

SIP Stakeholder Forum Meeting Wednesday 8th November 2023 – 13h30-15h30 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.

13:30-13:35pm – Welcome – Patrice Forget, SIP Chair; EFIC

Patrice Forget welcomed speakers and attendees to the event, introduced the Agenda of the event and gave a short update on the Societal Impact of Pain (SIP) Event, its objectives and long-term priorities.

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.

13h40-13h50 – SIP 2023 Achievements and Activities – Angela Cano, SIP; EFIC

2023 SIP Objectives:

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

- EU-OSHA Partnership Renewal.

SIP has recently hosted several events, including the SIP Pain and Digital Health online event (2022); the International Classification of Diseases online event (2022); and the Pain and Mental Health event at the European Parliament (2023). Looking ahead, SIP is preparing for the Access to Treatment Online Event and the European Parliament event, both scheduled for 2024.

2023 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 several Amendments to the EHDS, and while negotiations are still ongoing, one of the Amendments has been confirmed.
- **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 and subsequently including 24 Amendments (with many references to pain) in the Mental Health Report, which has already been approved by the ENVI Committee.
- **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.

[13h50-14h00 – Responses from the Pre-Event Survey – Angela Cano, SIP; EFIC](#)

SIP sent a pre-event survey to all SIP Stakeholder Forum members. The survey was sent to eighteen organisations, with five submitted responses by the day of the SIP Stakeholder Forum meeting. The survey will remain open until 23rd November. The main focus was on discerning the key priorities of participating organisations, both current and future, and understanding their strategies in response to the 2024 EU Elections. Additionally, SIP sought their insights on SIP's performance and overall assessment. Please find below a summary of the main key responses.

In 2023, the first priority for SIP Stakeholders, has been Mental Health, with a specific emphasis on harmonising mental health care practice and training. The second priority has been to provide access to innovative pain treatments, aiming to enhance the quality of life for individuals with chronic pain, closely followed by a focus on cancer initiatives. Further, as a third priority, strengthening the collaboration with other health professional organisations and addressing musculoskeletal disorders (MSDs), should be highlighted.

With regards to planning a Manifesto or related initiatives targeted at the EU Elections process, 60% of respondents voted affirmatively, while the remaining 40% voted negatively.

For those organizations planning a Manifesto, amongst others, the main call for the new EU mandate revolves around emphasising the importance of enhancing the knowledge about the physiotherapy profession and a European Mental Health Strategy.

Looking forward to 2024, mental health emerges as the predominant priority for all Stakeholders. The second priority will focus on Cancer and addressing shortages in the mental health care workforce. With regards to the third priority, Stakeholders plan to concentrate on addressing MSDs and promoting research in mental health care.

Regarding the visibility of SIP's work in 2023, SIP's efforts in the area of the International Classification of Diseases (ICD-11) have been noted as quite visible, and SIP's work on Pain and Mental Health has achieved a high level of visibility.

Stakeholders unanimously recognise SIP's strength lies in effectively connecting and working with different stakeholder groups on the topic of pain. On the other hand, Stakeholder noted that an area for improvement could be guiding SIP National Platform activities more closely.

In conclusion, with regards to SIP's 2024 objectives, Stakeholders suggested keeping pain high on the Health Policy Agenda, and continue to focus on Mental Health and Digital Health until the new EU Agenda is set. It is clear from the debate that all Stakeholders will continue to work on such topics for the foreseeable future. Once the new EU Agenda is published, SIP will reconsider its objectives and activities accordingly.

14:00-14:30 Stakeholder Presentations

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.

- **ECO (European Cancer Organization).**

Richard Price, Head of Policy, outlined the organisation's vision: reducing the cancer burden through multidisciplinary care. Their goal is to be a proactive, influential organisation ensuring quality care for every patient. He covered key focus areas—Quality Cancer Care, Digital Health, Workforce—and highlighted their involvement in EU projects (Interact-Europe, Protect-Europe, smartCARE) as coordinators and consortium members, emphasizing their commitment to innovation and collaboration in cancer care.

- **ECHAlliance**

Andy Bleaden, Community Director, announced the forthcoming launch of the Thematic Innovation Ecosystem on Cancer, uniting members from around the globe. This innovative model adopts a proven and successful multi-stakeholder approach, with a central focus on placing the patient/citizen at the heart of the initiative. The Thematic Innovation System is designed to offer a comprehensive array of resources, including an established network, platform, webinars, and community forums, fostering a collaborative environment for networking and shared insights.

- **EAN (The European Academy of Neurology)**

Martin Rakusa, EAN Representative, shared the vision of the organisation: to be the Home of Neurology, dedicated to advancing high-quality patient care, with a mission to alleviate the burden of neurological diseases. He highlighted the successful outcomes of the 9th Congress of the European Academy of Neurology and unveiled plans for the upcoming congress in Helsinki on 29 June – 2 July 2024. In addition, Martin Rakusa introduced the Advocacy Training for Neurologists program, specifically designed to equip neurologists with the skills needed for effective advocacy in support of neurology and brain health.

