain on society."_**

Marlene Mizzi, MEP for Malta, comes from a business background, but this did not stop her from understanding fully the problems pain sufferers can have in communicating their condition. In the past it had always just been the doctor's job to understand the pain patient, but now MEP Mizzi said it was vitally important that politicians were also aware of the issues, because "chronic pain not only impacts the sufferer or immediate people around them, but has an impact on society, even from the labour market point of view, even from the possibility of finding a job, even on the performance of that job, even on the potential of that person, so it has an economic impact as well." She continued stressing again that although the patient and pain was most important, "we cannot forget the impact on society, the economy, the cost to the health system and the future of our national health systems."

Miroslav Mikolášik who trained as a medical doctor in Prague and sits on the European Parliament's Committee on Environment, Public Health and Food Safety (ENVI), continued the debate agreeing with MEP Mizzi that there were still too many MEPs unaware of the seriousness of the impact of chronic pain on society.

"The hurdle is multi-faceted." he said, "There is no ownership, we have to work together interdisciplinarily, including this dimension of well-being, of happiness of the person, but also, of course, employment, sick leave and its economic consequences." The former doctor from Slovakia is convinced there are plenty of opportunities to push through the issue of pain further on the agenda both on EU and national levels. "If united, we can deliver." he concluded.

> ***"I deem crucial that we continue in our endeavour to push through the issue of pain further on the agenda both on EU and national levels."***

Roberta Metsola has represented Malta in Brussels since 2013 and is Chair of the Interest Group for Rheumatic and Musculoskeletal Diseases (RMDs). She told delegates that politicians had "spent too many years considering health to be something that is not a competence of the European Union." Despite the EU's Cross-border Health Directive, which entitles EU citizens to healthcare across the European Economic Area, MEP Metsola believes member states lack the appropriate competences when it come to chronic pain. This was why, she said, she had chosen to focus her interests on RMDs, "to make sure that the European Parliament continues to give attention to musculoskeletal diseases and the fact that these often go unreported and that they have a huge economic impact on society."

> ***"Dealing with chronic pain must be put on EU Member States' health care agenda. It cannot be ignored."***

There was a sense that the 4 MEPs on stage were committed to moving things forward and getting the message across to their fellow parliamentarians. Cypriot politician Takis Hadjigeorgiu concluded by reminding delegates at the symposium that MEPs were elected to serve and that they should especially take advantage of those (MEPs) that supported SIP. "Provide to us via email any question you want to put in front of a commission, any part of any idea which you want us to say in front of the assembly of the parliament, any amendment you want to see being approved – give it to us. If this cooperation will become a constant one then we will see the benefits of these efforts."

> ***"We have to fight in order to inject the term 'chronic pain' as a certain illness and push the governments and health systems to consider it a special issue needing special treatment."***

Bringing stakeholders together

Gabriel Baertschi

GABRIEL BAERTSCHI
Grünenthal, Germany

Gabriel Baertschi reinforced the need for pain patients to receive the optimal treatment, but was aware that the lack of training of medical professionals, restricted access to medicines and the absence of standardised care pathways were hampering patient access to adequate pain therapy. The new CEO of Grünenthal Group declared that industry also had its role to play in continuing to invest in pain. Baertschi went on to describe the Innovative Medicines Initiative (IMI), which in his opinion was "a very inspiring example of how policy can be utilised to benefit pain patients."

"We see it as our commitment, together with you all - patient representatives, academia and policy makers – to develop new, life-changing innovations, bringing benefit to patients in areas with a high unmet medical need."

In 2011, the IMI was introduced, which is currently the largest public private partnership (PPP) dedicated to pharmaceutical innovation and aims at speeding up the development of drug research. IMI represents a joining of forces in the healthcare sector and is a partnership between the European Union (represented by the European Commission) and the European pharmaceutical industry (represented by EFPIA, the European Federation of Pharmaceutical Industries and Associations). "We, as the entire industry, and you know EFPIA is the voice on the EU scene of 1,900 companies committed to R&D, feel a strong obligation to contribute to solutions overcoming those hurdles I touched on earlier" he said. And the success of IMI could, he felt, be reflected in the €3.3 billion budget commitment until 2024. The commission provides slightly more than half of the funds, while EFPIA invests the rest in-kind.

Baertschi also described how a vital part of IMI was the IMI2 Pain Group, which has been set up to push though solutions in pain. "The Pain Group, co-led by Grünenthal and Esteve, unites European pharmaceutical companies dedicated to better understand, treat and manage pain." He continued stressing that with this coming together of pharmaceutical companies alongside the best-skilled from academia, hospitals, SMEs, patient groups and regulatory bodies, "we are really seeing pain being advanced."

The new CEO of Grünenthal concluded his talk giving delegates a further insight into the pharmaceutical company's commitment to combating pain, a commitment he and his team were particularly excited about. "We have mapped a landscape of all pain conditions and what we are trying to do now is understand what the genetic reasons are for pain conditions."

He is also proud that Grünenthal focuses not only on large populations of patients, but also more niche areas, which, as he claims, "have been unfortunately abandoned by many pharmaceutical companies." Baertschi's closing words reiterated the strong obligation his company had, along with similar-minded stakeholders in the audience, to move the pain agenda forward.

Stakeholders and policy makers working together on pain

MARTIN SEYCHELL
Directorate General for Health and Food Safety (DG Sante), Belgium

Martin Seychell

> ***"Patients have a wealth of expertise, because they very often know most about their condition. They've been living with it and suffering from it for years and they know what works and what doesn't work."***

There had already been much speculation that something remarkable was going to be announced at SIP 2017 and the more than 300 delegates representing 29 nations and 250 pain-related organisations were not disappointed. Martin Seychell, Deputy Director General of DG Sante, used his illuminating speech at the symposium to formally announce the launch of a new pain expert group under the EU Health Policy Platform. Earlier in the year a similar platform had been set up to help patients with rare and complex diseases by opening up channels of communication and cooperation between health interest groups and organisations and the Commission. The aim of these platforms is to bridge gaps in the availability of treatments across the EU. "Our intention is very simple," Seychell explained, "we (at the Commission) want to bring expertise to the patient wherever possible and wherever that is not possible facilitate access of patients to diagnosis and treatment even across borders."

It seemed this year's symposium singled out the perspective of the pain patient more than ever before. Seychell commented on how invaluable the pain patient's individual experiences could be in this process. "Pain is not something that can be measured through clinical parameters," he said, "so the only way to find out about it is to ask the patient."

Seychell described how it had become clear over the years that patients tended to define outcomes under terms of functionality, rather than clinical parameters; for example, how the disease (or problem) prevented them from doing something they felt was important. "Patients have a wealth of expertise, because they know most about their condition. They've been living with it and suffering from it for years. They know what works."

The EU Health Policy Platform was born out of the European Commission's realisation there was a need for a more active and constant dialogue between stakeholders and the commission, and possibly more importantly, amongst the different stakeholders themselves, and not just from the healthcare perspective, but also including employers, insurance companies and trade unions, “because we know, for an issue like pain, it is not just going to be the medical treatment that will solve it,” Seychell explained, “you also need social support, you need psychological support, and you need a lot of other sources of expertise.”

This e-space for collaboration will be a mix of virtual and face-to-face discussions. Although the commission has put this platform in place, they will not be the driving force. “We see one of our main roles to act as a catalyst to bring all these actors together and make sure this is all done for the benefit of the patient.”

Seychell went on to describe further the purpose of this platform, “It will be a space where stakeholders can actually decide on what they want to discuss, what they want to present to the commission, identify issues that are important to them, potentially culminating in the preparation and submission of specific positions agreed among multiple stakeholders.”

These platforms will also be an opportunity to demonstrate areas of good practice. For years, projects and joint action groups have been developing recommendations, good practices, guidelines and other tools, yet in Seychell’s opinion this positive information has not been filtering through to the wider community. “Good practice does not travel well in the European Union, sometimes not even within the same member state. It remains well hidden in the local or regional level,” he told his attentive audience. “We need to change that!”

The platform will also be a further opportunity to bring Europe’s health sector into the digital age. It is digital technology that will facilitate the interaction between the different stakeholders. The Deputy Director General of DG Sante brought an enthusiasm and urgency to his presentation that was infectious and exciting. Everything seemed possible. Digitalisation, he said, would transform the way patient-reported outcomes could be measured. “Do it online. In real time.” he suggested. And then there was the huge mass of health data generated on a daily basis with only a fraction of it being used for research, “ We need to turn health data into a resource.” he added. But first of all he stressed, “We need to ensure that each of us has the right to access our personal health records irrespective of our physical location.”

In his closing words Seychell called on his 300-strong audience to be “very active” about this initiative. He had 2 take-home messages: “First, it is very good to be aware about the challenge of non-communicable diseases such as pain and what they mean to our health system. It is good to exchange points of view and information on how to tackle them. But what would really make the difference is whether and how we applied the knowledge.”

Panel Discussion

The final part of the morning session was dedicated to an engaging and informative panel discussion with the moderators putting questions to Martin Seychell (DG Sante), Chris Wells (EFIC) and Joop van Griensven (PAE). The following is a transcript of the discussion:

Michael von Fisenne: Are you satisfied with the session this morning?

Martin Seychell: Yes, it's becoming clear there is a lot we can do by working together. (Pain) is almost an invisible issue. Too many people suffer in silence. It is difficult to measure (pain) and our modern approach to health is about measurements, so this adds another challenge. But I think there are clear ways to address this. One of the indispensible things we have to do is ensure we capture the expertise and the experience of those who know most about pain and that is the patient, and of course those close to them. When we come to discussing how to fine tune our research efforts; how we can better describe outcomes; that perspective is absolutely vital.

Michael von Fisenne: That is perhaps because we have more advocates than ever before: the patients.

Chris Wells: Thank you Martin you picked up our (EFIC) tag line from 2001 “Don’t suffer in silence”. We still have this problem with GPs saying to their patients, “what do you expect, you’re 70”? Well, I am 70 next year and I most certainly don’t want to hear those words from my GP. A very important thing the cost of pain to society is estimated at €34 billion per year. We can’t afford this in the EU. (With reference to the launch of the new pain group platform just announced by Martin Seychell) So sharing best practices and forwarding that knowledge throughout Europe will actually save money. We’re not here asking for a blank cheque.

Joop van Griensven: We need to talk about best practices for the patients, not for the doctor. Best practices for the patients are always the best outcome for every treatment. That would be the main message on this platform as well. This really is a call to all patients to make use of this EU Commission platform, so everyone will know the best way to treat patients and from that you can figure out all the money questions. Improving their quality of life should be the ultimate goal for having that platform

Donna Walsh: (Martin), you mentioned earlier we need to generate more evidence for policy makers and decision makers, if we want them to focus on this particular topic. Is there something specific you think is lacking at the moment in terms of that evidence base that we as a multi- stakeholder platform could provide?

Martin Seychell: There's an old saying: "What is not measured, does not get done", and policy making has to be evidence-based. This is a big challenge because the way we have collected evidence historically has been largely statistical. You do surveys; you spend a number of years validating and then elaborating them; and you come up with a set of numbers; and sometimes it takes so long it becomes historical data. And sometimes it doesn't really capture the real issues.

This doesn't have to be the only way. There are a lot of untapped sources for evidence: first of all, the patients themselves and those closest to them. If you want to talk about outcomes, they can tell you a great deal about outcomes that are successful, or less so. And that is useful information.

The second challenge is how to move towards real world and real time information. This is no longer a pipe dream. Big data or use of every day devices; why not have an app (where) I could actually give my feedback to my doctor and to the health system in general about my experience with (a) treatment. That can be done in real time as we speak from the comfort of our own home and our own private setting. Why isn't it done? Because it needs to be organised; it needs to be standardised; it needs to be incentivised. It's all about using things like big data, but also health systems; if you go for a 15-minute consultation with your GP, the moment you walk into that clinic, you start generating data. Your measurements are taken all the time. How much of that is used to improve practice; to fine tune the approach? Very little. Hospitals generate prodigious amounts of data. It's not used systematically, and then we have big challenges because we have to invest billions to try and understand what works and what doesn't. I know I am simplifying things here, but at the heart of it, we have not caught up with the digital age.

