

SIP National Platform Meeting 14th May 2024 Zoom

Attendees

- SIP Team: Liisa Jutila (PAE/SIP), Patrice Forget (EFIC/SIP), Sam Kynman (EFIC/SIP), Angela Cano Palomares (EFIC/SIP), Giacomo Quaglio (EFIC/SIP), Raluca Marcu (EFIC/SIP).
- SIP National Platform Representatives.

Welcome and Introductions

- Angela Cano Palomares (ACP), from EFIC/SIP, opened the National Platform Call and explained the Agenda of the day.
- Liisa Jutila, Pain Alliance Europe Board Member, introduced herself as deputy Chair for the meeting as Deirdre Ryan, SIP Co-Chair, could not be in attendance on the day. She joined Patrice Forget, SIP's Chair, in the initial remarks for the meeting.
- EFIC Communications and Advocacy trainee, Giacomo Quaglio introduced himself to the SIP National Platform Representatives.

SIP 2024 Priorities and Objectives

ACP went through the activities SIP is currently undertaking to tackle the new and upcoming EU Mandate. Activities include:

- Participation in political party Manifestos + Meetings: ALDE, EPP, S&D
- Joining other EU organisations Manifestos: ECO
- Tracking MEPs on their upcoming plans
- Engagement with leading candidates and EU Commission.

Further, ACP stated that up until the European elections, SIP will continue to focus on its 2024 priorities, namely:

- Digital Health – European Health Data Space
- ICD-11
- Mental Health
- Access to Treatment

Looking forward to the 2nd half of 2024, SIP's priorities will include:

- Updated priorities if needed based on new EU Health Policy Agenda

SIP Governance Model

ACP kindly reminded attendees to update their SIP National Platform Governance document and plans for 2024, and to send it back to her at angela.palomares@efic.org to ensure the best support in 2024.

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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 scientific framework of the SIP platform is under the responsibility of EFIC and the strategic direction of the project is defined by both partners. The pharmaceutical companies Grünenthal GmbH and GSK are the main sponsors of the Societal Impact of Pain (SIP) platform

SIP Activities Q2 2024

European Health Data Space (EHDS) Update:

- The European Parliament EHDS Report was ratified at the Plenary Session on 11th December 2023.
- The Trialogues between the European Parliament and the Council of the European Union, started on 30th January 2024 and finalised on 15th March 2024.
- The Joint Text was approved by the European Parliament on 24th April, and the Council of the European Union will do the same in October 2024.
- SIP successfully included an International Classification Coding system for diseases reference 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

SIP National Platforms:

- Denmark: Lars Bye Møller asked about the different classification systems used, namely the ICPC used in Denmark for primary care and ICD-11. Patrice Forget stated that is **safe to expect harmonisation with ICD-11**.

Digital Health/ICD-11 – European Health Data Space (EHDS)

- EHDS Follow-up work (i.e. engagement with Health Perm. Reps and policymakers working on the EHDS) - **Completed**
- Development of ICD-11 Leaflet - **Completed**

SIP National Platforms:

- Health Ministry/Official outreach: ICD-11 and Digital Health P.P - **Ongoing**
 - Finland: Ongoing process, with some difficulties due to the conflicts with regards to shared responsibility (municipalities vs regions).
 - Switzerland: Ongoing progress, as the national healthcare system is heavily dependent on various stakeholders.
 - Portugal: Set to meet the new health minister at national level, while some local governments have recently changed.
 - Germany: Set to have parliamentary meetings in June. ICD-11 roll-out is quite advanced in Germany.
- Translation of ICD-11 Leaflet – **To start shortly: ACP will send the necessary materials for translation.**

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Mental Health

- Develop a valuable resource on mental health and pain: Leaflet on SIP Joint Statement on Pain and Mental Health – **To start shortly**
- Monitor EU Policy on the topic - **Ongoing**
- Letter to the Editor on Pain and Mental Health - **Ongoing**

SIP National Platforms:

ACP asked if focusing on mental health at this point in time (given that the bulk of work took place in 2023) would be counterproductive, as Access to Treatment is the main focus at the moment. National Platforms agreed, therefore, it was concluded that ACP would send the materials for translation in case the topic is of interest at national level.

