

WHO WE ARE

The personal and socio-economic impact of acute and chronic pain within and beyond health systems, illustrates the urgency for European governments and the EU institutions to put the societal impact of pain on their policy agenda. To this end the European Pain Federation (EFIC®, a federation of scientific societies), Pain Alliance Europe (PAE, a federation of patient advocacy groups), Active Citizenship Network (ACN) and the pharmaceutical company Grünenthal GmbH joined forces to initiate the **Societal Impact of Pain (SIP) platform** in 2009. Today SIP is a multi-stakeholder platform that promotes better care for patients with acute and chronic pain. The scientific aims of SIP have been endorsed by over 300 international and national pain advocacy groups, scientific organisations and authorities (SIP, 2018).

WHY THIS PAPER

In 2018, the European Commission will make comprehensive proposals for the next generation of financial programmes for the post-2020 Multiannual Financial Framework. As part of this process, the Commission has opened a public consultation on EU funds in the area of investment, research & innovation, SMEs and single market. The SIP platform would like to take an active part by responding to the public consultation and sending this position paper to highlight the importance of strengthening pain research (basic science, clinical science, epidemiological research) as a priority in the EU 9th Framework Program (FP9).

OUR CALL TO ACTION

Basic and clinical sciences have demonstrated the feasibility of care pathways for pain management in all types of acute and chronic pain, but healthcare systems frequently do not guarantee general access for patients to these. Furthermore, many mechanisms of pain as a biopsychosocial phenomenon are not fully understood: this is true at the molecular and cellular level, and even more so at a behavioural and social level, when it comes to a comprehensive understanding of the individuals suffering from pain and their social environment both at home and in the work place. How can we tackle the burden of pain on individuals and societies if we don't monitor its severity (magnitude, distress and disability), assess its mechanisms and explore solutions to address it in a holistic manner?

To respond to this challenge, we ask for increased investment in research (basic science, clinical science, epidemiological research) on the societal impact of pain as a priority in future EU framework programmes and in particular in FP9.

THE BURDEN OF PAIN

Being a major symptom in many medical conditions, pain can interfere with a person's quality of life and general functioning. People in pain can experience impairments in attention, control, working memory, mental flexibility, problem solving and information processing speed (Hart, Wade, & Martelli, 2003). Pain is associated with increased depression, anxiety, fear, and anger (Bruehl, Burns, Chung, & Chont, 2009). In the presence of chronic pain, other dimensions of health (physical, psychological, social) are severely reduced (Elliott, Smith, Penny, Chambers, & Smith, 1999) (Smith, et al., 2001). Chronic pain is related to low self-rated health in the general population (Mäntyselkä, Turunen, Ahonen, & Kumpusalo, 2003). Moreover, severe chronic pain is associated with an increased risk of ten-year mortality, independent of socio-demographic factors (Torrance, Elliott, Lee, & Smith, 2010). In daily life, risk factors associated with chronic pain include socio-demographic, clinical, psychological and biological factors. as pain increases the risk of other social problems, including social exclusion, loss of income and can even result in poverty (van Hecke, Torrance, & Smith, 2013) (Pain Concern, 2016) (Phillips, et al., 2008). Pain is

commonly connected with numerous chronic health conditions, such as cancer and musculoskeletal diseases (Roberto, et al., 2016) (Majithia, Loprinzi, & Smith, 2016) (IASP, 2009) (Mieritz, Forman, Mieritz, Hartvigsen, & Christensen, 2016). Indeed, chronic pain is one of the most common co-morbidities of other long-term illnesses (Barnett, et al., 2012). And yet there is no comprehensive estimation of the biopsychosocial burden of pain due to insufficient coding in current health care statistics. However, the epidemiological data we do have paint a troubling picture. Chronic pain affects at least 20% of the adult population in Europe. Musculoskeletal and joint pain, back pain, neuropathic pain, abdominal pain, and headache dominate (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). A large proportion of physician visits are caused by pain complaints (Gureje, Simon, & Von Korff, 2001) (Mäntyselkä, et al., 2001) (Koleva, 2005). Therefore, pain places a severe strain on the individual but also on society, including an enormous economic burden to health care systems (Eccleston, Wells, & Morlion, 2017). Experts estimate that half of all citizens living in the EU at some point in their lives suffer from back pain. Approximately 15 percent of these citizens with back pain are on sick leave for over one month (Bevan, et al., 2009). Worldwide chronic pain conditions (in particular back pain) are by far the greatest cause of disability (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, Reducing Temporary Work Absence Through Early Intervention: The case of MSDs in the EU, 2013). Unsurprisingly chronic pain is one of the major reasons why people exit the labour market prematurely and it contributes significantly to disability retirement (Saastamoinen, et al., 2012).