Health needs to undergo a transformational change. We have to accept hospitals are not very useful for chronic pain and chronic conditions. We need to move to a patient-based care and not a hospital-based care, because (hospitals) are designed to deal with acute manifestations, certainly not with early intervention and not with long-term management. We need to move towards integrated care, we need to support people in their own homes; in their own communities; and we need to make sure there are enough sources of information as close to the patient as possible.

PLENARY SESSION 3

ALFRED SANT, MEP, Group of the Progressive Alliance of Socialists and Democrats (S&D)
BART MORLION, European Pain Federation, EFIC®

Reporter: ANDREW LITTLEJOHN

Alfred Sant

Addressing pain in policy

ALFRED SANT, MEP

Progressive Alliance of Socialists and Democrats (S&D), Malta

Alfred Sant MEP began with a strong message to doctors in particular about the importance of education. He referred to a survey of European doctors, which revealed that less than half of the surveyed physicians used tools to assess pain in patients. "Almost one-fifth of them do not record pain in their medical notes." he said. "Pain is such a variable concept," he continued, "that both patients and healthcare providers need special skills to be able to deal with the condition."

He also warned against patients being prescribed treatments where there was still insubstantial evidence as to their effect. He alleged that many patients with long-term pain were often offered a "cure" through new forms of treatment, which were ineffective. "We need to be careful." he said, "We cannot offer hope to patients that are unfounded, as we will be doing more harm than good." He called on health professionals not to support new treatments until there was solid proof that they were effective.

MEP Sant continued by reminding delegates of the great economic costs associated with chronic pain and how the financial burden was mostly incurred in the social and employment fields. "Pain has such a devastating effect on a person's quality of life," he remarked, "that it translates into declining productivity, reduced workforce participation and an increase in spending on social allowances."

> ***"Pain imposes a heavy burden on individuals' private lives and leads to enormous costs for healthcare systems as well as for our societies and economies"***

With the right treatment chronic pain patients could become more productive and would stay in the workforce longer, thus continuing to generate an independent income. MEP Sant is convinced that the right treatment coupled with educational campaigns would reduce the strain on the healthcare system and boost economic activity. "This is why I believe it is urgent that EU social and employment recommendations on workforce participation also begin to address, in a meaningful way, the issue of pain."

For the final part of this section of his talk, the Maltese MEP focused on the need for the continuation, and sharing, of research. “Continuous study on chronic pain is essential on both a national and European level, so as to explore the nature and the cause of pain.” he said, “The availability of EU wide comparable cross-border data is pivotal for such studies to be successful in contributing towards the planning of health services and of health educational programmes.” Educational activities and campaigns should also be rolled out on a national and Europe-wide basis.

MEP Sant continued by praising Malta for its support of SIP 2017. He was also proud that the Maltese government was taking the issue of pain seriously and understood its impact, in general and in particular, on society. “In this regard,” he explained, “in 2015, we opened our first pain clinic which we consider as a specialised pain management centre.” He hopes this model can be implemented in as many countries as possible across Europe, but, as he said, “in order to do this we need platforms like SIP to give visibility to the very important issue of pain treatment.”

MEP Sant brought his presentation to a close confident that the recommendations for action agreed at the symposium would lead, as in previous years, to “substantial policy developments” and that his support was unwavering. “From my side,” he concluded, “I am committed to support any initiative taken forward in the European parliament to address the societal impact of pain on your behalf.”

Gertrude A. Buttigieg **Silvana Fanalista**

Report from the SIP Malta Pre-Symposium

GERTRUDE A. BUTTIGIEG
(Malta Health Network) and
SILVANA FANALISTA
(No Pain Foundation), Malta

Gertrude Buttigieg and Silvana Fanalista gave an overview of the results of the Maltese Pre-Symposium where the Malta Consensus statement was discussed at length. The scope of the statement was to lay out a roadmap to address accurately the issue of chronic pain. There was general agreement that the proposed recommendations in Malta's Consensus paper addressing the country's societal impact of pain were realistic and achievable given the good will of all involved. The paper seeks to drive through policy by applying knowledge, skills and human sensitivity from pain professionals, as well as encouraging more collaboration with the pain patient.

Implementation of a strategic plan carried out by the Ministry of Health, focused on Pain approach within the different regions


Paloma Casado

PALOMA CASADO
Ministry of Health, Spain

The Spanish healthcare system is reportedly one of the most decentralized health systems in the world. The Ministry of Health is in charge of fostering cohesion and quality on every healthcare activity, which means central government develop strategies on health and the country's 17 Autonomous Regions develop their own strategic plans in line with the national strategy. Paloma Casado used her time in front of SIP delegates to describe some of the challenges she and her colleagues faced in integrating their key recommendations across the regions.

> ***"Pain is a priority health problem because of its frequency, its impact on a person's quality of life and its high societal and economic impact, so that a whole biopsychosocial approach is required. It also requires an integrated and coordinated health care system"***

Casado told delegates that pain was a prioritized health problem in Spain "because of its frequency, impact on quality of life and the high socioeconomic costs of treating chronic pain". In 2012 a strategy for tackling chronicity, and in particular chronic pain, was set up in the National Health System. This led to a national plan to address pain, which put patients at its centre and included life cycle perspectives and social determinants of health, as well as the need for continuing care and patient empowerment. Casado also referred to the national framework document which was launched in 2014 to improve pain management.

The autonomous regions were then expected to implement the recommended strategic lines stated in the national framework paper. Pain was to be prioritised in strategies and health policies with the focus on prevention, improving the assessment of pain and encouraging an integrated care plan. Patient empowerment was also paramount and there was a need to reduce inequalities and train both healthcare professionals and patients. Casado described these strategic lines as "concrete actions to be developed by the Autonomous Regions" Key elements were also detected to help the 17 regions define their autonomous plans. Those were: to raise awareness in the population; to promote training of professionals; to take into account pain as a mainstream element; and to ensure that pain is present in every healthcare action. Casado explained that there was also a need for an integrated approach to care and there should be focused attention given to self care. It was also important to take into account not only pharmacological treatment, but a non-pharma approach.

Much was expected of the Autonomous Regions and Casado told delegates there had been many challenges to contend with but that progress had been made even if enforcement levels were varied. According to the Ministry of Health, the Pain Management Regional Plan has been, or is about to be, implemented in all areas. Regional technical committees have been established in many regions. This is to assess pain at a regional level. In other areas, hospital pain management committees have been set up to take into account primary and secondary care. There are Network Schools for Citizens in every region, Casado explained, and here “pain is at the core of the curriculum to empower patients”. Pain management in children has been implemented in at least 4 regions and Casado would like to see this strategy being rolled out further. Every region recognises pain as the 5th vital sign. Despite the challenges Casado seemed happy with the results, “Although our key proposals have not been implemented 100%” she said, “we are on the way to achieving this.” Finally Casado explained how detecting and celebrating best practices was a sure-fire way to motivate and ensure action plans get implemented.

Impact of pain on labour and employment

ANTONELLA CARDONE
Fit for Work Global Alliance at the Work Foundation, UK

Antonella Cardone

What is good work? That was one of the rhetorical questions Antonella Cardone put to the audience during Friday afternoon's plenum at SIP 2017. Responding to her own question, the Executive Director of the Fit for Work Global Alliance described it as "work that is fulfilling, sufficiently well paid, stimulating and motivating." Cardone described how a large body of evidence showed that employment had a positive effect on the health and wellbeing of people. "Health and work are interrelated." she said. "Good health enables people to be productive workers." Conversely, she continued, health problems had a huge financial and social impact on the workforce. "(They) can reduce labour market participation and income, and bad employment conditions or unemployment can negatively affect physical and mental health. "Our vision," she continued "is that good work can benefit all: individuals, organisations, and communities."

> ***"Working with pain can be a challenge and has a high impact on productivity at the workplace both in terms of absenteeism (lost workdays) and presenteeism (reduced performance while at work)."***

The Work Foundation has a wealth of experience, developed through projects and studies on the impact of chronic diseases on work outcomes, such as: presenteeism, absenteeism, job retention and return to work. In most countries back pain accounts for the largest proportion of lost working days of all musculoskeletal conditions. In the UK, for example, 12.5% of all sick days were attributable to back pain. Cardone described how the costs of back pain in the EU were very considerable and had been estimated to exceed €12billion each year. Studies show that some 80% of healthcare costs were generated by the 10% of those with chronic back pain and disability.

One of the many conundrums facing organizations like the Work Foundation are that many people with a chronic condition and pain would reportedly like to work and see work as a valuable part of their recovery, "because work gives a sense of purpose, gives a reason to get up in the morning." she said. Cardone called for more support in getting people back to work. "Workability", she said, "should become a priority outcome of the clinical care as this will lead to maximising work productivity, inclusiveness and therapeutic benefits for the patient.

Cardone continued by describing some contextual factors to explain why it was now more important than ever to address the issue of work and health. Her first point referred to the ageing workforce. Across the EU there are twice as many workers aged 50 or over than there are aged 25 or younger - a disparity, Cardone said, that is expected to worsen for several decades to come. "With an ageing population there is a greater risk of poor health and premature withdrawal from the labour market." she warned. The pension crisis was also highlighted as being a reason for a proportion of older workers having to stay in work longer. So with an ageing workforce increasingly having to retire later "the productive capacity of the workforce risks being compromised by ill-health." she stated. Cardone briefly referred to the most recent findings of the OECD/ European Commission joint report, Health at a Glance, which revealed that, on average across EU countries, the share of the population aged over 65 had increased from less than 10% in 1960 to nearly 20% in 2015. This figure is projected to increase further to nearly 30% by 2060. Currently, around 50 million EU citizens are estimated to suffer from two or more chronic conditions, and most of these people are over 65. "As the population continues to live longer, there is now more than ever a need for an improvement in the diagnosis and management of people with chronic pain." she said

Cardone concluded stating that early intervention was one of the best ways to keep people active and at work. The employee also needed support and understanding to help them stay in work, return to work and remain productive. And finally, to the healthcare professionals she said work should be seen as a clinical outcome, focusing on capacity, not incapacity. "In the UK," Cardone stated, "doctors are encouraged to write a "fit note", rather than a sick note!"

European collaboration on medicine; what it means for patients with pain-related conditions


Juan Garcia-Burgos

JUAN GARCIA-BURGOS
European Medicines Agency (EMA), UK

Juan Garcia-Burgos described the strong role patients play in the work EMA carries out. The EMA is an EU body and is responsible for evaluating medicines for approval. Once the drugs are approved the agency is also responsible for overseeing all the information that becomes available about these medicines to ensure and guarantee that at every moment they remain safe and effective to patients.

The EMA was created in 1995 and has collaborated with patients from the beginning, although as Garcia-Burgos said, it was initially not looked upon favourably, "We had a lot of reluctance from scientific experts where dealing with the assessment was concerned, as it was new to have patients on board." But, he continued, this was the starting point and from the beginning "it was clear there were a lot of benefits to having these views and these collaborations."

> ***"The European Medicines Agency (EMA) praises the work of patient organisations to improve health outcomes and patients' quality of life."***

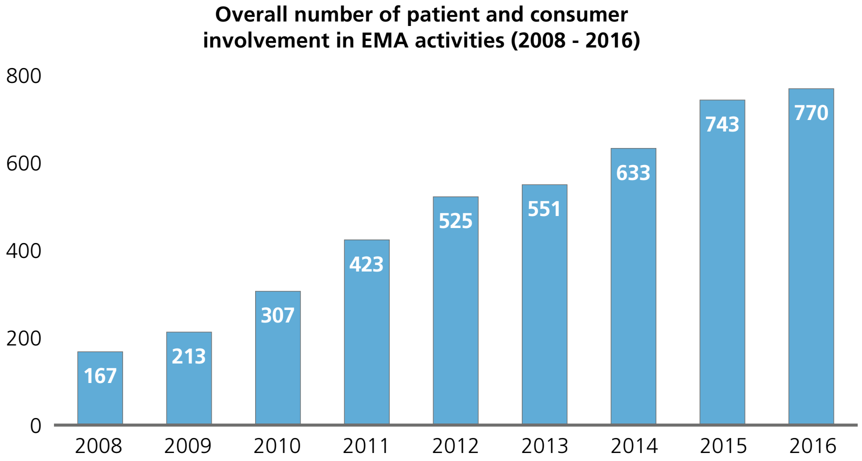
In 2006 a permanent Patients and Consumers Working Party (PCWP) was created paving the way for patient representative groups to meet regularly with the agency to ensure ongoing patient feedback.

