

Societal Impact of Pain (SIP) Platform Annual Report 2024

Introduction

The below report is provided to demonstrate the activities and impact of the [Societal Impact of Pain \(SIP\) platform](#). While the impact of advocacy is often difficult to quantify, due to the long-term nature of relationship building and the policy process, this report can go some way to demonstrating real impact. The report shows key activities, a written qualitative analysis, as well as some key performance metrics.

SIP Key Achievements in 2024

| Key Achievements | Explanation |
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| <p>Progressing the roll-out of new WHO coding on chronic pain via EU Legislation: ONGOING</p> | <p>SIP has worked with MEPs to place the International Classification of Diseases (ICD-11) implementation on the agenda at European level. This has been done via the new EU legislative proposal entitled the European Health Data Space (EHDS), where ICD-11 has been proposed as a standard for interoperability across Europe. Many MEPs have supported this proposal and the Parliament's lead MEP (the 'Rapporteur') included amendments to this end. ICD-11 is considered transformative in how chronic pain conditions are included, to better support patients in navigating the healthcare system. Following the Trilogues, the EHDS Joint Text was approved by the European Parliament in April 2024, and the Council will follow before the end of 2024. <u>The Joint Text includes a reference to ICD, within 'Annex 1; Main characteristics of priority categories of personal electronic health data for primary use; Patient Summary'</u>. SIP will continue to follow the implementation process, by aligning with different organisations whose area of work has also been positively affected by ICD-11.</p> |
| <p>SIP Book of Evidence on the Burden of Pain: ONGOING</p> | <p>The Societal Impact of Pain (SIP) Platform, developed a Book of Evidence on the Burden of Pain. This 'Book of Evidence' was created for individuals from a non-scientific background (e.g. policymakers and funding organisations) to gain an insight into what pain is, understand different definitions used (e.g. acute pain, neuropathic pain, nociceptive pain), and the debilitating effects pain has on patients and societies. The Recommendations highlighted at the end of the document are a call to action by the European Commission, European Parliament, European Council and civil society to address the societal impact of pain and enhance, support and advance access to treatment for all Europeans. The translations will support the activities at national</p> |

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| | level. SIP will provide advocacy trainings to support National Platforms activities. |
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Key Policy Priorities in 2024

- Pain and Digital Medicine (targeting the EU Health Data Space)
- International Classification of Diseases – 11th Revision (ICD-11) (targeting the EU Health Data Space)
- Pain and Mental Health (targeting the EU Mental Health Strategy)
- Access to Treatment – The Burden of Pain

Key Activities in 2024

- Outreach and engagement with members of the European Parliament and Health Permanent Representatives on the topic of ICD-11, Pain and Mental Health and Access to Treatment.
- Outreach and engagement to the Council Presidency on the topic of ICD-11, Pain and Mental Health and Access to Treatment.
- Outreach and engagement with WHO Brussels Liaison Office and inclusion as a member of the WHO-FIC European Network.
- Development of ICD-11 Position Paper infographic.
- Development of a Pain and Mental Health position paper infographic.
- Inclusion of ICD within the European Health Data Space Regulation.
- Inclusion of pain and pain-related messages within the European Parliament Mental Health Report in the context of the European Mental Health Strategy.
- Translation of the Pain and Mental Health Position Paper and Infographic into the different SIP National Platforms languages.
- Publication of four articles in different scientific journals on the topic of Pain and Mental Health, Cancer and ICD-11:
 - [The pain and mental health comorbidity](#) - Epidemiology and Psychiatric Sciences - Cambridge University Press · Oct 3, 2024
 - [Prison healthcare: overcrowding, understaffing, a drug epidemic, and an ageing population in an unfit Victorian estate](#) - BMJ · Sep 2, 2024
 - [Importance of pain management in cancer patients and survivors](#) - Annals of Oncology · Feb 2, 2024
- Development of the SIP Book of Evidence on the Burden of Pain.
- Translation of the SIP Book of Evidence on the Burden of Pain to the different SIP National Platform languages.
- Development of 5 infographics and 9 social media visuals on the SIP Book of Evidence on the Burden of Pain.