- **EBC (European Brain Council)**

Dieyenaba Faye, Project Officer, initiated her presentation by highlighting significant EU and EBC Partner-funded projects: VoT Chronic Pain, a research initiative focused on brain disorders in Europe, and the Coordination & Support Action (CSA) Brain Health project. She provided insights into their past event, "Brain Innovation Days," focused around fostering resilience and promoting better brain health for future generations. Dieyenaba Faye also announced the forthcoming event, "Our Brain Our Future," scheduled for 28th November 2023.

- **EFPA (European Federation of Psychologists' Associations)**

John Francis Leader, Board Member, underscored EFPA's proactive engagement in mental health advocacy across Europe and with international collaborators. He introduced the Seven Points of the European Mental Health Strategy:

- Commitment to mental health in all policies.
- Mental health as a core part of societal crises responses: Emphasizing the importance of mental health in addressing and responding to societal crises.
- Community-oriented mental health services.
- Mental wellbeing in the workplace: Prioritising mental health in the workplace, citing research such as the H-WORK project.
- The impact of climate change on mental health, especially for the young: Proposing support programs, particularly for children and young people, within settings like schools.
- Mental health training standards and regulation.
- Equality of access to mental health, including digitalisation.

- **GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks)**

Karl Lavó, Policy and Communications Officer, outlined the organisation's key objectives, aimed at enhancing mental health initiatives. These include improving the provision, reliability, and quality of information for mental health patients, combating stigma and misinformation, fostering collaboration within the mental health field, and enhancing overall awareness, knowledge, and understanding.

He provided insights into their ongoing activities, such as the European Personality Award, a special recognition for individuals who have made noteworthy contributions to the field of mental health. Additionally, he highlighted the organisation's involvement in European Years, which serve as EU-wide campaigns to educate and inform citizens while directing the focus on Member States. Furthermore, Karl Lavó discussed the MEP Alliance for Mental Health, a crucial initiative dedicated to bringing together Members of the European Parliament (MEPs) and relevant stakeholders. This alliance aims to advocate for the development of sound EU policies contributing to the prevention of mental ill health and ensuring the provision of appropriate, high-quality services.

- **EPA (European Psychiatric Association)**

Lara Grosso, Scientific and Policy Officer, detailed EPA's upcoming initiative—a manifesto set to be released in December 2023. This manifesto will focus on preventing mental health care protection and harmonising training practices in the mental health field. Notably, EPA is organising an event at the European Parliament on 6th December 2023, where they will officially unveil the manifesto.

14h30-14h45: How is SIP Approaching the New EU Mandate

During this segment of the meeting, we delved into SIP's strategies for addressing the new EU mandate. Throughout the year, SIP engaged in discussions and attended different meetings, with various political parties, including ALDE, EPP, and S&D and contributed to their Political Party Manifestos. Our efforts focused on integrating our priorities, such as mental health, pain education and research, into their agendas.

In addition, SIP actively participated in endorsing and contributing to Manifestos from other organisations, such as ECO's Manifesto. Further, SIP is closely monitoring Members of the European Parliament (MEPs) with regards to their upcoming plans.

Looking ahead, SIP plans to engage with the Spitzen Candidates and to enhance its collaboration with the EU Commission.

14h45-15h00: How are our partners approaching the new EU Mandate

As reflected in the pre-event survey, Stakeholders stated that feeding into Manifestos or preparing own manifestos (depending on their capacity) is how they are currently preparing for the upcoming EU Elections.

Patrice Forget encouraged everyone to keep in touch with SIP to explore avenues for further collaboration in 2024.

15h00-15h20: What should SIP focus on in 2024?

Building on SIP's efforts throughout the year and incorporating feedback from Stakeholders and SIP National Platforms, along with considerations with regards to the upcoming elections, SIP has outlined a set of 2024 priorities and activities. It's important to note that these plans are not fixed and remain open to modification or expansion as we closely monitor the upcoming EU Agenda. The planned activities include:

- Launching the SIP Book of Evidence on the Burden of Pain and translating it into the SIP National Platform languages, followed by dissemination at both EU and national levels.
- Translating the SIP Joint Statement on Pain and Mental Health.
- Pain and Mental health – SIP will keep the topic in its agenda and priorities until seen where it stands in the next mandate.
- Support the roll-out of ICD-11 at national level and continue to emphasise its importance at EU level.
- Organise bilateral calls with Stakeholder Forum members.
- Engage with the new campaign by EU-OSHA, which will run for the next few years.

15h20-15h30: Closure

Deirdre Ryan closed the meeting with a few reminders. Stakeholders are encouraged to endorse the SIP Stakeholder Forum Memorandum of Understanding (SIP SF MoU) to enhance their engagement in the SIP Stakeholder Forum, which has the following objectives:

- Inclusion of all pertinent healthcare professional, patient, and civil society organisations with an interest in pain policy (or related policies).
- Establishment of a forum for voluntary discussions, cross-promotion, and collaboration on SIP's projects and events, as well as those of respective members.
- Facilitation of expert input and review of SIP positions on various policy topics, on a voluntary basis.
- Collaboration to fortify the policy positions of the SIP Platform.

Deirdre Ryan reminded Stakeholders that they are welcomed to share their news on the SIP Newsletter and concluded by thanking all Stakeholders for their participation in the meeting and reminded them that they can stay updated on all new developments through SIP's social media channels.

Meeting closed at 15h30 CET.