The PCWP framework was reviewed 8 years later and since 2014 there has been a systematic inclusion of real life experiences in all EMA assessments. In 2017 the agency confirmed the setting up of Europe's first public hearing in this field.

The regulatory process to have medicines approved is complex, as it involves e.g. several committees, regulations and legislation, so as the head of EMA's Public Engagement Department explained, education is key. "It is like a maze for patients who approach this for the first time. That is why it is important that we provide sufficient training and support, so that they can really understand the complexity and provide the necessary input at all stages of a medicine's lifecycle."

Although patients have been involved with EMA since the mid-90s, more formal reporting of just how many participate has only been in operation since 2008 and in less than 10 years that number had increased 7-fold. “In 2008, 167 patients participated in different activities,” Garcia-Burgos explained, “and data from last year (2016) shows there were 770 reported cases. I think now we can say patients are involved in every stage of the process and I think this is something to praise and be proud of.”

Increasing number of patients in EMA activities



Overall number of patient and consumer involvement in EMA activities (2008 - 2016)

Garcia-Burgos is convinced patients are fulfilling a role which scientists cannot. “They bring a critical view that the scientific community cannot bring, which is the real life experience of the disease. Living with the disease and having this is really essential.” Patients also advise on the feasibility of planned investigations or clinical trials. “Very often there are end points proposed which may be impractical or unfeasible and it is only by having the patients on board that we can have these early warnings so that we can rectify in due time.” he said. Patient input is also vital when it comes to communicating a message. “Sometimes we get lost in our scientific jargon,” Garcia-Burgos told delegates, “and it is the patients who help us put all these regulatory outcomes into meaningful and easy-to-follow reports for the lay reader.” Patients also help, through their organisations, to disseminate information that is maybe important for patients specifically with similar diseases. Despite getting off to a rocky start more than twenty years ago, Garcia-Burgos was convinced the EMA was in a better place now than ever before thanks to its policy on patient involvement. “After so many years experience,” he concluded, “it has benefitted the system much in terms of being more open, transparent and I think we have more trust from society and from the patients in what we do, which is essential for public health.”

The new chapter on the fight against pain

Isabelle Macal

ISABELLE MACAL, MARTINE CHAUVIN, RODRIGUE DELEENS
AFVD, France

Isabelle Macal is president of the Association Francophone pour Vaincre les Douleurs (AFVD), the French-speaking association dedicated to patients with a variety of pain-related conditions. Macal took to the floor alongside peer educator and founder of AFVD, Martine Chauvin and pain specialist Rodrigue Deleens. The president of AFVD began by giving an overview of the pain situation in France. It is estimated that around 15 million French citizens have some form of chronic pain.

Although chronic pain is not considered a chronic sickness in France it has an important place on the country's health agenda. "17 educational programmes are studying this and 15 other programmes are specialising in the clinical pathology of pain," she said, "and therefore we hope very soon it will be considered a chronic sickness."

> ***"This patient association works in partnership with people with chronic illnesses, with their entourage and with health professionals in support in the management of pain."***

Macal touched on Therapeutic Education of the Patient (TEP), a university degree course which she herself studied and which is designed to help patients acquire or maintain the competences they need in order to manage their life better with a chronic condition. For further explanation of such therapeutic education programmes she handed the microphone to Martine Chauvin who also completed the degree course and now works with patients as an "expert patient".

Therapeutic learning takes into account the reality of the patient's experience, his posture as an actor and the alliance with the healthcare team. Describing the course Chauvin now helps teach she said: "The object of the programme is to give patients as much autonomy as possible and eventually live completely without us." The multi-faceted team helps the patient develop his knowledge on the complexity of chronic pain. However, as Chauvin explained, "Generally, a large number of patients continue to find themselves in therapeutic isolation and we cannot help them."

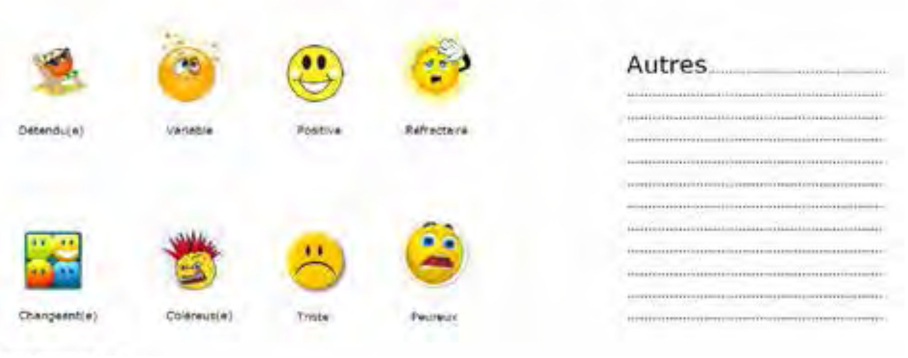
Martine Chauvin

> ***"The expert patient is an essential link in therapeutic education."***

TEP is designed in four modules and as the founder of AFVD explained work is done in collective groups, but with individual attention. "We have groups where everybody can express themselves and then there are sessions focussing on breathing, posture and physical activities." she explained. "Other sessions are more to do with psychology and we explore what could have led to the pain patient's current situation. Finally the last session is set up by the expert patient and in this session the pupil speaks about his problems and his experiences and we try to find solutions to this."

Chauvin also described some of the pedagogical tools used to create this programme, one of which was intended to bring a smile to the faces of the pain patients. "Whether in a good mood or a bad mood, if you are in pain you are seldom in a good mood. So with a few smileys patients start to realise the importance of humour and they actually identify themselves with a particular character each day.

L'échelle de l'humeur



The microphone was then handed to Rodrigue Deleens, a pain doctor who works in hospitals in the therapeutic section. Interested in TEP, Deleens collaborates actively with several patient associations, including the AFVD, to improve the programmes implemented, as well as the policies promoting these programmes. Teaching sessions are not only designed for the patient, but also for the carers and Deleens described the strong alliance built up between teacher and student. "Even when we work in a group, there are no two patients that actually require the same treatment." he said. "Therefore we have to adapt ourselves to each and every person involved. These patients become our family.

“The therapeutic education of patients is a challenge, let’s work together to improve the management of chronic pain and the quality of life for patients!”

We work with them and they become our friends. Specific pathologies have to be cared for specifically.” Of course this tailor-made approach comes at a cost and Deleens revealed that most on the healthcare team worked free of charge and that money was so tight they were unsure how long they could secure their premises. In the end, the pain specialist concluded that all involved would just have to trust that the agencies that finance the programme would continue to be sympathetic to this multidisciplinary and multi-professional approach.

Rodrigue Deleens

Karim Berkouk

What EU policy can do for conditions such as chronic pain?

KARIM BERKOUK
DG Research and Innovation, Belgium

The European commission has substantially invested in pain research with about €20 million per year in the last 10 years. Now with the advent of personalised medicine and big data for patient-centred approaches Karim Berkouk, deputy head of non-communicable diseases and the challenge of healthy ageing in research and innovation, described how the hope of his agency was now to accelerate a meaningful management of pain research for European citizens and beyond. However, there were still many challenges to overcome. “Non-communicable diseases, this is the biggest challenge in Europe.” he declared. Berkouk estimated that 86% of deaths in Europe were caused by non-communicable diseases and it is such a burden because these conditions are chronic.

> ***“The complexity of pain requires new approaches. This is the reason why the European Commission is pursuing the path of personalised medicine and develops patient-centred approaches.”***

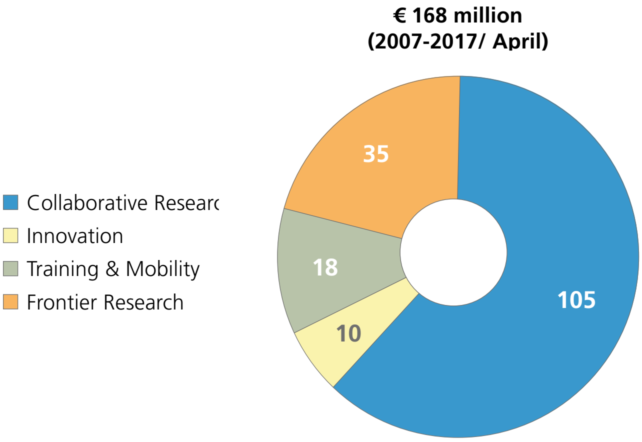
“In the past we had infectious diseases, acute events, whereas now we have chronic diseases and what that means in practice – once you have one you have it for life and with the management of chronic disease comes the pain that will have to be managed for the rest of your life.” In addition to that society is ageing, so more susceptible to chronic diseases. “The burden on the healthcare system is going to be tremendous.” he continued. “Add to that the recent escalation of prices for drugs and vaccines the health care system won’t be able to cope.” On top of all this, Berkouk touched on the inequalities in the system, “not only between countries, not only between regions,” he claimed, “but even within cities.”

Following these sobering facts, Berkouk went on to describe his agency’s hopes for Horizon 2020, the EU Framework Programme for Research and Development. Horizon 2020 is the biggest EU Research and Innovation programme with an overall budget of €80 billion over 7 years, between 2014 and 2020. It is the third largest budget at the Commission after agriculture and the structural fund, which focuses on increased economic activity. Horizon 2020 is built on 3 pillars: excellent science, industrial leadership and innovation and societal challenges. Pillar one intends to strive at excellence through supporting the best ideas in the European research council. Talent will be developed within Europe and training fellowships; for example, the Marie Curie fellowships could provide opportunities to support research on the basic mechanisms of pain. The second pillar, industrial leadership, is aimed at helping industrial innovation in Europe to flourish, mainly through ICT and manufacturing science.

The third area focuses on the societal challenges, of which there are several, from climate change to food and safety. The good news is that Pillar 3, which receives the largest budget of €31 billion, allocates €7.3 billion of the total to societal challenges on health. Berkouk believes these amounts show the commitment of member states, but also to parliament and the population to the issue of health. "What we try to do with our pain research is answer two questions: how pain is generated and can this process be prevented, halted, modulated or even reversed." The agency also now takes much more of a patient-centred approach. "Compared to 10 years ago when patient participation was an exception, now more than half of the projects and policy design involve patient groups." Berkouk told delegates.

He went on to describe how in the last 10 years (2007 – 2017), the European Commission had invested some €168 million in basic research and better understanding of related pathways and pathophysiologies, innovative treatments and diagnostics as well as in better management of pain and related social and socioeconomic implications and advancements of health care systems to improve the health status and wellbeing of patients suffering with pain.

EU pain research – what's being funded FP7 & HORIZON 2020



Translational research
- acute pain
- chronic pain
- biomarkers
- imaging
- models
- technology
- prevention
- early detection
- clinical trials

One example given was the DOLORisk campaign, a collaborative research project which Berkouk described as perfectly exemplifying the idea of personalised medicine. “They try to stratify patients based on the physiological and psychological factors. The idea is that once you have better stratified the patient you will be able to develop a risk model for neuropathic pain.”

As with other departments at the Commission, digitalisation is slowly taking hold at DG Research and Innovation where teams of researchers are trying to capitalise on the data revolution. “We have an ambitious project now called the European Science Cloud Initiative where we want to put all the data from our projects so that they can be assessed and standardised.”

In conclusion, Karim Berkouk looked ahead and gave a flavour of what is to come in the next two years. “Personalised medicine and global health will be on the agenda.” he explained. “There will be an emphasis on environment and e-health for Active and Healthy Ageing and also Big Data and Trusted Big Data.”

The Innovative Medicines Initiative (IMI) and pain research

ELISABETTA VAUDANO
IMI, Belgium

Elisabetta Vaudano

The intention of IMI is to accelerate the delivery of therapies and develop the next generation of vaccines, medicines and treatments, which as Elisabetta Vaudano remarked, has still a long way to go. “If we think about treatment of pain, many drugs used today were also being used 100 years ago, so not really innovative and new. And then on top of that if we look at the success of treatment we can only say around one third of patients are well treated. So there is a lot of work to do.”

