

SIP Stakeholder Forum Meeting Wednesday 16th October 2024 – 15h00-17h00 CET

Context

In Europe, there are approximately 740 million people, most of whom experience an episode of severe pain at some point in their life. For approximately 20 percent, that pain is chronic pain. This means that, at present, 150 million people are experiencing pain across Europe, approximately equal to the population of France and Germany combined.

In the year 2018, SIP introduced its Joint Statement, a pivotal document encompassing a comprehensive set of recommendations for the European Commission, Member States, and civil society to address and mitigate the societal repercussions of pain. These recommendations function as the overarching and guiding principles for SIP, and they are thoughtfully categorized into four key domains: health indicators, research, employment, and education.

The SIP Stakeholder Forum is dedicated to achieving several critical objectives:

- **Inclusivity:** It seeks to engage all pertinent healthcare professional, patient, and civil society organizations that share an interest in pain policy and related matters.
- **Collaboration:** The Forum serves as a platform for open dialogue, mutual promotion, and voluntary collaboration on SIP's initiatives and the projects and events of its individual members.
- **Expert Input:** It facilitates the invaluable contribution of expert insights and reviews of SIP's stances on various policy issues on a voluntary basis.
- **Policy Enhancement:** The Forum fosters collective efforts to reinforce and refine the policy positions advocated by the SIP platform, strengthening the influence and impact of the organization's policy endeavours.

The SIP team (the European Pain Federation EFIC and Pain Alliance Europe PAE), ensures the day-to-day management of the Stakeholder Forum. In accordance with the SIP governance model, the scientific framework of the SF is under the responsibility of EFIC, and the strategic policy objectives of the SF are defined by both EFIC and PAE. SIP reserves the right to any final editorial decisions when concerning the drafting of SIP position papers. SIP Stakeholder Forum members can add their support and logos to SIP position papers, on a case-by-case basis, as they wish.

Pre-Requisites

SIP Stakeholder Forum member organisations should:

- Have an interest in pain policy.
- Have an international or European scope.
- Declare possible conflicts of interest.

This year's SIP Stakeholder Forum meeting gathered 21 attendees from different organisations, with the main aim of understanding each other's key priorities, both current and future, and understanding each other's strategies in response to the 2024 EU Elections.

15:00-15:10 – Welcome and Background on SIP – Joanne O’Brien Kelly, EFIC Advocacy Co-Chair and Board Member/ Liisa Jutila, PAE Board Member and SIP Co-Chair

Liisa and Joanne welcomed attendees to the event, and Angela provided an introduction to the Societal Impact of Pain (SIP) initiative, outlining its general objectives and focus areas.

The Societal Impact of Pain (SIP) platform is a multi-stakeholder partnership led by the European Pain Federation EFIC and Pain Alliance Europe (PAE), which aims to raise awareness of pain and change pain policies. The platform provides opportunities for discussion for health care professionals, pain advocacy groups, politicians, healthcare insurance providers, representatives of health authorities, regulators, and budget holders.

The SIP National Platforms are comprised of healthcare professional / scientific and patient representative bodies from all over Europe with an interest in pain, and there are several SIP National Platforms across Europe, such as, Belgium, Finland, France, Germany, Ireland, Malta, Netherlands, Portugal, Slovenia, Spain and Switzerland.

The main objectives of SIP are as follows:

- 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.

The long-term priorities of SIP are as follows:

- Pain as an indicator: Develop instruments to assess the societal impact of pain (pain as a quality indicator).
- Pain education: Prioritise pain education for health care professionals, patients, policymakers and the public.
- Pain in employment: Initiate policies addressing the impact of pain on employment and include pain in relevant existing initiatives.
- Pain research: Increase investment in research on the societal impact of pain.

15:10-15:15 – SIP 2023 Achievements and Activities – Angela Cano, SIP; EFIC

2024 SIP Objectives:

- Pain and Digital Health.
- International Classification of Diseases (ICD-11).
- Pain and Mental Health.
- Access to Treatment.

