

SIP National Platform Meeting 28th November 2024 Zoom

Attendees

- SIP Team: Liisa Jutila (PAE/SIP), Patrice Forget (EFIC/SIP), Angela Cano Palomares (EFIC/SIP), Marta Bartnicka (EFIC/SIP), Oda Steensen (EFIC/SIP).
- SIP National Platform Representatives.

Welcome and Objectives

- Angela Cano Palomares (**ACP**), from EFIC/SIP, opened the National Platform Call and explained the Agenda of the day.
- Patrice Forget (**PF**), SIP's Chair, introduced himself and introduced Liisa Jutila (**LJ**) (PAE/SIP) as a Board Member of Pain Alliance Europe.
- EFIC Communications and Advocacy trainee, Oda Steensen introduced herself to the SIP National Platform Representatives.

SIP Governance Model – An update

ACP provided key updates on the SIP Governance Model and plans for collaboration moving forward:

- She introduced the SIP Governance Model to support SIP National Platforms by enabling national forums and providing a structured approach to projects and priorities through a dedicated template.
- She emphasised the importance of sharing information on SIP activities to highlight their value, address funding challenges, and align with SIP National Platforms' agendas.
- **ACP** reminded attendees of the Governance Model document, which outlines management priorities and provides a framework for organising initiatives, assuring her and her team's availability for support.
- She discussed the SIP Plan for Sponsors template, designed to help sponsors understand fund allocation and reinforce transparency and support.
- **ACP** encouraged attendees to share updated Governance Models and Sponsorship Plans with her team and reminded them to submit updated SIP National Platform Governance documents and plans for 2024–2025 to angela.palomares@efic.org.

The New EU Mandate

ACP provided an update on the new EU Mandate and its implications for SIP, referencing the Political Guidelines 2024–2029 published by Ursula von der Leyen, which outline key EU priorities. She highlighted that while the document mentions "painkillers," the focus will shift towards the Critical Medicines Act. **ACP** noted that this provides an opportunity to expand conversations around pain management and procurement of critical medicines.

Regarding preventive health, she explained that efforts would focus on non-communicable diseases alongside the continuation of the Beating Cancer Plan, although the Commission may broaden its focus to other health areas. **ACP** also provided updates on the European Health Data Space (EHDS), informing attendees that while the Council and Commission have reached a joint statement, the Council's approval, expected in autumn, has yet to materialise. Implementation is set to begin early next year, and SIP will focus on leveraging this development.

She also mentioned the appointment of the new EU Health Commissioner, Olivier Várhelyi, noting that his initial portfolio may evolve, and it remains uncertain how he will share responsibilities with other commissioners.

PF commented on the billions of euros being invested in this area, emphasising the importance of participating in initiatives that impact patients, as this resonates with decision-makers.

LJ expressed optimism about the recognition of pain at this level, noting that it offers hope for future advancements, particularly through the inclusion of pain in ICD-11, which will elevate the issue within EU decision-making processes.

SIP *National* *Platforms:*

- Portugal: Maria Teresa Flor de Lima raised a concern about the issue of low health literacy in Portuguese society and asked whether SIP might be interested in addressing the prevention of pain.

ACP acknowledged the importance of health literacy, noting that it is a critical topic for EFIC's campaigns. She emphasised the need to carefully define and prioritise specific areas of focus within health literacy efforts. Further, **PF** highlighted that mental health could serve as a transferable topic when considering health literacy initiatives. He stressed the importance of using the right terminology to facilitate effective communication and the necessity of finding suitable methods to engage and convey messages.

- Habenom Gedey, speaking from Ireland, shared his involvement in an interdisciplinary project and requested support from the committee regarding the ECHO project. **PF** encouraged Habenom to follow up by sending an email detailing his request.

SIP Priorities

ACP also outlined SIP's 2024 priorities, highlighting the work achieved and reminding everyone of the next steps.