The aims of IMI are aligned with the WHO´s 2013 Priority Medicines Report for Europe and the World. Vaudano believes that IMI’s fully collaborative approach with stakeholders from the public and private sectors is the best way forward if our future health challenges are to be tackled properly. IMI is unique because it is able to leverage resources from many different stakeholders and pull together the skills and experiences from a large spread of sectors: e.g. patient organisations, small/medium sized enterprises (SMEs), academics, hospitals and big industry.

Pain, and in particular chronic pain, has been an area of focus for IMI from its very beginning with the implementation of the EUROPAIN project (2009 – 2015). And in the portfolio of pain projects now being developed by the new strategic group on pain, pain is put at the centre. Pain fits very well in the vision for the new IMI2 arm of Horizon 2020, which as Vaudano explained "is really to try to move from treatment for a population, the pain population, which is very heterogeneous, to an improved more individual approach based on stratification of different groups of people that hopefully will better respond to treatment and also have fewer side effects."

"The effective management of pain is an increasing concern in the medical arena, and in the broader economic and political environment. The only way to tackle effectively this challenge is to join forces in an open collaborative way involving all stakeholders, both from the public and private sectors, and keeping the patients in the centre."

The Strategic Pain Group, a satellite of the IMI2 Strategic Governance Group, was formed in recognition of the continuing high need for improving the understanding, treatment and management of pain. Vaudano described how the magnitude and complexity of these goals required complementary expertise and multi-disciplinary approaches, which, she stressed would be best assured by public-private partnerships. The pain group also unites European pharmaceutical companies dedicated to understand better, treat and manage pain.

“We have a very active pain industry team, already quite busy, and here what is important is that we have all the major players in pain in Europe, a group normally competing against each other, sitting round the table discussing the major challenges they have.” Vaudano believes this cooperation should lead to the development of a portfolio of concrete pain projects.

The pain group selects pre-competitive pain research areas of particular strategic and societal value. It enables a portfolio of concrete pain projects which address a broad spectrum of challenges in the pre-competitive space (not asset related) ranging from pain target identification to real world clinical evidence of efficacy. Solutions are sought in partnership with consortia of partners selected via open and competitive Calls for Proposals.

In conclusion, Vaudano described a new and forward-thinking project in the pipeline. “We will have around €25 million for pain and the future project will build an innovative pain platform covering and integrating three key areas: the use of Patient Reported Outcome Measures to improve the management of acute and chronic pain; we will look at how to improve the effect of drugs on the different parts of the pain pathway; and there will be more focus on chronic pelvic pain, which is an area of unmet need.”

Outlook and Closing

For the closing 10 minutes of SIP 2017 Bart Morlion, president-elect of EFIC and Joop van Griensven, president of PAE were invited to take to the stage to give their conclusion of SIP 2017.

The following is a transcript of their closing words:

Bart Morlion: Before wrapping up I want to give you a message, because meetings like this are also a starting point and for a few years we've built up a momentum, which is growing and growing. What just happened here in Malta is that many of us can leave this meeting with homework, because we really have a new initiative to work on: for instance, the setting up of the European Expert Group on the Social Impact of Pain is a very important achievement and I want to give a very broad call to everyone. Please join this initiative, so that we can really step up once again to above 300 organisations teaming up for the benefit of patients suffering from pain. We have made a start now and we have to work on this.

The key recommendations from the working groups; development of instruments to assess the societal impact of pain. Once again this is a very important point and we heard some very good examples from regions within Europe. Also, clearly on a European level and on a national level there should be more attention given to the reintegration of patients with pain into the workforce, and once again and this has been repeated many times, we still need to improve our education. We have clearly made steps forward. Nevertheless, there is a huge difference between the different regions in Europe and we have a lot of work to

do as professionals, but also with regards to education for the general public and patients. And then especially the last two talks (Horizon 2020 and IMI) clearly demonstrated that on a European level, there are very good initiatives, but every initiative still needs to step up. We call for further engagement and investment in research.

Before handing over to Joop, I would really like to thank the partnership once again with Pain Alliance Europe, Active Citizenship Network, not to mention the No Pain Foundation and Maltese Health Network, who helped us in being hosted by the Maltese government.

Joop van Griensven: I enjoyed these days. We heard some great news. ICD 11 will be implemented next year which is a benefit for the patients because of the coding we'll be using. The platform! That will be a benefit for the patients. We saw some commitment from MEPs spoken out today; we saw the commitment from DG Sante spoken out today; we saw the commitment of you in the workshops; and I think we should be proud of ourselves…proud for 2 days, until the end of the weekend. But on Monday, when you are back at work, you should go to your computers and the first thing you have to do is join the expert group. The second thing you have to do is review the ICD11 proposals and the third thing you have to do, and this is what we have heard all day long from the recommendations they have made, and that is to make a special call to national authorities to do something. And you can influence the national authorities. So what we have achieved now on a European level, let that be an example that you can achieve a lot on a national level when you cooperate with each other, as we are cooperating on a European level, the same way is possible on a national level. And I think that is the main message I got from this SIP symposium.

MALTA
EU2017

SIP
Societal Impact of Pain

SUPPORTING INITIATIVES

The Global Alliance for Patient Access (GAfPA) Workshop

Introduction

Reporter: JUTTA AHMERKAMP-BÖHME

The GAfPA workshop at the 2017 SIP conference in Malta focused on policy advocacy. The striking message: "Effective lobbying is not a question of size, but rather of technique and strategy! Even a small organisation can have a loud and powerful voice as long as it knows when and how to use it."

The workshop was split into three parts. First, Brian Kennedy, Executive Director of the Global Alliance for Patient Access (GAfPA), presented six key factors to successful advocacy. Next, three official SIP partner organisations, EFIC, ACN and PAE, highlighted their most recent efforts and achievements in advocacy work in chronic pain. Finally, the attendees were asked to put into practice what they had heard and learned during the afternoon.

“Can Davids beat the Goliaths?”

Brian Kennedy

BRIAN KENNEDY, EXECUTIVE DIRECTOR
Global Alliance for Patient Access (GAfPA), USA

> ***“The voices of patients and their healthcare providers are essential to ensure informed policymaking.”***

In his presentation, Brian Kennedy from GAfPA took up the biblical story of David and Goliath and applied it to advocating in our modern society. GAfPA is an international network of physicians and patient advocates that trains advocates to pursue access to appropriate medical care and therapies. Kennedy explained, “If you do not get involved, nothing will happen”, to his attentive audience, which had arrived a day early at SIP 2017 to take part in the GAfPA workshop. According to Kennedy, it has always been the “power of the few” approach that has caused the biggest changes in history. Six key factors, he advised the 40 delegates, were the basis for fruitful and effective advocacy.

First, “a message has to be delivered,“ Kennedy said. As it is the message that matters most, it is absolutely necessary that it fits the messenger. Those messengers must answer any questions and should identify the societal benefits of the policy under discussion.

Communication is the second key factor to success. Most people tend to remember stories better than facts and figures; thus, storytelling may be the most powerful means of communicating one’s position. The doctor-patient relationship or a patient‘s personal experience, among other stories, can contribute to a better understanding.

According to Kennedy, the third step is the identification of a champion, of an elected policymaker who will support the messenger and his message. The more a champion can identify with the topic, the more successful his efforts will be. “Make your issue their issue,” he stressed.

“Build relationships!” was the fourth message. It takes a lot of time to get to know people, but it is worth the effort, he said. Decision makers in political and social forums should be approached and ideally be invited to get to know the organisation in question. Kennedy promoted the use of social media to help establish new contacts.

Expertise and good media skills are a “must” when it comes to advocacy. Kennedy emphasized as the fifth principle that media often set the narrative and that they were generally considered to reflect real life. Thus, opinion editorials may help to clear the way for further action.

And finally Kennedy explained how the voice of a few people who are informed and organized can be more compelling than even the voice of large, prominent influencers. Physicians and patients who are willing to engage on policy issues should ideally “build a long-term coalition.”

European Pain Federation, challenges and success in advocacy campaigns

Chris Wells Sam Kynman

CHRIS WELLS, PRESIDENT
SAM KYNMAN, EXECUTIVE DIRECTOR
EFIC, Belgium

Chris Wells, President of the European Pain Foundation, invited the attendees to take a look at the organisation's past. Founded in 1993 as European Federation of IASP Chapters, EFIC today represents 37 countries and more than 20,000 health care professionals all over Europe. The list of activities and initiatives focusing on pain is considerable.

> ***"Since 2011, the European Pain Federation EFIC® has worked, together with European and national policy makers, on the "Road Map for Action" outlining how to effectively address the societal impact of pain at policy level. Five years later, we are seeing some concrete results!"***

One of the greatest achievements: the "Declaration on Pain," published in 2001 to increase governmental awareness and to strengthen pain research. For the first time pain had been recognized as a disease.

At the end of his short presentation, Chris Wells welcomed Sam Kynman as the new Executive Director of the European Pain Foundation and introduced him winkingly as the "man for future successes and strategies."

Mariano Votta

Addressing the Patient's right to avoid pain: Advocacy activities at a national and EU level

MARIANO VOTTA, DIRECTOR

Active Citizenship Network (ACN), Italy

> *"Making the invisible visible on chronic pain."*

ACN as a part of Cittadinanzattiva has been established in 2001 and counts more than 100 EU civic and patients' organisations today. Mariano Votta explained that a considerable number of projects and campaigns had been organised in the past 15 years – among others, the European Charter of Patients' Rights – with 14 rights aiming to avoid suffering and unnecessary pain – and the Pain Patient Pathway Recommendations. Mariano Votta described the strategy behind these achievements: Citizens are directly involved, and alliances of public and private sectors, experts, organisations etc. play a role. Furthermore, ACN supports multi-level activities to strengthen the chronic pain voice across Europe.

Joop van Griensven

Are there benefits to working together as patient associations in Europe?

JOOP VAN GRIENSVEN, PRESIDENT

Pain Alliance Europe

> *"A better quality of life starts with believing the patients and giving them the treatment they believe in."*

Joop van Griensven received a resounding and clear, "Yes!" when he asked whether patient alliances in Europe would profit from more cooperation. After this opening question, van Griensven focused on a number of key issues. In particular, he mentioned a survey as a good tool to raise awareness for pain patients and their needs. Depending on the topic, the choice of questions and the groups involved (members, board, outsiders, etc.), a survey can be used to spread the basic ideas of PAE, such as improving patients' quality of life.

Interactive Session & Conclusion

In the final part of the workshop, the attendees split into three groups and explored barriers to effective pain treatment. They were asked to propose ways of convincing policymakers of the necessity to get involved and take action.

The groups' work was insightful. Participants mentioned gaps such as the poor education of healthcare professionals and the lack of patient access to integrated pain treatment. They also pointed out that politicians in Europe would rather make short-term decisions than consider the long view, as they were under pressure to show results to stand a chance of being re-elected. In general, participants concluded, actions should be taken on a local level first and should then be enhanced to a national and perhaps international level. Experts from various disciplines should be involved to spread the message. It was more than obvious that at the end of the session that attendees left prepared to advocate to policymakers in their home countries.

The final remarks of this report should be given over to the American author Margaret Mead, quoted by Brian Kennedy. She strongly believed in the "power of a few," saying:

> **"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."**

So what about you?

#Release the Pain
Closing of the Red Balloon Project

Joop Van Griensven, the president of PAE, and a chronic pain sufferer himself, launched the Red Balloon Project in 2016. Continually surprised by the lack of awareness of chronic pain, Joop said this campaign's goal was to increase public awareness: "Chronic pain patients are not visible within European society although it is the most prevalent health condition. It is also the most common reason why people are visiting their GP and yet it is not well known by health care professionals, policymakers, politicians and the general public. This lack of awareness is astonishing given that almost everyone has some kind of contact with it – whether they suffer from chronic pain, know someone with chronic pain, care for someone with chronic pain or work with someone with chronic pain. With this project we would like to increase public awareness around chronic pain and its management and try to get them involved in changing the situation for the better."