2024 SIP Policy Priorities

- **Digital health / Indicators policy activities:** With regards to digital health policy activities, SIP has been actively involved in translating and disseminating the SIP position paper on Digital Health and the SIP Roadmap Monitor.
- **SIP ICD-11 Policy Activities:** Following the ICD-11 SIP event in November 2022, SIP is actively disseminating its ICD-11 Recommendations, the recently launched (June 2023) SIP position paper on ICD-11, and advocating for the inclusion of ICD-11 as a reference in the European Health Database (EHDS). Notably, SIP has successfully incorporated a reference to ICD within the EHDS Regulation, as part of Annex 1; Patient Summaries’.
- **Pain and Mental Health:** At the beginning of 2023, SIP developed together with different EU organisations a Joint Statement on Pain and Mental Health (May 2023). This Statement was officially launched at an event held in the European Parliament in October 2023. Additionally, SIP actively engaged and collaborated with SANT Committee members to ensure its Recommendations were taken into consideration when drafting the Report, resulting in the inclusion of more than 25 references to pain and pain-related topics within the Report, which was approved by the Plenary in December 2023.
- **Access to treatment activities:** Access to treatment has been one of SIP objectives this year, pursuing it in collaboration with SIP National Platforms. Currently, SIP is in the process of developing a Book of Evidence on the Burden of Pain. The Book of Evidence describes and defines pain; the biopsychosocial model of pain treatment; the International Classification of Diseases (ICD-11); the main pain conditions, comorbidities and treatment options; patient testimonies; and a series of Recommendations targeted at the EU Institutions and national governments. The Book of Evidence will be translated into the SIP National Platform languages, and it will then be utilised for national and EU advocacy activities.

15:15-15:45 – SIP National Platform Roundtable – SIP National Platforms

This section provides a concise summary of SIP National Platforms’ key activities and approaches to addressing chronic pain, with efforts ranging from advocacy and awareness initiatives to concrete steps in policy and research.

SIP Portugal

Maria Teresa Flor de Lima (MTFL) highlighted SIP Portugal's commitment to advancing research, education, and action. Key activities planned include:

- Finalising and launching “SIP PT Reflection” by end of 2024 to engage policymakers.
- Completing the "Pain in Employment" research project and enhancing advocacy efforts.
- Translating and disseminating SIP documents to increase reach and impact.

SIP Belgium

Ellen Gepts (EG) explained that despite delays from COVID-19, SIP Belgium has relaunched under André Mouraux in 2024, with plans to hold a stakeholder meeting by year-end. Future steps include:

- Convening the first stakeholder meeting by end of 2024.
- Establishing a coordinated network involving specialists and primary healthcare providers.

- Driving awareness and education initiatives focusing on pain's societal impact.

SIP Ireland

Anna Kiernan (AK) shared SIP Ireland's re-establishment in 2024 as a collaborative platform between the Irish Pain Society and Chronic Pain Ireland. In 2025, SIP Ireland priorities include:

- Development of a National Model of Care - Identifying how the model can support SIP platform needs.
- Utilisation of SIP Book of Evidence - Supporting requests for resources for the Irish chronic pain population.
- Defining platform priorities - Creating a foundation for strategic planning and advocacy.

SIP Malta

Gertrude Buttigieg (GB) presented on SIP Malta's work under the Malta Health Network, emphasising their Erasmus+ project on managing chronic diseases in the workplace. SIP Malta continues to:

- Support the Erasmus+ project by raising awareness of chronic pain challenges in workplaces.
- Foster collaborations with local organisations to further inclusion efforts.

SIP Denmark

Lars Bye Møller (LBM) discussed SIP Denmark's support for healthcare reforms addressing chronic pain and FAKS's advocacy role. SIP Denmark stays committed to:

- Supporting the implementation of ICD-11 and establishing a national clinical pain database.
- Coordinating public awareness on chronic pain in collaboration with SDU.
- Rolling out a stigma-reduction campaign focused on chronic patients' intimacy issues.