- SIP Book of Evidence National Case Studies
- Organisation of a multi-stakeholder policy event on Access to Treatment, particularly to launch the SIP Book of Evidence on the Burden of Pain.
- Development of a Policy Framework on the Delivery of Pain Care.
- Development of a Policy Framework on the Delivery of Pain Care Infographic.
- SIP Present at National Societies Congresses and meetings.
- SIP Workshop at EFIC 2025 Lyon.

Impact of the Societal Impact of Pain (SIP) Platform on Pain Policy?

In late 2023, the Societal Impact of Pain (SIP) Platform set bi-annual policy priorities and objectives for 2024. In the last two years, SIP has grown substantially, with the systematic involvement of scientific expert-review in the development and launch of SIP Position Papers; the development of multi-stakeholder policy events; continued collaboration with the European Union Agency for Safety and Health at Work (EU-OSHA); inclusion of SIP as a member of the WHO-FIC European Network; as well as the strengthening and growth of the SIP Stakeholder Forum, Network and the SIP National Platforms, placing both at the centre of driving the policy activities and direction of SIP annually. All without losing sight of key EU health policy priorities and initiatives relevant to SIP core objectives.

SIP has continued to expand and nurture existing, as well as new relationships with European policymakers with a focus on health policy and institutions, particularly in the context of the European elections, as well as the SIP Stakeholder Forum and network of sibling organisations, by doing in-person meetings and policy focused events.

SIP has strengthened and grown substantially its online presence, showcasing all SIP activities and events through its different communications channels, such as Facebook, Twitter, and LinkedIn. Further, SIP has also launched a new, more user-friendly website. The quarterly SIP Newsletter continues to be a great success in terms of opening rates, and so is SIP's participation in different advocacy and awareness campaigns.

The inclusion of pain as a disease under the World Health Organization (WHO) 11th revision of the International Classification of Diseases (ICD-11) is a key development, which came into effect in 2022, which will facilitate the recording and reporting of pain diagnoses in a standardised format. Following the ICD-11 related event in late 2022 entitled 'Pain in the International Classification of diseases: A SIP Event', where experts in the field discussed ICD-11 extensively, and SIP's engagement with the European Health Data Space (EHDS), Rapporteur MEP Sokol, ensured the File addressed the needs of the pain community.

More specifically, SIP successfully included in the European Health Data Space (EHDS) Regulation, a reference to the International Classification of Diseases (ICD-11). An International Classification Coding system for diseases is now included within the Joint Text of the European Parliament and the Council of the European Union. More concretely 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. The European Parliament approved the EHDS Joint Text in their Plenary Session on 24th April. The Council will do so before the end of 2024.

In 2023 and 2024, SIP also focused on Pain and Mental Health, targeting the [European Mental Health Strategy](#) (providing a response to the Roadmap and Consultation launched by the European Commission) and, ahead of its launch, SIP published a Joint Statement on Pain and Mental on the close link between both matters, in collaboration with ten different organisations, working in the field of pain, pain-related or mental health policies. The nine recommendations in this document call upon EU and national policy makers to ensure a range of aspects related to pain and mental health are acknowledged in health policy. Further, SIP organised an in-person event at the European Parliament, on World Mental Health Day, 10th October, to politically launch the SIP Joint Statement on Pain and Mental Health. The event was hosted by MEP Vind (S&D) and MEP Sokol (EPP), with MEP Montserrat (EPP), and MEP Saliba (S&D) also providing an address. SIP engaged with the Rapporteur and Shadow Rapporteurs of the SANT Sub-Committee Report on Mental Health, SIP's messages on the topic were carefully looked at and included in the Report. SIP successfully included 25 amendments in the final Report, ratified at the Plenary Session on 11th December 2023. Following the recently published 2024-2029 Political Guidelines and Mission Letter – the two key documents that provide the policy pathway for the next European Commission term and the Mandate for the next Health Commissioner respectively – mental health will remain a priority at EU level and therefore, SIP will continue to monitor and engage on the topic as needed.