Following its goal "to improve pain management across Europe", the Red Balloon Campaign was launched at the annual "Societal Impact of Pain" (SIP) symposium, entitled "SIP 2016: Time for Action!" Pain Alliance Europe has developed this project in collaboration with Boston Scientific.

The campaign's powerful symbol was the red balloon being filled with pain and then released. The participants have taken pictures with a red balloon, either releasing it or bursting it to #releasethepain.

The mission of the project was to raise awareness around chronic pain, the people affected by it and its impact on the global community; to engage people around the issue, activating conversation, understanding, and reaching out; but also to trigger change via meetings and events in the EU Parliament. It delivers a powerful message to policy makers and healthcare providers that a change is needed to provide better pain management for patients across Europe.

The power of social media was leveraged as a tool to bring the European community together for the cause. One year later, the project has the following accomplishments to report:

- 6.5M people reached
- 2300 balloons released
- 6300 website visitors

Liisa Jutila, Vice President of Pain Alliance Europe has been closely involved in this project and she kindly shared with us her insights into this action: "The idea of The Red Balloon has been so enthusiastically received and people reacted directly to the symbol. #releasethepain created a space for expression, dialogue and empathy, and when bringing people together around a problem, they naturally start looking for solutions.

We have learned so much since we started working on this project, and we will definitely use the experience to develop further ideas. From carefully deciding on a symbol for a new campaign to the selection of the tools and service providers, details should be carefully considered each time and nothing should be left to chance. Using all the appropriate tools and being present on all social media channels is also a challenge that needs to be met. It became so obvious that a social media presence is vital and we need to learn the best way to make it work for the patients and their cause.

Nothing is as valuable as the knowledge one gets from experience, and the fact that this project closes this year is only the beginning for new ideas, as there is so much work to do for the pain patients."

The event to close the project took place in Malta during the SIP Symposium (SIP 2017), where participants were invited to burst dozens of red balloons that were released following the pre-symposium SIP Malta event, and share their insights related to chronic pain in powerful short messages left on a red balloon wall.


“Send pain flying off”


“Do all you can to release pain from your patients”


“Pain takes over your life”


“United
by pain”


“Pain:
Me first,
you second”


“Don’t let
pain control
you”

”EU Civic Prize on Chronic Pain - Collecting good practices”

Four best practice activities were awarded at SIP 2017 in Malta at Casino Maltese by the President of the Maltese Republic, Marie-Louise Coleiro Preca, thanks to the “EU Civic prize on Chronic Pain”, promoted by Active Citizenship Network-Cittadinanzattiva during the annual symposium on the “Societal Impact of Pain” (SIP).

Active Citizenship Network (ACN) launched the project ”EU Civic Prize on Chronic Pain - Collecting good practices” to show some of the existing good practices in Europe in terms of the struggle against pain, and based on the selection of the practices presented by different healthcare stakeholders. The prize provided an occasion to demonstrate what the community can offer in terms of good practices as well as sharing experiences useful for raising awareness about the condition, enhancing the body of knowledge of positive cases and successes, and strengthening commitment on this topic. This initiative allowed ACN to collect 30 examples of Good Practice, received from 11 different countries: Malta 2; UK 6; Spain 8; Portugal 2; Ireland 1; Italy 6; Germany 1; Denmark 1; Finland 1; Netherlands 1; Russia 1. The good practices gathered have been published in a report that is available at www.activecitenship.net.

Active Citizenship Network is responsible for the scientific design and content of this Project that has been realized with the financial and non-financial support of Grünenthal GmbH and Pfizer Inc.

"With the aim to contribute to the value of the experiences gathered during the EU Prize, Active Citizenship Network, together with the Spanish Foundation Sine Dolore, has promoted the Pain Euro-Mediterranean Coalition”, declared Mariano Votta, Director of ACN-Cittadinanzattiva, “which not only is the first civic Hub-incubator of best practices against pain across Europe, but also an agora of operators of good practices on pain. Hopefully, the Coalition will ensure longer life to the good practices themselves and will identify conditions to replicate or implement them in other contexts as well."

The 4 Winners

The Jury of Active Citizenship Network-Cittadinanzattiva, composed of health experts, selected the 4 winners using the following four criteria: reproducibility, innovation, added value, appropriateness. The winners will be given an expenses-paid visit to other winners' headquarters and a publication in English in a suitable journal.

The winner for the category CLINICAL PRACTICES:

"Physical activity in women with fibromyalgia: the al-Ándalus project" from the Department of Physical Education and Sport, Faculty of Sport Sciences, University of Granada, Spain.

The Jury Panel commented: "This is an excellent well-organised and collaborative project involving 8 universities in Andalusia, multidisciplinary teams and patient organisations. Also, an external academic link for researchers has been established. This work has incorporated sites outside of the traditional health care settings, e.g. private gyms and swimming pools, and investigated a condition that is often neglected by health care professionals".

The winner for the category PATIENTS' EMPOWERMENT:

"Attending lessons of expert patients: advice for the physicians to improve their care of cluster headache patients" from the Alleanza Cefalalgici Cluster, European Headache Alliance, Italy

The Jury Panel commented: This work showed great innovation in gathering expert patients in four countries across Europe to assist health care practitioners in the management of cluster headaches. It is a very well thought out submission on an uncommon, but important, painful condition. It is good to see everyone working together to highlight this condition and improves the management of patients with this condition and their quality of life.

The winner for the category INNOVATION:

"Non-pharmacological treatment of chronic pain: a multimodal approach." from San Raffaele Hospital, Italy

The Jury Panel commented: “This work is truly innovative. The team is using a virtual reality setting plus neuropsychological support to permit the development of personalised and specific rehabilitative exercises, plus remote communication with the patient’s home environment. It is really very exciting”.

The winner for the category PROFESSIONAL EDUCATION:

"Patients as Teachers in Health Professional Education" from the Pelvic Pain Support Network (PPSN), UK

The Jury Panel commented: “Many universities are using patients as part of undergraduate education, but this is the first time that I have seen the course formally written up. It is excellent that this now involves two universities (Leeds and Southampton), and I hope that there are plans to increase uptake of this type of education in other universities and for other conditions. It is excellent that the patient and a family member have been involved as this emphasises the family impact of pain. There was a well thought through systematic involvement of patients in formal nursing and medical education and the project showed good collaboration between patients, educators and clinicians”.

Opening Speech from President of Malta Republic Marie-Louise Coleiro Preca

It is my pleasure to open this award ceremony, celebrating the European Union Civic Prize. I would like to commend all the participants, for their contributions to this research project, to collect good practices, upon which the European Civic Prize on Chronic Pain has been established.

On the other hand, I would like to take the opportunity to congratulate the recipients of this award. Let me also take this opportunity to thank all of you, for your many years of work, forming new connections among different organisations; sharing best practices; and for organising this symposium, to continue to raise awareness about chronic pain and its effects. Thanks to the work of the six main organisations, facilitating this event, and your collaborators, we are sending a powerful statement, through this symposium, about our united commitment, to safeguard the wellbeing of all people living with chronic pain. In my various meetings with members from the "ME, CFS and Fibromyalgia Alliance", an NGO which is actively advocating for chronic pain sufferers in Malta, I have had the opportunity to hear first-hand experiences, of people living with such conditions. Through my connection with members from this Maltese alliance, I have learnt that,

when our systems are unable to provide effective outreach and sustained support, many sufferers feel that their quality of life is diminished. While their families, communities, and the whole of society are also very negatively affected. I believe that the issue of chronic pain must take more importance within our healthcare systems and policies, both nationally and at the widest possible European levels, for us to continue to push for proactive and effective change.

Creating, and sustaining further connections, between civil society activists, from around the world, will highlight, even more, the vast numbers of people who are being affected. I am convinced that it will also create a spirit of solidarity among sufferers, their families, and other members of society.

Indicators from the International Association for the Study of Pain, and the European Pain Federation, state, that one in five people suffer from moderate to severe chronic pain. Furthermore, one in three are unable, or less able, to maintain an independent lifestyle due to their pain. The effect of their pain also means that one in four people report that their relationships, with family and friends, are severely strained.

According to Professor Harald Breivik, former president of the European Pain Federation, and I quote; "Chronic pain is one of the most underestimated healthcare problems in the world today, causing major consequences for the quality of life of the sufferer, and a major burden on the healthcare system in the Western world."

Speaking about fibromyalgia specifically, data from the World Health Organisation says that its prevalence is between 3 and 6 percent of the global population.

These indicators should convince all across the world to work together, in greater synergy, across civil society and diverse medical sectors, to encourage greater awareness. However, civil society must also continue with their efforts to push authorities to take action, on behalf of all people who live with chronic pain. For example, I believe that a European level policy should be drafted, to specifically target these concerns.

People living with chronic pain are not only dealing with the pain itself, but also with uncertainty, discomfort, and confusion. Often, sufferers report feeling overwhelmed when they are dealing with their situation. These factors can all contribute to a disabling effect on the individual, who is, regardless, expected to continue to function in their places of work, their communities, and their societies.

I believe that there is still a worrying lack of respect and understanding, for people living with chronic pain. This is a cause for great concern. Therefore, I believe that we must, first of all, encourage more knowledge about the underlying challenges faced by people living with chronic pain. This means looking at the problem of ableism, within our societies.

As many of us know, ableism refers to practices and prevailing attitudes, which are present in our communities and institutions. These practices and attitudes often devalue and limit the potential of persons with disabilities, or people living with disabling conditions, which could also be an invisible disability. We must raise awareness about the fact, that our systems, institutions, and policies are not always responding, in an adequate and effective manner, to the legitimate needs of people who are living with disabling conditions. Such a situation means that many of our public and private places, services, education, and social outreach, are not fully inclusive. Indeed, they can become a source of exclusion, making it difficult for us to achieve the full and equitable participation of all citizens, including those with disabling conditions. This reality is often invisible to those who do not have disabilities, or disabling conditions, or to those who are not yet sensitive to these issues.

Pain is a worldwide problem. Indicators from the World Health Organisation assert that 20 percent of adults suffer from pain, around the globe, and 10 percent are newly diagnosed with chronic pain each year. Moreover, studies tell us that women are overrepresented among these indicators. Such challenges are of particular importance when we talk about the experiences of women and minority groups, who are primarily affected.

There is a lack of research on chronic pain worldwide, and this is particularly evident in the Maltese context. The first study conducted in Malta, to focus on the voices of women with fibromyalgia, was carried out in 2015 by Angie Chircop Coleiro. The study, entitled "Working with Fibromyalgia: The lived experience of women with fibromyalgia in the workplace", states that, although many affected women said they were reluctant to be perceived as disabled, fibromyalgia has a clearly disabling effect on their lives. Let me quote from this study, where women said that it was, "a burden not just to them, but also on their families. Thus, they believe that gaining disability status can provide them with some form of official recognition, as well as financial aid."

Furthermore, an international study entitled "Defining Racial and Ethnic Disparities in Pain Management", which appeared in the Journal of Clinical Orthopaedics and Related Research, states that, and I quote, "Racial and ethnic minorities consistently receive less adequate treatment for acute and chronic pain". (Mossey, 2011)

Racial or ethnic minority individuals, living with issues of chronic pain, need to be empowered to seek and receive appropriate support and care. It is essential that the medical professionals who are treating such individuals are aware of their own attitudes and potential prejudices, which may be making the problem, for the sufferer, more difficult. There must be more emphasis to develop strategies, and again, I quote from the study on "Defining Racial and Ethnic Disparities in Pain Management", that we must do more, "to overcome unconscious, but potentially harmful, negative stereotyping of minority patients."

These facts point to the complex realities experienced by chronic pain sufferers, and the need to deal with them in an intersectional way. We must ensure that gender, and racial or ethnic background inform the way authorities formulate and implement their policies. I believe that stronger synergies between civil society and medical professionals would be a powerful catalyst to highlight these intersectional concerns. I also believe that such synergies can also encourage authorities to acknowledge the disabling effect of chronic pain, and to respond accordingly, across institutions and public services.

We must promote issues of chronic pain as a matter of urgent importance, including to the medical community. I believe that, due to the effects of ableism, we must do more to create a necessary social and cultural change, through education and awareness, in our attitudes, towards people living with chronic pain. We must also emphasise the disproportionate number of women who are living with conditions of chronic pain, and the particular challenges faced by minority groups in accessing necessary support and care.