Digital Health/ICD-11 – European Health Data Space

- Digital Health & ICD-11 Position Papers - **Completed**
- Inclusion of ICD-11 in EHDS EP Report – **Completed**
- Inclusion of ICD-11 in EHDS Joint Text – **Completed**
- Development of ICD-11 leaflet – **Completed**
- Political Engagement at EU and National Level – **Ongoing**
- ICD 11 Letter to the Editor on the European Journal of Pain – **Completed**
- Translation of Digital Health & ICD-11 Position Papers and materials – **Ongoing**
- Joint Statement on ICD 11 with sibling organisations to support EHDS implementation – **To start shortly**

European Health Data Space

- **ACP** informed everyone that the Joint Text was approved by the European Parliament on the 24th of April, and the Council of the European Union will do the same in October 2024.

- Moreover, ACP reminded everyone that an International Classification Coding system for diseases is included within the Joint Text, as part of ‘**Annex 1: Main characteristics of priority categories of personal electronic health data for primary use; Patient Summary**’, Stating ‘**An International Classification Coding to classify ‘Current, resolved, closed or inactive problems’ within patient summaries**. This is a step in the right direction which will hopefully support the national roll-out of the International Classification of Diseases – 11th Revision.
- ACP kindly reminded everyone that the **next steps include**:
 - *Aligning with other European organisations that have been positively affected by ICD-11 to develop a common approach/position and get in touch with DG SANTE to follow up with the implementation of EHDS.*

Mental Health

- Pain and Mental Health Joint Statement – **Completed**
- Inclusion of pain and related topics in Mental Health EP Report - **Completed**
- Letter to the Editor on Pain and Mental Health – Epidemiology and Psychiatric Sciences & the BMJ – **Completed**
- Pain and Mental Health Workshop at #EFIC2025 – **Completed**
- Political Engagement at EU and National Level – **Completed**
- EU Parliament Pain and Mental Health Event October 2024 – **Completed**
- Translation of Pain and Mental Health Joint Statement and materials – **Ongoing**

Access to Treatment

- SIP Book of Evidence on the Burden of Pain - 6 MEPs endorsers - **Completed**
- The Burden of Pain National Case Studies - **Ongoing**
- Translation of SIP Book of Evidence on the Burden of Pain - **Completed**
- SIP Policy Framework on the Delivery of Pain & Leaflet - **Completed**
- Political Engagement at EU and National Level – **Completed**
- Infographics on SIP Book of Evidence on the Burden of Pain - **Ongoing**
- Access to Treatment Event on 16th October 2024 - **Completed**
- Translation of SIP Policy Framework on the Delivery of Pain & Leaflet - **Ongoing**

SIP

National

Platforms

- Sweden: Gunilla Göran announced that the Sweden National Working Group would have its first official startup meeting the following day. She mentioned plans to utilise the SIP Book of Evidence as a tool, expressing confidence in its potential effectiveness.

ACP responded by affirming EFIC’s focus for the coming year on supporting the advocacy efforts of national platforms. She acknowledged the potential challenges in adopting the SIP Book of Evidence and assured attendees that a workshop would be provided to help them maximise its use and effectively present it to others. **ACP** kindly reminded everyone that she is also committed to offering advocacy hooks and tactics to support these efforts.

EU-OSHA New Campaign: Safe & Healthy Work in the Digital Age

ACP informed everyone that EU OSHA has expressed interest in joining the next call to share insights into their ongoing initiatives. Their campaign aims to raise awareness about the impact of new technologies on work and workplaces and the associated occupational safety and health challenges and opportunities.

- Social media engagement + Also in collaboration with ER-WCPT
- Joint webinar on campaign theme
- Joint Resources
- Publish an article on the EU-OSHA website

Possible presentation for the next or upcoming SIP National Platform Call!

SIP National Platform Round-Table

ACP shared several updates, providing an overview of recent events and outlining plans for the future.

SIP Access to Treatment Event De-Brief

ACP provided an update on the successful *Access to Treatment* event held on 16 October 2024. She highlighted the key outcomes and achievements of the event, emphasising its positive impact and engagement:

- 20 Speakers in total
- 4 MEPs: MEP Sokol (EPP), MEP Saliba (S&D), MEP Kulja (EPP), and MEP Andriukaitis (S&D)
- 3 Sessions:
 - Defining treatment and promoting access
 - Promotion of prevention and healthy lifestyles
 - Access to essential medicines and current challenges
- 80 registrants in total
- 50-60 attendees in total
- Video Report and written Report, slides and quotes now available on our website
- Good balance between science, patient perspectives, and policy
- Good debate sessions
- Lessons for the future:
 - Less presentations and more debate times
 - Include break

