

## SIP National Platform Meeting 25<sup>th</sup> September 2025 Zoom

### Attendees

- SIP Team: Nadia Malliou (PAE/SIP), Patrice Forget (EFIC/SIP), Angela Cano Palomares (EFIC/SIP), Marta Bartnicka (EFIC/SIP), Hannah Kampos-Green, (EFIC/SIP), Marzia Ley (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 Nadia Malliou (**NM**) (PAE/SIP) as a President of Pain Alliance Europe.
- **NM** sent apologies on behalf of Liisa Jutila (**LJ**), Board Member of Pain Alliance Europe, who could not attend the meeting.
- EFIC Communications and Advocacy trainee, Marzia Ley (**ML**) introduced herself to the SIP National Platform Representatives.
- Marta Bartnicka (**MB**), from EFIC/SIP, informed everyone that she will be leaving EFIC/SIP as of 1 October 2025 onwards.

### SIP Event Schedule

- **ACP** provided an overview of upcoming events in October:
  - On **14 October**, all participants should arrive in Brussels.
  - Travel reimbursement: up to €300 per platform is available to cover travel costs for one patient representative per platform. If no patient is available, funding may be redirected to a healthcare professional representative, though preference is for patients.
  - On **15 October**, the SIP Advocacy Toolkit training will take place at the SIP offices from 09:30–12:00.
  - In the afternoon, the SIP Stakeholder Forum will be held, targeted only at EU organisations. The aim is to focus the discussion on EU health policy priorities.
  - On **16 October**, the SIP event at the European Parliament will take place from 11:30–13:30. All participants should bring the same ID used for registration, as this will be required for entry. Travel home is planned for the afternoon of 16 October.
  - ACP reminded everyone that registration for the Parliament event is mandatory.
- **PF** encouraged participants to spread the word about the events and to share any questions or suggestions.
- **ACP** also informed everyone to that no official social events are scheduled, but the team can recommend restaurants or help book a group dinner, which would be at participants' own expense.

### SIP 2025 Plan Priorities

- **ACP** also provided updates on SIP priorities. She explained that current workstreams include the European Health Data Space (EHDS)/ICD-11, access to treatment, preventive health, and the partnership with EU-OSHA.

- **ACP** provided an update on the priorities which looks as follows:

#### *ICD-11 & European Health Data Space*

- Monitor EHDS Implementation Timeline – **Ongoing**
- ICD-11 Joint Statement – **Ongoing**
- Engagement with EU Institutions (i.e., chronic pain hearing) – **Ongoing**
- Outreach to governmental bodies in charge of ICD-11/classifications in the country and support ICD-11 roll-out at national level – **Ongoing**

#### *Access to Treatment*

- Dissemination of SIP BoE; SIP PFDPC; SIP Infographics with stakeholders, EU Institutions and European and national meetings - **Ongoing**
- Translation of the SIP Infographics - **Ongoing**
- Complete and submit to scientific journals the SIP Case Studies - **Ongoing**
- Update of the SIP PFDPC to include a prevention section and development of a complementary leaflet – **Completed**
- Development of an Advocacy Toolkit - **Completed**

#### *Preventative Health*

- Monitor upcoming policy on prevention, NCD's, and CVD's (i.e., CVD Plan) - **Ongoing**
- Preventative Health Position Paper - **Completed**
- Translation Preventative Health Position Paper – **To begin shortly**
- Engage with the EU Commission, Council of the EU, and Parliament on such new developments to ensure SIP's priorities are included within any new upcoming policy (i.e., EP event and CVD Plan SIP feedback) – **Ongoing**

#### *EU-OSHA Partnership*

- Develop a joint webinar with ER-WCPT, on theme of the new campaign, related to SIP's workplace adaptation and integration position paper + the OTM campaign resources and new developing leaflet on pain and work – **Completed**
- EU-OSHA at SIP NPC - **Completed**
- Engagement on social media, in particular, during the European Week of Safety and Health at work, and dissemination of valuable resources - **Completed**

#### SIP National Platform Updates

- **PF** highlighted the importance of national platforms and their updates. He added that pain must be addressed comprehensively, covering primary and secondary prevention and different audiences. Further, he added that non-communicable diseases (NCDs), such as cardiovascular conditions, are also relevant.
- **PF** informed everyone that the European Commission is increasingly delegating investments to national level, aligning with political trends and decentralisation. Thus, he added that National platforms are therefore more important than ever, ensuring a bi-directional exchange of learning across countries.
- **ACP** thanked **PF** and invited National Platforms for further updates.