Finally, we must assert that chronic pain is an issue of relevance to public health. We must assert that authorities, including the European Union, should incorporate chronic pain into their strategies for effective outreach, across our societies.

In conclusion, let me once again congratulate today's all participants in this research project, and today's award winners, for their substantial contributions to the strengthening of this sector. I hope that you shall continue to collaborate, and produce timely, and relevant, good practices and policy recommendations, which reflect the real experiences of people living with chronic pain. Let us keep emphasising that we need to act, now.

In the words of popular author John Green, who is himself a chronic pain sufferer, and I quote, "Language is always inadequate in the face of pain."

However, we must keep trying, as best as we can, to create empowering spaces for people, struggling with chronic pain, to give a voice to their narratives. It is sometimes impossible to accurately convey the intensity and the impact that chronic pain can have, on the lives of sufferers and their families. Sometimes, words fail us, and it is in those moments that we must show the most solidarity and support. We cannot allow anybody to feel alone, isolated, or ignored with their pain. We must work together to continue improving our institutions, communities, and societies, ensuring that they respect the experiences of all; that they are truly inclusive and fully participatory; and that they celebrate the dignity, and the potential, of each and every person, by putting in place the necessary good practices and policies in our healthcare systems.

Thank you for your attention.

H. E. Marie-Louise Coleiro Preca
President of Malta

German Breakfast Session
Pain care in the DACH healthcare systems

Reporter: CHRISTINE SCHIESSL

The treatment of chronic pain is one of the most complex medical care settings: adequate pain therapy is not only oriented towards an interdisciplinary and multi-professional approach, but also requires intensive patient care and continuous patient involvement in the treatment process. However, pain therapy is not the only way to deal with this complex treatment setting: almost all chronic diseases require that a patient receives ongoing care in a therapeutic environment and under the care of a number of different specialists. However, there is little to see of such approaches currently in a medical and care system that is highly fragmented.

This is all the more dramatic because the care of chronic diseases in the industrialized world is now almost 80% of the total cost of care, while only about 20% is attributable to acute care.

Against this backdrop, it is worth noting that current pain care therapy may cause deficits and hinder development possibilities in the general healthcare system. The suggestion is that the more chronic pain patients and their therapeutic teams find their place in the system with all treatment procedures adminstratively mapped out, care systems will be better prepared to face the challenge of chronic diseases.

Multimodal pain therapy is the goal

The early morning event raised the question: What can care systems learn from a recognised, multimodal patient-centered care system and how can we be part of this care world?

The event was organized as a "public roundtable" session with contributions from experts in the audience being thoroughly encouraged. The following stakeholders were invited to the debate: health policy-makers from the German-speaking health care systems of the DACH region (Germany, Austria, Switzerland), physicians working in pain medicine and palliative medicine, and a patient representative.

The discussion was based on the relevant publications from the RKI series "Federal Health Reporting": No. 2 ("Death Support"), No. 7 ("Chronic Pain") and No. 53 ("Backache"). In addition, the various opinions of the German Council of Health Experts, as well as the health records of the health insurance funds, were taken into account.

Pain therapy in comparison

> ***"It is time to move from raising awareness and attention to committing to action on pain treatment. Chronic pain is one of the largest cost blocks in healthcare and one of the largest economic cost blocks resulting from job losses. SIP provides a platform to learn from one another. We must use the opportunity to learn from the diverse approaches used by different countries."***
> *Albrecht Kloepfer*

Albrecht Kloepfer welcomed the invited guests and the numerous audience members. In the first round, Kloepfer asked the experts to present the care situation in their respective countries or regions, with particular reference to the question: Is pain therapy, with its cross-sectoral, multi-professional approach with the active involvement of the patient, a paradigm for chronic diseases?

Christof Veit initially reacted with a counter-question: "Is QoL a good quality indicator?" According to him, current quality indicators are not suitable to meet today's challenges of quality measurement. For this purpose, the IQTIG is carrying out an assessment of what is needed to meet today's challenges. Dr. Wolf Diemer found that sector dissemination was a "major obstacle" for receiving good care. However, pain therapy could be a good paradigm. André Ljutov explained that the Swiss health system was more complicated than the German one. Each canton is autonomous and has its own regulations. Pain therapy is treated very negatively. On the one hand there is no specialization for pain

therapy, anybody can call themselves a pain therapist. On the other hand, the therapy is not remunerated except when dealing with "interventional and stationary multimodal pain therapy", which reinforced Ljutov's belief that Switzerland offered a "certain lack of appropriate care".

> ***"We have to pool all our forces and to act in concert to reach our objective: A nationwide coverage of high quality pain management, which meets international criteria!"***
>
> *Wolfgang Jaksch*

Johannes Thormälen considered two major themes for pain therapy in Germany, which would come as a necessary challenge to create good pain care. On the one hand, with reference to quality, he asked what "good" pain care actually meant and how it could be reliably measured? On the other hand, as there is such a lack of joined-up thinking in this sector, he claimed many of the care plans for the chronically ill would fail anyway. Janina Dieber, Wolfgang Jaksch and Wolfgang Wiesmayr described the situation in Austria.

Care good, access bad

Britta Lambers, a pain patient from the German self-help organization Schmerzlos e.V. also took part in the roundtable discussion. She described the situation from a pain patient’s point of view. She said her care was basically good, but finding access to an appropriate therapy was the problem. In her opinion, patients needed much more support in finding the appropriate programme to suit their individual needs.

While medical and psychological structures are often already quite good in the context of multimodal pain therapy, there is practically always a lack of expertise in the areas of social work and counseling. Lambers made the case for a greater involvement of the patient in the treatment process. This collaboration was paramount for the success of the therapy. From her point of view, policy and health care providers used far too little of the patient's expertise - "the patient as a useful resource is currently underused," Lambers stated.

> ***“Facing the demographic development, there is one question to raise importantly – which nation will be able to afford the increasing numbers of early retirement caused by chronic pain syndrome? Also from patients´ view, there is a strong need to include job preservation as one of the main therapy targets.”***
>
> *Britta Lambers*

A nationwide lack of new recruits

On the subject of training, representatives from all three countries complained about a further challenge: the recruitment problem. On the one hand, there was little interest in ongoing training in the field of pain medicine, and on the other hand, to find a skilled pain doctor with the necessary qualifications was a major challenge. The attitude of the physician is an essential part of the quality criteria.

In Germany, the subject "Pain Medicine" was introduced in 2012 with the amendment of the Approval Regulations for Physicians (ÄAppO). Thus it became a recognized teaching subject with official examinations. Joachim Nadstawek complained about the lack of implementation of this amendment. There are some universities that only spend a few hours on this topic. Thomas Tölle (from the auditorium) reminded the panel that it was the decision of the respective faculties to implement any provision of the amended Approbation Regulations – But, in principle, It should be possible to offer a certain number of hours, as is done at the Charité hospital in Berlin.

> ***"Practised integrated supply concepts for patients with chronic pain should be transferred to the general supply of those patients to guarantee a real inter/multidisciplinary therapy. Therefore a change of thinking in the health system of Germany is absolutely necessary. Inter/multidisciplinary medicine is the chance for the future and has to be honoured and has to be paid."***
>
> *Joachim Nadstawek*

Reimbursement Systems in Focus

Veit said there was a need to define quality. It must be clear "what you get for it". Purely monetary incentivised systems were problematic. Ljutow believes that incentivised systems would potentially endanger the risk of expansion. Sanctions were a possibility. Another possibility was the quality-oriented remuneration or the retroactive remuneration in the case of quality.

> ***"Pain management addresses the quality of life for so many patients. It deserves systematic and systemwide action."***
> *Christof Veit*

Nadstawek pointed out that restrictions on the ambulatory remuneration system in Germany "put care in a straight jacket". Due to quality assurance, the ambulatory pain physician is not permitted to treat more than 300 pain patients each quarter, which led to around nine-tenths of all pain patients not being treated properly. In order to deal with the inappropriate healthcare patients were experiencing, Nadstawek described how his association had developed an initiative to help finance outpatient pain care. The government White Paper calls for the introduction of a "specialized outpatient pain care" (SASV) in a specialized ambulatory palliative care setting. According to this, pain patients should be able to be treated extensively and intensely on an outpatient basis by interdisciplinary teams.

Psychiatrists, physiotherapists, sports and occupational therapists, and pain nurses work together in a coordinated and multimodal manner. This could lead to a reduction in the pain burden as well as high return rates of patients to the working life, Nadstawek explained.

Veit emphasized that, in addition to the demand for changing care structures, the discussion and definition of the desired goals and results, above all the patient use, should be a high priority and in the following order: "What results do we want to achieve? Which processes are necessary? What structures do we need? "

What can health systems learn from pain therapy?

The experts agreed that pain medicine is an ideal example of interdisciplinary, multi-professional teamwork, functioning strategies and patient orientation and empowerment. In addition, pain therapy is a trailblazer for many chronic diseases.

Moderation:
ALBRECHT KLOEPFER
Office for Health Policy Communication, Berlin.

Subscriber:
CHRISTOF VEIT, Head of the Institute for Quality Assurance and Transparency in Health Care (IQTIG)

WOLF DIEMER, Herne Evangelical Hospital

ANDRÉ LJUTOW, President Swiss Society for the Study of Pain, SGSS; Senior Medical Center for Pain Medicine SPZ Nottwil

JOHANNES THORMÄLEN, GWQ ServicePlus AG

WOLFGANG WIESMAYR, Department of Palliative Medicine, Upper Austrian Chamber of Physicians

JOACHIM NADSTAWEK, Chairman of the Executive Board of Schmertherapeuten Deutschl ands, BVSD

JANINA DIEBER, Landeskrankenhaus Hartberg, Steiermark

WOLFGANG JAKSCH, Präsident Österreichische Schmerzgesellschaft

BRITTA LAMBERS, Patientenvertretung SchmerzLOS e.V.

Who else supported **SIP 2017?**

On the SIP platform website (www.SIP-Platform.eu) you will find the names of more than 300 organisations that endorsed the objectives of the SIP platform and meetings. As well as receiving resoundingly positive support from members of the European parliament and representative institutions who participated directly in SIP 2017's working group and plenary sessions, we also received encouraging support from the following persons:

Clara Eugenia Aguilera García

CLARA EUGENIA AGUILERA GARCÍA, MEP
Member of the European Parliament, Spain,
Group of the Progressive Alliance of Socialists
and Democrats (S&D)

"Pain and its impact in society should be addressed by the European Union."

Heinz K. Becker

HEINZ K. BECKER, MEP
Member of the European Parliament, Austria,
Group of the European People's Party (EPP)

"Together with SIP I want to continue raising awareness of the impact of pain and identify policies at European level to improve pain care."

NICOLA CAPUTO, MEP
Member of the European Parliament, Italy,
Group of the Progressive Alliance of Socialists
and Democrats (S&D)

"I am supporting the SIP symposium as I would like to work with pain experts to ensure that the Cross-Border Healthcare Directive functions in the way it was intended, namely protecting patients' right to seek treatment outside their home country when they are experiencing a high degree of pain."

Nicola Caputo

THERESE COMODINI CACHIA, MEP
Member of the European Parliament, Malta,
Group of the European People's Party (EPP)

"This year too, I support the Symposium dealing with the impact of pain because of its significance & implications on our everyday life. I congratulate the Malta Health Network for their work in building joint-platforms with our European counterparts to address this challenge. Let us join forces to lend a helping hand towards helping people live a better life."

Therese Comodini Cachia

MIRIAM DALLI, MEP
Member of the European Parliament, Malta,
Group of the Progressive Alliance of Socialists
and Democrats (S&D)

"The European Union must provide guidelines to all Member States, to consider pain in its own right."

Miriam Dalli

José Inácio Faria

JOSÉ INÁCIO FARIA, MEP

Member of the European Parliament, Portugal,
Group of the European People's Party (EPP)

"Our health systems need organizational improvement in order to deal, in the best way possible, with pain patients; we are often concerned with the financial aspects of our national health systems, but first of all, we must prioritize quality of care, and promote patient-centred healthcare provision."