EXISTING POLICIES AND NEW DIRECTIONS

On behalf of pain patients, their families, health care professionals and all involved in pain care, the partners of the **Societal Impact of Pain (SIP) platform**, are grateful for the EU support to pain research in the last decade. From 2007 to 2017, the European Commission had invested some €168 million in pain research. A concrete example is that pain has been mentioned in one call for proposal on [Novel patient-centred approaches for survivorship, palliation and/or end-of-life care](#) in the current 8th Framework Programme (FP8/Horizon 2020). But this amounts to less than 1% of health research funding by the EU, and the percentage for the United States National Institutes of Health has been similarly low. This funding level appears inappropriate for a condition that, both as a symptom and a disease, is the leading contributor to the global burden of disease (Vos, et al., 2016).

Under the Innovative Medicines Initiative (IMI and IMI2) a group of European pharmaceutical companies has made specific investments into funding pain research in Europe. This has resulted in the formation of several pain research consortia (e.g. EuroPain, NGN-PET, IMI-PainCare) that have made landmark contributions towards the development of new pain medicines. **We welcome these contributions and call for IMI funding to be maintained.** At the same time, we call for additional funding that can address non- pharmacological multimodal pain management approaches (physiotherapy, psychotherapy, interventions, surgeries).

We believe that existing EU plans will be beneficial to pain research in the future. We are pleased to see the recommendations of the recent report “Investing in the European future we want” on **prioritising research and innovation in EU and national budgets** (Lamy, et al., 2017). The Report also recommend **doubling the budget of the post-2020 EU research**

and innovation programme. We are convinced that **pain research is the ideal candidate for a mission-oriented approach** that the Commission plans to adopt in the upcoming FP9. In fact, given its crosscutting nature, pain should be considered as a quality indicator for the achievement of many health missions such as increase of healthy lifespan and life quality of cancer survivors. Pain management plays a crucial role in tackling musculoskeletal diseases, nervous system diseases, and noncommunicable diseases more broadly. **To this end, investing EU funds in the development of pain as a quality indicator will be of paramount importance to measure the impact of mission-oriented research.**

We support the Lamy Report's suggestion that partnerships (public-private and public-public) with industry, foundations and public authorities should be taken forward in as far as they mobilise joint investment in established missions, through a simple and flexible cofunding mechanism (Lamy, et al., 2017).

CHALLENGES YET TO ADDRESS

Despite the progress to date, there is a long way to go to address the **societal impact of pain** and an **increased focus on research is a key component** of this. For instance, the current call on 'novel patient-centred approaches for survivorship, palliation and/or end-of-life care' focuses only on a limited amount of pain-related areas. Pain affects more areas of life and thus more research is needed. Long-term survivors of cancer have different needs from patients with terminal cancer, successful treatment of chronic inflammatory diseases often leaves patients in a chronic pain state, many patients with diabetes suffer from a painful neuropathy, successful surgery may be associated with a residual post-surgical chronic pain. These are just a few examples where **pain started as a symptom**, but has turned into the **leading health complaint** over time, with its own biology, and its own functional consequences, and hence should be considered a **disease in its own right** (EFIC, 2001) (SIP Roadmap, 2011). Chronic pain is expected to be included in the 11th Revision of the International Classification of Diseases (ICD-11), due by 2018 (Treede, et al., 2015).