LJ agreed that the event was held with great success. She said that it might be beneficial to add a little bit of timing in the future

SIP

Stakeholder

Forum

De-Brief

ACP provided an overview on the successful SIP Stakeholder Forum held on 16 October 2024:

- 20 attendees approx.:
 - SIP National Platforms
 - Industry
 - Stakeholders – Sibling organisations
- Lively debate:
 - Both ECO and ESC agreed and approved SIP's 2025 Plan
 - Discussion of challenges ahead with the discrepancies between the Council and the Parliament, and the need to keep pushing for Parliament priorities.

- Improvements for the future:
 - Important sticking to the allocated plan
 - More dedicated time for questions and debate with stakeholders as these are useful for SIP NPs
 - Include breaks

Stakeholder Case Studies

European Cancer Organisation

- ECO presented their vision on reducing cancer burden across Europe.
- ECO highlighted their aim on being proactive, and influential on quality care.
- ECO presented their areas of work, which include, quality cancer care, digital health and workforce development.
- They presented the evolution and context of the Beating Cancer Plan, tracing the progression from its inception in 2019, to the drafting and publication in 2021.
- They outlined the key stages, including current developments and implementation phases at EU and national level and noted next steps to complete, refresh and expand the Plan.

European Society of Cardiology

- ESC presented their plan to establish and EU Cardiovascular Health Plan, which included two strategic action lines: a) Promoting an understanding that cardiovascular health impacts all policy areas and b) Developing a network of national cardiac societies to influence both local and EU policymakers.
- ESC reflected on their achievements: a) Vote CV Health 2024 campaign and b) High level ministerial conference on CV Health.
- ESC shared their plan and campaign tactics which included embracing different reasons for the same outcome, deploying alliances, making the issues something policymakers can run on, and being helpful.

Proposed Priorities and Action Plan for SIP in 2025

ACP presented the proposed priorities and action plans for SIP in 2025, which included:

- Engage with the EU Commission Ursula von der Leyen, Health Commissioners and Policymakers on access to pain treatment.
- 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).
- Training and support for SIP National Platforms on different advocacy topics and priorities (i.e. advocacy toolkit; SIP Book of Evidence).
- Monitor new policies, particularly on Mental Health.

SIP National Platform Updates

ACP informed everyone that they can submit their case studies as abstracts. She noted that if one of their patient representatives was already attending the Congress, their participation would be counted. In addition, **ACP** provided an update on the case studies EFIC has already received and expressed the intention to print and display them at the EFIC booth. She encouraged others who wished to have their

case studies presented to submit them by the end of January, with further details to be provided in a follow-up email. **ACP** also suggested that submitting these case studies to scientific journals would be a great opportunity.

Questions and Support Required

SIP National Platforms:

- Denmark: Lars Bye Møller asked whether SIP would validate the information and numbers provided, expressing concern that some information might be biased.

ACP assured him that sources would indeed be provided, with a colleague currently working on verifying and checking all data. **PF** suggested that the Book of Evidence could serve as a reliable source.

- Belgium: André Mouraux proposed that if enough posters were available, SIP could consider organising designated poster walk-arounds focused on specific topics. He noted that if there were typically 10 posters per walk, this could be a viable option, with the SPC responsible for organising the submission.

ACP encouraged everyone to take part, reminding them that the submission deadline for posters is the 2nd of December. She also mentioned that she would send a reminder email to everyone regarding this opportunity, particularly emphasising the submission details discussed in the meeting. The deadline for new cases was also reiterated.

SIP Communications, next steps and closure

ACP closed the meeting with a kind reminder about the following key points:

- The SIP Newsletter will be sent out on 13 December 2024. Everyone is kindly asked to submit any comments by **6 December 2024**.
- **ACP** encouraged everyone to stay connected by following SIP's communication channels, including social media, the website, and the newsletter.
- The next SIP National Platform call for 2025 will be announced soon, with the calls to be sent out shortly.

ACP and **LJ** concluded the meeting. They expressed their joy in seeing everyone's participation and looked forward to the next meeting in the New Year.