Theresa Griffin

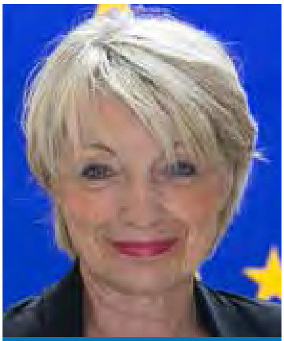
THERESA GRIFFIN, MEP

Member of the European Parliament, United Kingdom,
Group of the Progressive Alliance of Socialists and
Democrats (S&D)

"Throughout my political career I have held the strong belief that everyone should have access to quality employment – regardless of their circumstances. One difficult and underdebated barrier into work is poorly managed pain. Chronic pain and lack of proper holistic pain management often pushes individuals into early retirement, or keeps them out of work, when they would otherwise chose to keep working."

FRANÇOISE GROSSETÊTE, MEP
Member of the European Parliament, France,
Group of the European People's Party (EPP)

"I whole hardly support the objectives of the symposium on the Societal Impact of Pain where all stakeholders seek to improve pain policy under the motto "Time for Action!"."



Françoise Grossetête

MARIAN HARKIN, MEP
Member of the European Parliament, Ireland,
Group of the Alliance of Liberals and Democrats
for Europe (ALDE)

"The Societal Impact of Pain is a campaign I have supported for a number of years. Chronic pain can have a significant impact on patients individually as well as on our health systems and societies. This year I want other Members of the European Parliament to join me to push for improved policies affecting pain care."

Marian Harkin

Giovanni La Via

GIOVANNI LA VIA, MEP
Member of the European Parliament, Italy,
Group of the European People's Party (EPP)

Piernicola Pedicini

PIERNICOLA PEDICINI, MEP
Member of the European Parliament, Italy,
Europe of Freedom and Direct Democracy Group

"The SIP symposium is an important opportunity to address the issues of pain and cancer care."

Sabine Verheyen

SABINE VERHEYEN, MEP
Member of the European Parliament, Germany,
Group of the European People's Party (EPP)

"I consider pain treatment as extremely important because untreated pain can cause first and foremost great distress to the patients."

SIP 2017

Abstract & Background

MALTA EU2017

SIP

RED COOPERATION BETWEEN
ARE SYSTEMS TACKLING THE
CIETAL IMPACT OF PAIN!

#sip2017

MALTA
EU2017

SIP
Societal Impact of Pain

ENDORSING ORGANISATIONS

Since the start of the SIP platform the scientific objectives of the SIP symposia and events have been endorsed by the following organisations, listed in alphabetical order:

Please contact sip-platform@grunenthal.com if your organisation wants to be added to the list of endorser on the website https://www.sip-platform.eu or if the contact details or logos have changed.

1. **European Pain Federation EFIC®**
   www.efic.org

2. **Grünenthal GmbH**
   www.grunenthal.com

3. **Pain Alliance Europe (PAE)**
   www.pae-eu.eu

4. **Cittadinanzattiva**
   http://www.cittadinanzattiva.it/

5. **Malta Health Network**
   www.maltahealthnetwork.org

6. **No Pain Foundation**
   www.nopainfoundation.org

7. **Academia de Ciencias Médicas de Bilbao**
   www.acmbilbao.org

8. **ACTHealthy Lab, ALGEA Group University of Cyprus**
   www.algea.com.cy

9. **Action on Pain**
   www.action-on-pain.co.uk/

10. **AGE Platform Europe**
    www.age-platform.eu

11. **Agencia de Calidad Sanitaria de Andalucia**
www.juntadeandalucia.es/agenciadecalidadsanitaria

12. **Albanian Pain Association**
www.health-pain.al/

13. **ALGOS. Recerca en dolor**
algos-dpsico.urv.cat/es/

14. **Allianz Chronischer Schmerz Österreich – Alliance Chronic Pain Austria**
www.schmerz-allianz.at

15. **ALPADOC – Association Luxembourgeoise des Patients à Douleurs Chroniques**
www.alpadoc.lu

16. **Alvleesklierververeniging Nederland AVKV**
www.alvleesklierververeniging.nl/ik-ben-patient.aspx

17. **Arthiritis and Rheumatism Association of Malta**
www.aramalta.com

18. **ASL 4 Teramo**
fabiana.dantonio@aslteramo.it

19. **Asociación Andaluza del Dolor**
www.asociacionandaluzadeldolor.es/

20. **Asociación Corunesa de Fibromialgia y Síndrome de Fatiga Crónica (ACOFIFA)**
www.acofifa.org

21. **Asociación de Fibromialgia y Sindrome de Fatiga Cronica de la Comunidad de Madrid (AFINSYFACRO)**
www.afinsyfacro.es/

22. **Asociación española de enfermería de anestesia-reanimación y terapia del dolor (aseedar-td)**
www.aseedar-td.org

23. **Asociación Nacional de Enfermería Comunitaria (AEC)**
www.enfermeriacomunitaria.org

24. **Asociacioni Shëndetësor Profesional**
www.pha-ks.com

25. **Associação Atlântica de Apoio ao Doente Machado Joseph**
http://www.aaadmj.com/

26. **Associação de Doentes de Dor Crónica Açores (ADDCA)**
addcacores@iol.pt, addcadirecao@iol.pt

27. **Associacao Portuguesa de cuidados Paliativos - Nucleo Regional des Azores**
www.apcp.com.pt

28. **Associacao Portuguesa de cuidados Paliativos**
www.apcp.com.pt

29. **Associacao Portuguesa para o Estudo da Dor**
www.aped-dor.org

30. **Association Extremena de Fibromialgia**
www.afibroex.com/

Association for Pain Therapy Bosnia and Herzegovina
www.apt-bh.ba
31.

Association francaise de la cystite interstitielle (AFCI)
www.asso-afci.org
32.

Association Francophone pour Vaincre les Douleurs (AFVD)
www.association-afvd.com
33.

Associazione Italiana per lo Studio del Dolore (AISD)
www.aisd.it
34.

Associazione Sammarinese per lo Studio del Dolore
www.assd-rsm.org
35.

BackCare, The Charity for Back and Neck Pain
www.backcare.org.uk/
36.

Belgian Back Society
www.belgianbacksociety.be
37.

Belgian Pain Society
www.belgianpainsociety.org
38.

Berufsverband der Ärzte und Psychologischen Psychotherapeuten in der Schmerz- und Palliativmedizin in Deutschland e.V.
www.bv-schmerz.de
39.

Berufsverband Deutscher Anästhesisten e.V. BDA
www.bda.de
40.

41. **Bijniervereninging NVACP**
www.nvacp.nl

42. **Bildungswerk Aachen: Servicestelle Hospizarbeit für die Städte Region Aachen**
www.servicestelle-hospizarbeit.de

43. **Brain, Mind and Pain (MEP Interest Group)**
www.brainmindpain.eu

44. **Brigada de Sanidad del Ejército de Tierra Ejército Españo**
fconben@et.mde.es

45. **British Pain Society**
www.britishpainsociety.org

46. **Bulgarian Association for Study and Treatment of Pain (BASTP)**
www.rtb-mu.com/anestsoc

47. **Bürger Inititative Gesundheit e.V.**
www.buerger-initiative-gesundheit.de

48. **Catedra de Dolor Infantil, Universitat Roviar I Virgili**
www.catedradeldolor.com

49. **CEADE Coordinadora Espanola de Asociaciones de Espondilitis**
www.espondilitis.es

50. **Center for Palliative Medicine, Medical Ethics and Communication Skills**
www.mef.unizg.hr

CHANGE PAIN Initiative
www.change-pain.com/ 51.

Chronic Pain Ireland
www.chronicpain.ie/ 52.

Chronic Pain Policy Coalition CPPC
www.policyconnect.org.uk 53.

CLA - Cercle Luxembourgeois d'Algologie
Zithaklinik (Clinique de la douleur)
www.douleurs.lu 54.

Colegio Oficial de Medicos de Caceres
www.comeca.org 55.

Collectif Doloplus
www.doloplus.com/ 56.

Conartritis (Coodinadora Nacional de Artritis)
www.conartritis.org/ 57.

Consejo Andaluz de Colegios Farmaceuticos
www.cacof.es 58.

COST Action TD1005 – Pain Assessment in Patients with Impaired Cognition, especially Dementia
www.cost-td1005.net 59.

Croatian Association for the Treatment of Pain (CATP)
www.hdlb.org 60.

61. **Cystitis & Overactive Bladder Foundation COB**
www.cobfoundation.org

62. **Deustche Gesellshaft zum Studium des Schmerzes e.V. DGGS**
www.dgss.org/

63. **Deutscher Forschungsverbund Neuropathischer Schmerz**
dfns@lrz.tum.de

64. **Deutsche Gesellschaft für Anästhesiologie und Intensivmedizin (DGAI)**
www.dgai.de

65. **Deutsche Gesellschaft für Neurologie**
www.dgn.org

66. **Deutsche Gesellschaft für Orthopädie und Orthopädische Chirurgie e.V. (DGOOC)**
www.dgooc.de

67. **Deutsche Gesellschaft für Psychologische Schmerztherapie und - forschung (DGPSF)**
www.dgpsf.de

68. **Deutsche Gesellschaft für Schmerztherapie e.V. (DGS)**
www.dgschmerztherapie.de/

69. **Deutsche Kinder Palliativ Stiftung**
www.palliativ-portal.de/

70. **Deutsche Palliativ Stiftung**
www.PalliativStiftung.de/

Deutsche Schmerzgesellschaft e.V.
www.dgss.org
71.

Deutsche Schmerzliga e.V.
www.schmerzliga.de/
72.

Deutsche Seniorenliga e.V.
www.deutsche-seniorenliga.de/
73.

Deutsche Wachkoma Gesellschaft
www.schaedel-hirnpatienten.de
74.

Deutscher Orthopäden-Verband e.V. (DOV)
www.dov-online.de
75.

DGVP e.V. fur Gesundheit Deutsche Gesellschaft für Versicherte und Patienten
www.dgvp.de
76.

Direcao Regional de Saude - Plano Regional de Saude 2014-16
www.azores.gov.pt
77.

Douleurs sans Frontières
www.douleur.org
78.

Dutch Pain Society
www.dutchpainsociety.nl
79.

Dwarslaesie Organisatie Nederland
www.dwarslaesie.nl
80.

81. **Endometriosis Association of Ireland**
www.endometriosis.ie

82. **Escuela Canaria de Salud y Servicios Sociales (ESSSCAN)**
www.essscan.es

83. **Estonian Pain Society**
www.valu.ee

84. **EURAG Österreich**
www.dgvp.de

85. **European Academy of Neurology EAN**
www.eaneurology.org

86. **European ADPKD Forum EAF**
www.pkdinternational.org/
eaf_adpkd_forum_policy_report_2015/

87. **European Association for Palliative Care EAPC**
www.eapcnet.eu

88. **European Brain Council**
www.europeanbraincouncil.org/

89. **European Cancer Patient Coalition (ECPC)**
www.ecpc.org

90. **European College of Neuropsychopharmacology**
www.ecnp.eu

European Confederation of Care Home Organisations ECHO
www.echo-eu.com
91.

European Digital Peer Patient Alliance EUDiPPA
Facebook: /EUDIPPA/
92.

European Federation of National Associations of Orthopaedics and Traumatology (EFORT)
www.efort.org/
93.

European Federation of Neurological Associations (EFNA)
www.efna.net
94.

European Headache Alliance
www.e-h-a.eu
95.

European League Against Pain EULAP
www.eulap.org
96.

European Network of Fibromyalgia Associations
www.enfa-europe.eu/
97.

European Patient Forum EPF
www.eu-patient.eu
98.

European Platform for Patients' Organisations, Science and Industry (EPPOSI)
www.epposi.org/
99.

European Society for Regional Anaesthesia & Pain Therapy (ESRA)
www.esraeurope.org
100.