### SIP Finland

- Satu Nieminen (**SN**) shared national developments. She informed everyone that the Association has been the most active member of the Finnish SIP platform, participating in the Parliamentary Pain and Migraine Network and the National Musculoskeletal Programme.
- She added that SIP Finland also represents Finland in the Global Alliance for Musculoskeletal Health Network, which has called on the UN General Assembly to include musculoskeletal disorders (MSDs) in the NCD programme. She however informed everyone that this request has been declined for now, but the perspective will be integrated.
- **SN** added that National activity in Finland is currently limited due to severe NGO funding challenges, but they hope to resume in 2026 if resources allow.
- **ACP** thanked **SN** and invited further updates.

### SIP Portugal

- Maria Teresa Flor de Lima (**MTFL**) reported on progress in Portugal. She informed everyone that SIP Portugal has recently held a parliamentary meeting on ICD-11, where the Health Commission is proposing to government and health ministers to adopt ICD-11. She added that discussions also covered health literacy, social prescribing, and workplace law revisions, with the aim of including chronic pain.
- **MTFL** added that plans for 2025 include:
  - Two national social media campaigns.
  - Two conferences for pain professionals, led by the Portuguese Association for the Study of Pain (17–18 October, National Pain Day).
  - A partners' forum.
- Lastly, **MTFL** suggested co-organising a webinar with CROP to explain ICD-11 and its benefits to policymakers and organisations in Portugal.
- **ACP** congratulated **MTFL** and highlighted parallel progress in Sweden.

### SIP Sweden

- Gunilla Goran (**GG**) provided an update from SIP Sweden, informing everyone that the National Board of Healthcare and Welfare has completed the translation of ICD-11, to be published in early 2026, with full adoption foreseen by 2028. She added that this allows Swedish professionals to start referencing ICD-11 from next year.
- **GG** added that SIP Sweden will promote ICD-11 during the National Pain Conference (16–17 October 2025), where they have a dedicated slot.
- Mathias Andersson (**MA**) added further updates, including activities on Pain Awareness Day that will feature a national webinar and quiz, widely promoted across organisations.
- **ACP** welcomed the progress from Sweden.

### SIP Denmark

- Lars Bye Moeller (**LBM**) informed everyone that in Denmark the regions (responsible for secondary care) require further analysis before implementation. He asked whether Sweden's rollout includes not just translation but also integration into digital systems and whether funding has been allocated.
- Moreover, he highlighted that Denmark uses ICPC (International Classification of Primary Care) in primary care, which must be mapped to ICD-11.

- **GG** responded that she could not provide a definitive answer at the meeting but will follow up with colleagues from the National Board of Health and Welfare.
- **MA** offered to share an English translation of the Swedish national board's documentation and posted it in the chat.
- **ACP** noted that the upcoming WHO European Work Plan (2026–2028) includes three references to pain. Once published, the document will be circulated to all.
- **MTFL** suggested inviting Swedish colleagues to a future meeting to present their ICD-11 experience, highlighting both benefits and challenges, to help other national platforms.
- **PF** supported the proposal and emphasised the need to address obstacles such as the ICD-11/ICPC interface. He clarified that ICD-11 and ICPC are complementary, not competing systems:
  - ICD-11 = diagnostic classification.
  - ICPC = symptom and process oriented.
- Further, **PF** stressed that ICD-11 is simpler than ICD-10, but digitalisation and adaptation work remain necessary. He added that WHO is already working on integration approaches, and national feedback on barriers will be valuable.
- **MTFL** confirmed that the translation to Portuguese is underway. She added that the main obstacles remain the transition from ICD-10 to ICD-11 and digitalisation costs.
- **LBM** underlined that each national platform should map the institutions responsible for different aspects of ICD-11 (translation, digital systems, primary care mapping, financing). He added that in Denmark, initial reluctance came from regions citing lack of clinical benefits.
- Further, **LBM** stressed that advocacy from organisations and psychiatry specialists helped change perceptions, particularly regarding the improved classification of chronic pain in ICD-11.
- **ACP** thanked all contributors and moved to national updates.