- Translation of SIP Joint Statement on Pain and Mental Health: **To be developed in the coming months**
- Translation of Infographic on SIP Joint Statement on Pain and Mental Health: **To be developed in the coming months**
 - Finland: Mental health is a huge issue affecting the younger generations. Currently, the focus is there and the link with pain (despite its relevance) has not yet been made.
 - Spain: Is experiencing a similar situation.

Access to Treatment

- Publish SIP Book of Evidence - **Completed**
- Develop + Publish National Platforms Case Studies - **Ongoing**
- Develop + Publish SIP National Pain Plan Model - **Ongoing**
- Develop + Publish Summary on SIP National Pain Plan Model – **To start shortly**
- Translation of SIP Book of Evidence - **Ongoing**

SIP National Platforms:

- Translation of SIP National Pain Plan Model – **To start shortly**
- Providing Case Studies - **Ongoing and ACP will send a reminder as a follow-up email.**

2024 SIP Activities – Q1 – Q4

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

Raise awareness about the impact of new technologies on work and workplaces and the associated occupational safety and health challenges and opportunities.

- Joint webinar on campaign theme
- Joint Resources
- Publish an article on the EU-OSHA website

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Other:

- SIP Bi-lateral Calls - **Ongoing**
- SIP National Platform Interviews – **To start shortly**
- SIP Letter to the Editor in Cancer Pain – Published at Annals of Oncology:
[https://www.annalsofoncology.org/article/S0923-7534\(24\)00017-6/abstract](https://www.annalsofoncology.org/article/S0923-7534(24)00017-6/abstract)

SIP National Platform Round-Table

SIP Book of Evidence on the Burden of Pain

ACP shared the final version of the SIP Book of Evidence with all. ACP mentioned that the Book is being translated to all the SIP National Platform languages and they will be ready by early June.

ACP opened the floor for questions and comments and the SIP National Platforms discussed the possible uses of the Book. ACP stated that mostly it would be useful for advocacy activities such as, meeting with policymakers and funding organisations/companies, etc., to ensure a clear understanding of what is pain, as well as its relevance. Lars Bye Moller (Denmark) suggested a workshop to discuss the different ideas and uses further.

With regards to the SIP Book of Evidence Case Studies, ACP stated that SIP National Platforms have until 14th June, as a first deadline, to provide the Case Studies. Further, she stated that it's not necessary to complete all sections, just as much as possible.

SIP National Pain Plan Model

ACP stated that the SIP National Pain Plan Model will be available soon and will be sent to all. In the interest of time, ACP skipped this section, but a more in depth conversation will be held in the future.

SIP National Platforms Updates

Belgium: Provided updates on their meetings with various stakeholders (e.g. health insurances), expecting news in September.

Finland: Expressed excitement for the publication of the On the Move position paper in the EJP, as well as the Book of Evidence, stating their aim to address patients' difficulties at national level, despite the difficulties. They also mentioned that they are part of different Government working groups on pain.

France: Provided updates on their meetings with various stakeholders in Paris, including policymakers.

Germany: Provided updates on the reform of payment systems of hospital delivery, including the aim of extending it to pain patients. Further a meeting with the Government on 6th June will take place to discuss pain management and treatment.

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Netherlands: Is currently focused on a national pain campaign of education, while facilitating and supporting regional projects.

Portugal: Is currently disseminating SIP's materials (website, newsletters, member partners, position papers) and plans on meeting with policymakers in 2024.

Denmark: Is currently working on a project focusing on sex and intimacy; reaching out to the Minister of Health for funding matters; providing insight and advice on how to increase patient experience while hospitalised or having other types of interactions with healthcare professionals. Further, they completed a project with Haleon (3 patient videos - how chronic pain impacts the lives of patients), and are involved in an exclusive political network, along with other patient organisations in Denmark.

Sweden: The Swedish SIP National Platform just launched recently. They are having their first meetings and invitations, and are planning to have a workshop in 2024, where they will establish their Committee and goals, amongst others.

Switzerland: They are working on the promotion of ICD-11, collaborating with stakeholders in the form of conference.

SIP Communications, Next Steps and Closure

Liisa Jutila, highlighted that the SIP Newsletter will be going out on 31st May 2024, and kindly asked everyone to send their news by 24th May 2024. She reminded everyone about the SIP communication channels and about the SIP bi-lateral calls, which will continue to take place. Finally, she reminded everyone that the next SIP National Platform call will take place on 26th September 2024.

Liisa Jutila and Patrice Forget thanked everyone for their attendance and closed the meeting at 15h15 CEST.



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