There is a need for EU funds to address the mismatch between clinical need and research investment in most of the EU-member states. **A critical task is to determine a pathway for the basic science study of pain pathophysiology, prevention, treatment and management of pain conditions, and to establish effective mechanisms for knowledge translation.**

While efforts have been exerted to bring the patient voice into research design, we have still a long way to go to consistently include the input of people living with pain. Another important recommendation of the Lamy Report is **to capture and better communicate the impact of research** (Lamy, et al., 2017). We see patient involvement in such aspects of research as key. Whilst the patient perspective is paramount in all health research areas, it is even more so in pain management, given the personal and multidimensional nature of the pain experience. Through its partners, e.g. PAE, and participating or endorsing organisations the **SIP platform** is ideally positioned to provide the patient perspective on pain research.

RECOMMENDATIONS FOR CONCRETE ACTIONS

Below we propose some concrete actions as examples on how to strengthen pain research in FP9: The examples below summarise a list of research priorities that has been compiled on behalf of the SIP platform by pain research experts drawing from different national research priority lists. The European Pain Federation is currently working on the development of a

roadmap for research to define the current gaps and challenges in pain research within the identified priority areas.

Epidemiology

- Initiate and fund a burden of disease study on the societal impact of chronic pain in Europe.
- Support an EU-wide survey on chronic pain, both as a symptom and as a disease (e.g. using the upcoming ICD-11 codes of chronic pain).
- Combine this study with a survey on the availability of multimodal pain management services (out-patient and in-patient).
- Explore patients' perspective on how the dialogue with healthcare professionals impacts patients treatment acceptance.

Creation of registries

- Create a sustainable EU-wide registry of acute surgical pain and postsurgical pain conditions.
- Systematically register data of the societal impact chronic- and cancer related pain.
- Make these registries accessible for data mining on innovative approaches towards prevention and management of chronic pain.

Clinical research

- Initiate a funding program on non-pharmacological pain management (physiotherapy, psychotherapy, interventions).
- Support research into efficacy of rehabilitation programs for chronic pain (cooperation with insurance companies).
- Support clinical research on better management of pain in the elderly.

Development of screening tools

- Develop screening tools for primary care use that facilitate differential diagnosis of different types of chronic pain (nociceptive, neuropathic, nociplastic) and allow risk-stratification of patients with common chronic conditions with respect to development and prevention of chronic secondary pain conditions (diabetes, rheumatoid arthritis, osteoarthritis, inflammatory bowel disorders, chronic neuropathic pain).
- Integrate efforts with WHO (ICF: international classification of functioning, disability and health) by validating a "generic chronic pain core set" for global clinical use.

e-Health (including m-health) in pain

- Support research on the evaluation of electronic media (e.g. digitalized patient diaries) and telemedicine for communication among healthcare professionals and between healthcare professionals and patients.
- Develop of web and mobile platforms for continuous medical education on pain, including guideline development and guideline support in pain medicine.
- Initiate funding for development of mobile health (m-health) technologies for patient empowerment and self-care in multimodal pain treatment.

Behavioural research

- Initiate a funding program to study the learning mechanisms that underlie the development of avoidance or endurance behaviours, as well as the social and contextual variables that counteract pain related disability and distress.

- Include patient's insights to improve health care professionals' communication skills.

Systems level research

- Initiate a funding program to study the processing of pain-related signals in the spinal cord and brain of humans and of simple model organisms.
- Support development of innovative diagnostic tools.

Cellular and molecular research

- Initiate a funding program to study the interactions of peripheral nerve terminals with surrounding tissue, the immune system and the vascular system, to understand the peripheral generation of pain signals in musculoskeletal, inflammatory or cancer conditions and its prevention.

Development of precision medicine

- Support innovative approaches towards a mechanism-based treatment of pain, including surgical, interventional, pharmacological, behavioural, physiotherapeutic and other techniques.

Prevention

- Initiate a funding program to study the efficacy of primary prevention programmes at the work place (targeted on prevention of back pain and headache, and on early return to work) and secondary prevention programmes in rehabilitation (targeted at patients with postsurgical pain, cancer pain, musculoskeletal pain, neuropathic pain ...).
- Study the prevention of (further) chronification of pain.

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If you have any questions or comments on this paper, the partners of the SIP platform are happy to discuss.

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