SIP Spain

Anna Server (AS), Miren Revuelta (MR), and María Madariaga (MM) from SIP Spain highlighted new initiatives and stated that SIP Spain aims to:

- Actively participate in scientific events in 2025, while also promoting ICD-11 resources.
- Participate in IASP Scientific Symposia and Spanish Pain Congress in 2025.
- Enhance collaboration with Pain Alliance Europe and related organisations.

SIP Sweden

Gunilla Goran (GG) introduced SIP Sweden, established in 2024. Key activities for next year include:

- Establishing a steering committee and goals for SIP Sweden in November 2024.
- Hosting an education day and public kickoff event in March 2025.
- Identifying and securing potential sponsors for ongoing initiatives.

SIP Netherlands

André Wolff (AW) discussed SIP Netherlands' priorities, including website improvements, cross-border pain care, and implementing the Care Standard Pain. The future activities of SIP Netherlands include:

- Hosting a multidisciplinary congress in December 2024.
- Implementing the Care Standard Pain and developing chronic pain care guidelines.
- Exploring the possibility of hosting the 2027 EFIC Congress in Maastricht.

SIP Finland

Liisa Jutila (LJ) shared SIP Finland's efforts, focusing on the Pain and Migraine Task Force and the ICD-11 project. Activities planned for 2025 include:

- Completion of ICD-11 translations and implementation by January 2026.
- Continuation of the Pain and Migraine Task Force's outreach efforts.
- Organisation of a national seminar in autumn 2025 to raise awareness.

15:45-16:05 – Reflection on the New EU Health Policy Agenda

Sam Kynman (SK) introduced SIP's future priorities and recent EU developments, focusing on the 2024-2029 Political Guidelines and Health Mission Letter. He noted the inclusion of the term '*painkillers*' in guidelines, the new Critical Medicines Act, and a comprehensive preventative health strategy aimed at reducing NCD burdens. **SK** highlighted continued support for the Beating Cancer Plan, with efforts to ensure pain is addressed within this and related frameworks on cardiovascular diseases and mental health. Additionally, he emphasised SIP's planned engagement with the European Commission and policymakers to improve pain treatment access, the European Health Data Space implementation, and ongoing advocacy support for SIP National Platforms, particularly on mental health.

16:05-16:25 – Sibling Organisations Case Studies

The below stakeholder presentations offer a detailed overview of the current and forthcoming initiatives undertaken by our partners in the current and upcoming year. It provides valuable insights into the collaborative endeavours shaping our collective future, as well as clarity on how our partners are preparing and adjusting to the new and upcoming EU Health Policy Agenda.

- **ECO (European Cancer Organization)**

Richard Price (RP), a head of Policy at the European Cancer Organisation (ECO), outlined ECO's vision of reducing the cancer burden across Europe through a commitment to multidisciplinary care and multiprofessionalism. He further emphasised that ECO aims to be a proactive, influential organisation dedicated to ensuring quality care for every patient. Further, he presented ECO's strategic pillars, which focus on facilitation, policy and advocacy, and additional areas to support cancer control and patient outcomes across Europe.

Additionally, **RP** highlighted three primary focus areas of ECO's work:

- Quality Cancer Care
- Digital Health
- Workforce Development

RP detailed ECO's role in advancing the European Code of Cancer Practice, which serves as a core component of ECO's mission to uphold quality standards for cancer care across Europe. Then, he reviewed the evolution of the European Beating Cancer Plan, tracing its progression from its inception in 2019 through to the drafting and publication in 2021. He outlined key stages, including the current development and implementation phases at both EU and national levels, and noted the next steps to complete the EBCP, refresh the plan, and expand EU goals in cancer control.