#### SIP Belgium

- André Mouraux (**AM**) reported on SIP Belgium, adding that the platform has defined two main objectives:
  - Creating a SIP Belgium website targeting patients and the general public, using the Book of Evidence as a foundation, supplemented with local content for Belgium's linguistic communities.
  - Improving access to care for chronic pain patients, starting with collaboration with KCE (Belgian Health Care Knowledge Centre), which is launching a study on chronic pain management.
- He also added that SIP Belgium engaged with the Belgian Pain Society and presented at their recent congress (patient perspective on quality of care).
- Lastly, **AM** added that the platform is consolidating its stakeholder list and building interest through concrete actions.
- **ACP** congratulated SIP Belgium on its progress.

#### SIP Ireland

- Niamh Walsh (**NW**) reported on SIP Ireland, adding that the platform is at an early stage, developing its mission and objectives, supported by the SIP Advocacy Toolkit.
- She added that the platform is currently conducting a stakeholder analysis to identify key contacts and mutual benefits.
- **NW** informed everyone that Ireland lacks a national model of care for chronic pain, though one is under development. **NW** added that SIP Ireland has patient representation in this process.

- Further, **NW** added that during Pain Awareness Month, Chronic Pain Ireland ran the campaign “Beyond the Surface”, highlighting hidden struggles and stigma. **NW** informed everyone that SIP Ireland and its policy asks were included in the press release, and that the platform received national press and radio coverage.
- **ACP** commended Ireland’s visibility and campaign success.

### SIP Malta

- Gertrude Buttigieg (**GB**) reported that Malta Health Network recently organised six training sessions for patients, professionals, and organisations. She added that one of these sessions will be dedicated specifically to chronic pain (content still under development).
- **GB** added that next week, the Board will explore the possibility of applying for national funds. If successful, they plan to organise a national conference or symposium in 2026 to mark the 10th anniversary of SIP Malta. Further, **GB** added that the updates will be shared as planning develops.
- **ACP** congratulated SIP Malta.

### SIP 2022 Road Map Monitor

- **ACP** introduced the topic of the SIP Roadmap Monitor. She recalled that in 2022, SIP conducted a survey and report on how priorities were evolving across Europe. She kindly reminded everyone that objectives included:
  - Monitoring national implementation across EU countries.
  - Providing a comparative overview of pain-related policies and practices.
  - Supporting evidence-based advocacy with data and stakeholder input.
  - Facilitating exchange and alignment between countries.
  - Giving visibility to SIP national platforms.
- **ACP** kindly asked for reflections beyond ICD-11 on how countries are currently progressing.
- **LBM** shared that Denmark has maintained a national clinical database on pain for over 10 years, focused on data from interdisciplinary pain centres. He added that Denmark recently succeeded in securing recognition of complex chronic pain within the national clinical quality database (a steering tool for monitoring healthcare delivery).
- **ACP** thanked **LBM** and invited further input.
- **NM** noted that data collection is central for road mapping progress, whether through ICD-11 implementation, registries, or medication use data (including opioids, palliative care, and off-label/unlicensed use). She added that compared with 2020–2022, there are now more digital tools available to support better monitoring and follow-up across Europe.
- **ACP** asked how easy it currently is for SIP national platforms to gather such information, recalling that in 2022 data collection was challenging.
- **GG** responded that Sweden has had a national quality register for pain rehabilitation since 1998. She added that until recently, there was no register covering primary care, but this gap is now being addressed as part of the Swedish national pathway for pain care.
- **ACP** thanked **GG**.
- **LBM** asked whether Sweden’s new register covers acute or chronic pain, noting that Denmark’s register focuses specifically on complex chronic pain.
- **GG** clarified that the Swedish register relates specifically to rehabilitation of chronic pain, not acute pain. She added that acute pain is excluded from the national pathway and promised to follow up with more details later.



