“Pain must not rule our lives. Effective management of pain is a fundamental right for all.”

(Robert Johnstone, IAPO Board Member and patient advocate)

Over four hundred people from more than 30 countries attended the SIP 2012, 3rd Societal Impact of Pain Symposium at the ultra-modern, twin tower Bella Sky hotel and conference centre in Copenhagen, 29-31 May 2012, a meeting held during the Danish EU presidency. It was a truly multi-stakeholder meeting, with doctors from many disciplines dealing with chronic pain patients, health authorities, European Parliament, EU Commission DG Sanco, pharmaceutical industry and last but certainly not least representatives from many patient organisations focused on pain or diseases and conditions causing chronic pain, all with the aim of raising awareness on the societal impact of pain, exchanging national best practices and fostering European and national pain care policy projects. Jane Meijlink (IPBF) and Francoise Watel (AFCI France) were there to represent the IC patients.

The SIP 2012 symposium took place under the high patronage of the Italian Presidency of the Council of Ministers and the Italian Ministry of Health and was hosted by the Danish Association for Chronic Pain Patients (FAKS). The scientific framework of SIP 2012 was under the responsibility of the European Federation of IASP® Chapters (EFIC®), while the pharmaceutical company Grünenthal GmbH was responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP 2012 symposium were endorsed by more than 160 pain-related advocacy groups and scientific organisations.

“Marketplace” for endorsing patient organisations

The “Marketplace” was a great idea at SIP 2012 which could be adopted by other congresses since it took up relatively little space. Patient advocacy organisations and other non-profits who had endorsed SIP 2012 were provided with complimentary tables on which to display their information leaflets and brochures and from which much networking took place.

Pain Alliance Europe (PAE) had high profile at SIP

The new Pain Alliance Europe (President: Joop van Griensven, website: http://www.pae-eu.eu) took advantage of the opportunity to hold a general assembly of its members immediately prior to the start of the symposium in Denmark. The PAE enjoyed a high profile at this SIP symposium, with Joop van Griensven playing a leading role on many session panels. He and other PAE members, together with representatives from other patient organisations including the Danish FAKS, gave presentations on the patient perspective.

What is SIP?

The Societal Impact of Pain (SIP) is an international, multi-stakeholder platform created in 2010 and aims 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 and activities for an improved pain care in Europe.

The platform provides opportunities for discussion for healthcare professionals, pain advocacy groups, politicians, insurance companies, representatives of health authorities, regulators and budget holders. Further information can be found at www.sip-platform.eu.
Cost of chronic pain a great challenge
As noted by Professor Hans Kress (President EFIC), 500 million illness days are lost in the EU due to chronic pain and the cost of chronic pain within the EU is estimated as at least 35 billion euro per year. It is an economic, medical and societal burden that represents a great challenge. From a Danish perspective, Health Policy Manager Martin K. Pedersen from the Danish Chamber of Commerce described his view from an economic perspective: “The economic impact of pain is greater than most other health conditions. In Denmark it has been estimated that 1 million working days are lost annually as a result of chronic pain and in Sweden it has been suggested that the loss of productivity due to sick leave resulting from chronic pain constituted 91% of the socioeconomic cost of 9.2 billion Euros associated with the problem.”

“Reflection process on chronic diseases in the EU – the role of chronic pain”
The report “Reflection process on chronic diseases in the EU – the role of chronic pain” published during the symposium on 30 May, underlined that the overall impact of pain measured in terms of prevalence and cost is high. Anna Rosbach, Danish Member of the European Parliament, supported the findings of the report: “Chronic pain is a burden to millions of people in Europe. Because the pain is chronic it is often not considered a disease by society and health care systems. This must be changed. Chronic pain should no longer be given less attention and care than temporary pain.”

Positioning paper acknowledges chronic pain as a disease in its own right: European policy-makers challenged to respond
During SIP 2012, this European multi-stakeholder expert group finalised their positioning paper, demanding acknowledgement of chronic pain as a disease in its own right by EU governmental institutions and member state governments.

Webcasts:
The symposium presentations and statements can be enjoyed online as webcasts:
Webcasts for 30 May - plenary: http://www.sip-platform.eu/plenary-30-may.html
Webcasts for 31 May - plenary: http://www.sip-platform.eu/plenary-31-may.html

Workshops
Six workshops were held on the first symposium day. On the second day, findings from the special interest groups and workshops were presented and discussed

Workshop 1: Chronic Diseases: Chronic pain as a disease in its own right
The ICD-11 issue was also dealt with in Workshop 1: Chronic Diseases: Chronic pain as a disease in its own right which was live-web streamed for a worldwide audience.
The European Commission intends to support member states in a reflection process on chronic diseases to optimise the response. The workshop’s objective was therefore to investigate the position of pain in relation to chronic diseases and identify risk factors for a large number of chronic diseases which have pain as a concomitant disease and to produce a position statement on pain in relation to chronic diseases.
This workshop discussed the future position of chronic pain among ICD categories. ICD is the World Health Organisation International Classification of Diseases. The current ICD is ICD-10. ICD-11 is currently under development. Dr Robert Jacob from the World Health Organisation spoke to workshop delegates via a video connection about the development of ICD-11. The aim is to make the new ICD suitable for the new electronic health record environments and will operate in multiple languages. Dr Jacob also explained the definition of the term disease by the WHO.
Recognition of chronic pain as a disease in ICD-11 was extensively discussed and the majority voted in favour. However, not everyone was entirely convinced about the feasibility of this, some expressing doubts, in particular workshop co-chair Professor Eija Kalso (Finland) who is also president of the International Association for the Study of Pain (IASP).
It was noted that ICD-10 does not distinguish acute from chronic pain: so that all pain has simply been considered as a symptom of other disorders.
Delegates to this workshop wanted to see better education: to persuade healthcare professionals to consider the wider aspects of pain. They also underlined that “governments won’t act until they see that chronic pain is a trillion dollar economic opportunity that will also improve total quality of life for citizens.” Chronic pain needs cooperation between physicians, researchers, authorities, industry, stakeholders.