101. **European Society of Physical and Rehabilitation Medicine**
www.esprm.net/

102. **Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP)**
www.faecap.com

103. **Federalno Ministravo Zdravstva**
www.fmoh.gov.ba

104. **Federdolore-Società Italiana dei Clinici del Dolore**
www.federdolore.it

105. **Fibromyalgia Association of Sweden**
www.fibromyalgi.se

106. **Fibromyalgie en Samenleving (F.E.S.) - De Nationale Vereniging voor Fibromyalgiepatiënten**
www.fesinfo.nl

107. **Fit for Work Global Alliance**
www.fitforworkeurope.eu

108. **Focus Fibromyalgia Belgium ASBL**
www.focusfibromyalgie.be

109. **Fondazione IRCCS Intituto Nazionale dei Tumori di Milano**
www.istitutotumori.mi.it

110. **Fondazione ISAL**
www.fondazioneisal.it

Fondazione ISTUD
www.fondazioneistud.it
111.

Fondazione Paolo Procacci
www.fondazioneprocacci.org/
112.

Força 3P - Pessoas com Dor
www.forca3p.pt
113.

Foreningen Af Kroniske Smertepatienter (FAKS)
www.faks.dk
114.

Foro Espanol de Pacientes (FES)
www.webpacientes.org/fep
115.

Foundation Pijn-Hoop
www.pijn-hoop.nl/
116.

Fundació Acadèmia de Ciències Mèdiques i de la Salut de Catalunya i de Balears
www.academia.cat
117.

Fundacio Salut I Envelliment UAB
www.salut-envelliment.uab.cat
118.

Fundación Afectados y Afectadas Fibromialgia y Síndrome Fatiga Crónica
www.fundacionfatiga.org/
119.

Fundación para la Investigación en Salud (Fuinsa)
www.fuinsa.org/
120.

121. **Fundación Signo**
www.fundacionsigno.com

122. **Fundacja Chustka**
www.fundacjachustka.pl

123. **Funde Salud**
www.fundesalud.es

124. **Fundolor (Fundacion de la comundidad valenciana para el estudio y tratamiento del dolor)**
www.fundolor.org

125. **Generalitat Valenciana - Conselleria De Sanitat**
www.san.gva.es

126. **Geriatric Medicine Society e.V.**
www.geriatric-medicine.org

127. **German Maltese Medical Society**
www.germanmaltesecircle.org/gmms.htm

128. **Getidor: Grupo de Estudio, Trabajo e Investigación del Dolor Crónico en Rehabilitación**
xoan.miguens.udc.mais@gmail.com

129. **Gobierno de Canabria, Consejeria de Sanidad y Servicios Sociales**
leon_c@cantabria.es; hoyos_e@cantabria.es

130. **Health First Europe Secretariat**
www.healthfirsteurope.org

Hellenic Society of Agology
www.algologia.gr
131.

Hellenic Society of Palliative and Symptomatic Care of Cancer and non Cancer patients
www.grpalliative.org/
132.

Hereditaire Multiple Exostosen - Multiple Osteochondromen HME-MO
www.hme-mo.nl
133.

Herescon gmbh
www.herescon.com
134.

Hrvatsko Drustvo Palijantivnu Medicinu HLZ
www.palijativa.com
135.

Institut Català d'Oncologia
www.ico.gencat.cat
136.

Institut national d'assurance maladie-invalidité
www.riziv.fgov.be
137.

Institute for Research in Operative Medicine (IFOM)
www.uni-wh.de/ifom
138.

Instituto Aragonès de Ciencias de la Salud
www.iacs.aragon.es
139.

Instituto de Estudios de Ciencias de la Salud de Castilla y León
www.iecscyl.com
140.

141. **Instituto Mediterráneo de Dolor y Anestesia Regional (IMEDAR)**
www.imedar.com

142. **Instituto para el estudio y tratamiento integral de Dolor (IETID)**
www.ietd.es

143. **International Alliance of Patients' Organizations (IAPO)**
www.patientsorganizations.org

144. **International Association for Hospice and Palliative Care**
www.hospicecare.com

145. **International Headache Society**
www.ihs-headache.org

146. **International Painful Bladder Foundation (IPBF)**
www.painful-bladder.org

147. **IPO Porto**
carocha321@hotmail.com

148. **Irish Pain Society**
www.irishpainsociety.com

149. **Israel Pain Association**
www.ipa.org.il

150. **Italian Presidency of the Council of Ministers**

Junta de Andalucia - Consejeria de Salud y Bienestar Social www.juntadeandalucia.es/organismos/saludybienestarsocial.html	151.
L'Association Française de Lutte Anti-Rhumatismale francoisealliotlaunois@gmail.com	152.
Latvian Association for Study of Pain - LASP www.sapes.lv	153.
LeukaNET e.V. www.leuka.net/	154.
Lietuvos Skausmo Draugija www.skausmomedicina.it	155.
Lifting the Burden www.l-t-b.org/	156.
Liga Portuguesa Contra as Doencas Reumaticas www.lpcdr.org.pt	157.
Liga Reumatològica Catalana www.lligareumatologica.org	158.
Liga Reumatologica Espanola www.lire.es	159.
Liga Reumatológica Gallega (LRG) www.ligagalega.org	160.

161. **Malta Association of Physiotherapists**
www.physiomalta.com

162. **ME/CVS-Stichting Nederlands**
www.mecvs.nl

163. **MedAix Training GmbH / MedAix Laurensberg GmbH**
www.medaix.de

164. **Medicinska fakulteta Univerze v Mariboru**
www.mf.uni-mb.si/index.php/en

165. **Metges de Residències Geriàtriques del Vallès**
josep.sanchez.aldeguer@uab.cat

166. **Moldovian Society for the Study and Management of Pain**
www.neverpain.org

167. **Multinational Interstitial Cystitis Association (MICA)**
www.mica-online.org

168. **Myeloma Euronet Romania**
www.myeloma.ro/

169. **National Association of Patients with Rheumatoid Arthritis (ANDAR)**
www.andar-reuma.pt

170. **National Council for Palliative Care (NCPC)**
www.ncpc.org.uk

Nederlands Interstitial Cystitis Patients Organization (ICP) 171.
www.icpatienten.nl/

Nederlandse Vereniging van Hoofdpijnpatienten 172.
www.hoofdpijnpatienten.nl

Nederlandse Vereniging van Patienten met Sternocostoclaviculaire Hyperostose (SCCH) 173.
www.scch.nl

Nederlandse Vereniging van Rugpatiënten "de Wervelkolom" 174.
www.nvvr.nl

Neil Betteridge Associates 175.
neil@neilbetteridge.me.uk

Neurologiskt Handikappades Riksforbund 176.
www.nhr.se

Norsk Revmatikerforbund 177.
https://www.revmatiker.no

OSAKIDETZA - Departemento de la Salud del Gobierno Vasco 178.
www.osakidetza.euskadi.net

Osservatorio Italiano Cure Palliative (OICP) 179.
www.oicp.org

Osteoporose Vereniging 180.
www.osteoporosevereniging.nl

181. **Österreichische Gesellschaft für Geriatrie und Gerontologie ÖGGG**
www.geriatrie-online.at

182. **Österreichische Schmerzgesellschaft**
www.oesg.at/

183. **Österreichisches Rotes Kreuz**
www.roteskreuz.at

184. **Pain Alliance of Northern Ireland**
Twitter: @PainAllianceNI

185. **Pain Association Scotland**
www.chronicpaininfo.org

186. **Pain Concern**
www.painconcern.org.uk/

187. **Pain Nursing Magazine – Italian Online Journal**
www.painnursing.it

188. **PAIN OUT - improvement in postoperative PAIN**
www.pain-out.eu

189. **Pain Research Forum**
www.painresearchforum.org

190. **PAIN South Africa (PAINSA)**
www.painsa.co.za

Pain Toolkit
www.paintoolkit.org 191.

Pain UK
www.painuk.org 192.

Painaustralia
www.painaustralia.org.au/ 193.

Paliativos Andalucia
www.paliativosandalucia.com 194.

Palliactief
www.palliactief.nl/ 195.

Palliatives Netzwerk für die Region Aachen e.V.
www.servicestelle-hospizarbeit.de/ 196.

Patienten Vereniging Voor Neurostimulatie (PVVN)
www.pvvn.nl 197.

Patientenschutzorganisation Deutsche Hospiz Stiftung
www.patientenschuetzer.de 198.

Patientenvereniging CRPS
www.posttraumatischedystrofie.nl 199.

Pelvic Pain Support Network
www.pelvicpain.org.uk/ 200.

201. **Personskadeförbundet RTP**
www.rtp.se

202. **Pijn Platform Nederland (PPN)**
www.pijnplatform.nl/

203. **Plataforma SinDOLOR**
www.plataformasindolor.com/

204. **Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka**
www.szpiczak.org.pl

205. **Polskie Towarzystwo Badania Bolu**
www.ptbb.pl/

206. **Portuguese League Against Rheumatic Diseases (LPCDR)**
www.lpcdr.org.pt

207. **Presidenza della Regione Abruzzo**
www.regione.abruzzo.it/

208. **Prikkelbare Darm Syndroom Belangenvereniging**
www.pdsb.nl

209. **Programa de Prevenció i Atenció a la Cronicitat**
www.canalsalut.gencat.cat

210. **Red Espanola para Defensa de los Enfer Rede FM Sfc y Sqm**
www.facebook.com/Red-Espa%C3%B1ola-de-FM-SFCSQM-366279756915804/

Romanian Association for the Study of Pain (RASP)
www.arsd.ro
211.

RSI-Vereniging
www.rsi-vereniging.nl
212.

Russian Association for the Study of Pain (RASP)
www.painrussia.ru
213.

Russian Headache Research Society
www.headache-society.ru
214.

Samenwerkingsverband Pijnpatiënten naar een stem
www.pijnpatientennaar1stem.nl
215.

Sant Joan de Deu Hospital
www.hsjdbcn.org
216.

SARquavitae
www.sarquavitae.es
217.

SchmerzNetzNRW eG
www.schmerznetznrw.org
218.

Schweizer Gesellschaft zum Studium des Schmerzes
www.pain.ch/
219.

Schweizerische Kopfwehgesellschaft SKG
www.headache.ch
220.

221. **Shingles Support Society**
www.herpes.org.uk/shingles-support-society

222. **SINE DOLORE –**
Asociación Española de Pacientes Contra el Dolor
www.sinedolore.org

223. **SLOVENSKÁ SPOLOČNOSŤ PRE**
ŠTÚDIUM A LIEČBU BOLESTI
www.pain.sk/

224. **Slovensko združenje za lajšanje bolečine**
www.szzb.si/

225. **Sociedad Andaluza de Geriatría y Gerontología**
(SAGG)
www.sagg.org

226. **Sociedad Andaluza de Medicina Fisica y Rehabilitacion**
SAMFYRE
www.samfyre.net/

227. **Sociedad Aragonesa del Dolor**
www.sociedadaragonesadeldolor.sedolor.es

228. **Sociedad Aragonesa de Cuidados Paliativos**
www.cusirar.org

229. **Sociedad Asturiana de Medicina Física y Rehabilitación**
www.samefyr.com

230. **Sociedad Canaria del Dolor (SCD) – Canarian**
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Sociedad Espanola de Directives de Atención Primaria (SEDAP) www.sedap.es	237.
Sociedad Española de Directivos de la Salud (Sedisa) www.sedisa.net/	238.
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Societat Catalano-Balear de Cures Palliatives (SCBCP)
webs.academia.cat/societats/curespal
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Societé Francaise d' Etude et de Traitement de la Douleur (SFETD)
www.sfetd-douleur.org/
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Spanish Association of Patients with Neuropathic pain, Trigeminal neuralgia and mporomandibular pathology
www.pacientesatm.com
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Study in Multidisciplinary Pain Research SIMPAR
www.simpar.eu
275.

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www.suomenkipu.fi
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Swedish Pain Society
www.swedishpainsociety.com/
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Swiss Migraine Action
www.migraine.org.uk/
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Syringomyelie Patienten Vereninging
www.syringo-chiari.info
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281. **The Office of the Commissioner for Mental Health (CMH-Malta)**
http://www.mentalhealthcommissioner.gov.mt/

282. **The Pain Clinic**
http://www.painclinic.com.mt

283. **The Work Foundation**
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284. **Trigeminal Neuralgia Association**
www.tna.org.uk/

285. **Udruženje za Istraživanje i Tretman Bola Srbije (UITBS)**
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307. **Young Against Pain (YAP)**
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