RP highlighted that the ECO has submitted a formal letter to the incoming EU Health Commissioner, urging continuity and progress on the EBCP. The letter serves as a roadmap for ECO's expectations and contributions towards ongoing EU cancer initiatives. Further, **RP** emphasised critical goals within the EBCP, including the elimination of cancers caused by the papillomavirus and the aim of establishing a tobacco-free generation in Europe. Lastly, **RP** highlighted ECO's active participation in key EU projects—Interact-Europe, Protect-Europe, and smartCARE—as both a coordinator and consortium member.

- **ESC (European Society of Cardiology)**

James Kennedy (JK) from the European Society of Cardiology (ESC) discussed the ESC's ambitious plan to establish an EU Cardiovascular Health Plan that could serve as a model for global governments, ensuring consistent funding for research, infrastructure, and health worker support. To achieve this, two strategic action lines were presented:

- Promoting an understanding that cardiovascular health impacts all policy areas,
- And developing a network of national cardiac societies to influence both local and EU policymakers.

Reflecting on three years of progress, **JK** highlighted several achievements: "Vote Cardiovascular Health 2024," the elevation of cardiovascular health to an EU Council priority after 20 years, and the largest exhibition on cardiovascular disease at the European Parliament scheduled for December, which helped secure cardiovascular health on the EPP manifesto and led to a high-level Ministerial conference in Budapest in July 2024.

Looking ahead, **JK** stressed the need to align cardiovascular health with broader MEP priorities beyond healthcare alone by connecting it to areas such as air pollution, employment, research, and civil rights. He underscored the role of the European Alliance for Cardiovascular Health (EACH), the largest group of EU stakeholders in this area, with its call for national cardiovascular health plans, a data knowledge centre, and comprehensive health checks to prioritise prevention and early intervention. **JK** noted that the ESC's goal is to offer MEPs a platform to make clear commitments to cardiovascular health, supported by engagement materials, including social media resources, 87 recorded videos, and 100 signatures already secured from MEPs, with EACH members providing interview content in various languages to maximise impact across the EU.

Further, **JK** shared concerns about future challenges, highlighting the need to advance prevention policy beyond position papers, address resistance to disease-specific plans, and adapt to budget cuts despite growing demands. He expressed doubt about the European Parliament's ability to shape the Commission's direction, especially in prevention and rehabilitation policies, which currently seem underfunded.

Short Debate Following ESC' Presentation

Sam Kynman (SK) found the insights inspiring and emphasised the importance of capitalising on opportunities and collaborating with SIP National Platforms to strengthen advocacy skills. Key points of the discussion as follows:

- 1) **RP** pointed out that Member States and the new Commission's agenda would heavily dictate change, with Member States needing to advocate for their priorities at the European Parliament. **RP** acknowledged the numerous challenges ahead and the importance of a strong push for Parliamentary priorities. Given that there is a discrepancy between the Member States in the Council and the MEPs in the Parliament.
- 2) **SK** presented SIP's suggestions for its 2025 priorities and objectives, those being:
 - a. **Engage** with EU Commission Ursula von der Leyen, Health Commissioners and Policymakers on access to pain treatment.
 - b. **Monitor and support** the European Health Data Space implementation – Developing a common approach with other areas positively affected by ICD-11 (i.e. Dermatology, Neurology, Immunology and Allergens, Rare Diseases).
 - c. **Training and support** for SIP National Platforms on different advocacy topics and priorities (i.e. advocacy toolkit; SIP Book of Evidence).
 - d. **Monitor** new policies, particularly on Mental Health.

SK pointed out that promoting the EFIC Research Strategy will also be an activity to consider for 2025.
RP and JK confirmed that the above mentioned would be the appropriate path to follow.

Lars Bye Moller (LBM) raised a question on the effectiveness of influencing policymakers, to which **JK** responded, that emphasising the role of data in proving advocacy's value and the need for resource commitment and influential partnerships to amplify advocacy messages are key aspects to keep in mind.

16:25-17h00: Next Steps and Closure

Liisa Jutila closed the meeting thanking the NPs for the participation and their commitment to SIP's priorities, mentioning hers and Joanne's satisfaction for the advancements the project is making.

Meeting closed at 17h25 CET.