Professor Hans Kress (President EFIC) underlined the importance of chronic pain being seen as a different entity to acute pain. Acute pain has a biological warning function and is mainly not difficult to treat. Chronic pain is completely different and needs to be made visible.

Dr Stefano Coaccioli from Italy pointed out that the economic cost does not just concern medicine, but also a reduction in income generation. One of the biggest problems is non-specific pain where treatment is often not reimbursed by insurers.

Sean McDougal from Pain UK emphasised that chronic pain is one of the major reasons for seeking medical help, for early retirement and for discontinuation of work. Chronic pain represents a huge economic burden worldwide. And yet it is hard to sell chronic pain as an issue because it is fragmented and difficult to quantify.

**Workshop 2: Active & Healthy Ageing: Pain management for an improved quality of life.**

(Webcasts: [http://www.sip-platform.eu/155.html](http://www.sip-platform.eu/155.html))

Since the elderly represent one of the biggest growth markets, this group should be an important focus of attention. Concerning an ageing population and the increased prevalence of pain, a report on “Healthy ageing in relation to chronic pain in the European Union” has been published: key findings show that the quality of life increases significantly with the reduction of pain. With regard to the strong link between increasing age and chronic pain, adequate management of chronic pain may lead to improved quality of life and consequently healthier and more active ageing. The challenges of an ageing society were described by Orsi Nagy, policy analyst from the EU Commission (DG Sanco) and responsible for the European Innovation Partnership on Active and Healthy Ageing: “The ageing of society is not only one of the greatest achievements of the 21st century, but also a social and economic challenge for the European society. We have to commit ourselves to providing care to those in need, whilst giving ample opportunities to those that are active and healthy to continue to contribute to society.”

**Workshop 3: Improving pain management: Delivery results in best practice cooperation models.**

(Webcasts: [http://www.sip-platform.eu/156.html](http://www.sip-platform.eu/156.html))

This workshop discussed:

1. The cost to society – uninformed patients/practitioners referral practices.
2. Alternatives to traditional models of care – improved outcomes for practitioners and patients and reduced costs.
3. Why is best practice not universally adopted?

Ann Lloyd from the UK Patients Association took a look at what success should look like: it means satisfied patients with improved quality of life and care that is centred on their needs; satisfied therapists and good multidisciplinary cooperation; happy commissioners, employers and politicians because of reduced costs and improved outcomes; and finally better informed users and practitioners.

**Workshop 4: Benchmarking, education and research programmes on pain management in the European Union.**


This workshop concluded that while much has been achieved, a great deal still has to be done in the near future. Pain and the societal impact of pain should be on the agenda of all national and international institutions. Pain should be considered as a major health problem for society, impacting high costs. There is a high need for stability in funding for research and education and for pain care. Pain education needs to be implemented in academic and professional organisations.

**Workshop 5: Establishing multi-stakeholder pain platforms in Europe.**

(Webcasts: [http://www.sip-platform.eu/158.html](http://www.sip-platform.eu/158.html))

The purpose of this workshop was to share experiences on how far the “Road Map for Action” resulting from the previous SIP symposia has evolved within various countries in Europe and share best practice. 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. So far national action plans at governmental level exist in Portugal, France, Italy, Scotland and Wales.

Anna Rosbach, independent Danish member of the European Parliament, said that while chronic pain is a burden to millions of people in Europe, it is unfortunately often not given the same level of attention as chronic diseases by society, governments and health care systems. One reason for this can be that pain in many ways is less obvious to outsiders than many diseases are. She also said that we must ensure that chronic pain is approached in the same way we would if it was a disease. A very important first step towards this is to get chronic pain acknowledged on level with chronic diseases in all member countries. In order to achieve this, we need ways to show how important a factor pain can be for those who suffer from it. To do this, we need to try and measure it. Anna Rosbach also emphasised that patients need to be organised on a European level in order to create a strong voice. Efforts must be combined and we need to exchange our experiences with prevention and treatment across borders.

Workshop 6: Outlook of future pain management.
(Webcasts: http://www.sip-platform.eu/159.html)

This workshop gave delegates the chance to discuss future trends in policy-making for pain care. Dr Elisabetta Vaudano, giving a presentation on the organisation Europain, underlined that better pain treatment will reduce the socio-economic burden for patients and society. Pia Frederiksen from FAKS emphasised that interdisciplinarity is a necessity. Patients should early be examined from a holistic perspective. Both physically, mentally and socially. We have to realise that no two pain patients are alike, we must ensure an interdisciplinary, individual and qualitative treatment of each patient. She also observed that when you consider that one in five Europeans suffers from chronic pain, it is quite remarkable that it is not an area that is being taken more seriously. Robert Johnstone, patient advocate, emphasised the importance for the future of patient-centred healthcare, the Mind Body Spirit approach, patient reported outcome measures (PROMS) and the autonomy of the patient in society.

This review began with one quotation from Robert Johnstone and I would like to end with another:

“It’s good to be better, but it’s better to feel good.”

Further information:
More information on SIP available at www.sip-platform.eu

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