- **LBM** noted that in Sweden, it may be easier to gather primary care data since primary care is integrated into the system. He added that in Denmark, primary care operates differently (separate structure, not directly tied to the hospital system). **LBM** also noted that this makes it harder to involve them in the national quality database, as participation requires time and resources. He added that it is likely that Denmark will begin with secondary care and hospitals before expanding further.
- **GG** acknowledged the differences, attributing them to governmental approaches.
- **NM** added that data systems vary widely between countries, which limits harmonisation. She provided the example of Sweden, where ICD-11 is advancing, while other countries still use ICD-9 or ICD-10. She added that accessing meaningful data is often more difficult than accessing data itself. **NM** added that for the Roadmap Monitor to be useful, SIP must first clarify:
  - What kind of data is needed.
  - Which formats and tools to use.
  - Whether SIP should actively collect data itself.
- **NM** added that otherwise, there is a risk of fragmented registries that require complex harmonisation.
- **PF** agreed and suggested that one common and universally understood framework is financial data, since governments track spending and productivity losses. He added that pain has a major economic burden, and prevention could generate significant savings. Using this perspective could help SIP speak the language of policymakers. **PF** concluded by saying that while complex, this approach could simplify advocacy in the long term.
- **ACP** summarised the conversation by noting that there is consensus on the value of producing another SIP Roadmap Monitor, but with:
  - Clearer definitions of the data sought.
  - Harmonised terminology across countries.
  - Involvement of national platforms from the outset.
- Thus, **ACP** proposed establishing a working group to develop a first draft, which would then be reviewed by all platforms. She emphasised that national platforms must be closely involved, since the aim is to support them with evidence and comparisons.
- **PF** confirmed that the process should be bi-directional, with national platforms contributing insights while benefiting from shared tools.
- **ACP** thanked participants and confirmed to follow-up on next steps.

### SIP 2026 Objectives

- **ACP** then transitioned to planning for 2026 priorities and reminded participants that a short survey had been circulated prior to the NPC to gather input.
- **ACP** added that SIP priorities are always developed together with national platforms, and aligned with:
  - EU health policy agenda.
  - Stakeholder input at EU level.
  - Aim is to ensure a coherent strategy rather than fragmented actions.
- **ACP** informed everyone that from the survey responses, it is clear that national platforms would most value support in developing position papers. She also added that based on the survey responses many platforms are interested in co-leading or hosting activities, though this depends on funding and human resources.

- **ACP** added that, based on the survey results, platforms have been working on policy areas that are very much aligned with SIP's priorities. Many have focused on access to treatment and prevention, while others have also placed strong emphasis on the economic and social impact of pain, which coincides with SIP's intention to highlight this theme in 2026. Mental health was also underlined by several platforms, which **ACP** noted fits well with the rollout of the European Mental Health Strategy across EU countries.
- Looking ahead to 2026, **ACP** observed that platforms wish to maintain their focus on access to treatment, recognition of pain in EU and national health policies, NCDs, as well as the economic and social impact of pain. These are all areas that SIP is also considering for its upcoming priorities.
- **ACP** further noted that many platforms expressed willingness to contribute case studies, examples, or national policy data, which could be linked to the ongoing work on the Roadmap Monitor. However, she also acknowledged that there are resource-related challenges. In particular, platforms highlighted the need for financial resources, the importance of training new volunteers, and continued support for ICD-11 implementation. Some platforms also mentioned using opioid-related discussions to raise broader awareness of chronic pain, and several pointed to the need to address employment and the workforce impact of pain in national advocacy efforts.
- **ACP** concluded that all these insights will be analysed and integrated into the planning of SIP's 2026 objectives, and final priorities will be confirmed at the November platform call.
- **PF** closed with key reflections:
  - Advocacy begins with raising awareness, and platforms should make use of existing SIP tools and training opportunities.
  - Policymakers increasingly require robust data and evidence.
  - Beyond health system costs, SIP should highlight the wider economic impact of pain:
    - Work absenteeism and reduced productivity.
    - Personal costs to patients, which can be 5–6 times higher than the tax contributions they do not make.
    - Urged participants to keep these dimensions in mind when planning advocacy.
- **NM** kindly reminded everyone that the survey remains open, and platforms are encouraged to share and promote it. She added that broad participation from all countries strengthens SIP's advocacy at EU level. Lastly, she expressed appreciation for the active work and advocacy taking place across platforms.
- **NM** also warmly acknowledged progress in several countries, highlighting Sweden, Portugal, Denmark, Finland, Ireland, Belgium, and Malta.
- **ACP** and **NM** thanked all participants.

#### SIP Communications, next steps and closure

- **ACP** closed the meeting with a kind reminder about the following key points:
  - SIP bi-lateral calls should be still scheduled with SIP Belgium, SIP Slovenia, and SIP Ireland.
  - The SIP Newsletter will be sent out on 31 October 2025. Everyone is kindly asked to submit any comments and updates by **20 October 2025**.
  - Next SIP NPC will take place on **27 November 2025**, where SIP 2026 Plan will be presented.
  - **ACP** encouraged everyone to stay connected by following SIP's communication channels, including social media, the website, and the newsletter.

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