With regards to Access to Treatment, SIP developed a [Book of Evidence on the Burden of Pain](#). This 'Book of Evidence' was created for individuals from a non-scientific background (e.g. policymakers and funding organisations) to gain an insight into what pain is, understand different definitions used (e.g. acute pain, neuropathic pain, nociceptive pain), and the debilitating effects pain has on patients and societies. The document explains distinct types of pain conditions, how common they are, and treatment approaches. Further, the document explains crucial concepts and challenges in the pain field, including pain measurement and assessment, stigma, the importance of acknowledging the personal multidimensional nature of pain that requires an appreciation of the interplay between myriad biological/physical, psychological and sociocultural factors. Overall, this document should illustrate and describe what pain is and draw attention to the need for urgent policy action and increased funding for research. In particular, the recommendations highlighted at the end of the document are a call to action by the European Commission, European Parliament, European Council and civil society to address the societal impact of pain.

Further, SIP is currently working on the development of national case studies of the SIP Book of Evidence, which will provide examples of advocacy activities at national level, as well as concrete data on pain prevalence, disability, and pain management services.

In addition, SIP hosted an event entitled, '[Pain Treatment, Management and Prevention – Is Europe Providing Adequate Access?](#)' bringing together leading policymakers, pain specialists, and patient representatives. Held in Brussels, the event provided a critical forum for addressing the current state of pain management and accessibility across Europe. The discussions emphasised key barriers to accessing pain treatment, including shortages of essential medicines inconsistencies in the implementation of comprehensive pain care across member states, and technical barriers linked to European regulations. Participants engaged in productive dialogues about the importance of fully adopting ICD-11 to ensure proper recognition and treatment of chronic pain. The event highlighted the need for urgent action by policymakers to prioritise pain management within healthcare systems. Prominent figures from the European Parliament (MEPs), such as the event hosts MEP Saliba and MEP Kulja, as well as MEP Andriukaitis and MEP Sokol, alongside leading healthcare professionals, and attendees, including the Health Attachés of the Hungarian Permanent Representation (currently holding the Presidency of the Council of the European Union), and the Dutch Permanent

Representation, reviewed pivotal documents such as the SIP Book of Evidence and the EFIC Multimodal Pain Treatment Position Paper. These resources, aimed at guiding future policy decisions, were well received by participants and underscore the importance of adopting multimodal approaches and patient-centred strategies in addressing chronic pain. The event also marked the introduction of the European Day on Pain Awareness, set to be observed annually on the third Wednesday of October. This new initiative aims to foster increased understanding of chronic pain, reduce stigma, and advocate for necessary policy changes to improve care. The announcement was met with strong support from attendees, who acknowledged the significant impact of chronic pain on individuals and societies across Europe. The event concluded with a clear call to action: EU and national governments must recognise the burden of pain and implement more effective policies that guarantee access to high-quality pain management. An event report summarising the discussions and proposed next steps will be disseminated to guide future initiatives across Europe.

Finally all developed SIP materials, such as Position Papers, Joint Statement, and Books of Evidence, have been translated to all SIP National Platform languages to ensure their use in national advocacy campaigns.

Additionally, SIP, via EFIC being a member, continues to be involved in two EU4Health projects led by the European Cancer Organisation (ECO): INTERACT-EUROPE (Inter-speciality training programme) and SMART-CARE (cancer survivors electronic smart card), have successfully concluded with pain taken into account in both projects. Moreover, SIP is part of the European Commission Beating Cancer Plan Stakeholder Group in the EU Policy Platform. Further, SIP continues to be part of the thematic group 'Quality of Life' of the Stakeholder Contact Group on Europe's Beating Cancer Plan, where input is provided to the Commission on the implementation of Europe's Beating Cancer Plan and the Horizon Europe Cancer Mission, in areas under the remit of the thematic group.

SIP has renewed its partnership with EU-OSHA, and will be a collaborator in their 2023-2025 campaign focused on safe and healthy work in the digital age.

As a result of the SIP National Platform meetings, the 2024 SIP Stakeholder Forum meeting, and the analysis of the new and upcoming EU Health Policy Agenda via the publication, by the European Commission, of the 2024-2029 Political Guidelines and the Health Mission Letter, SIP will focus on engaging with the European Commission President Ursula von der Leyen, Health Commissioner and Policymakers on Access to Treatment; monitoring and supporting the European Health Data Space implementation, by developing a common approach with other areas positively affected by ICD-11; providing trainings and support to SIP National Platforms on different advocacy topics and priorities; and monitoring new policies, particularly on Mental Health and other non-communicable diseases.

Key Performance Metrics

The metrics below provide an insight into how SIP is performing. The metrics relate to the calendar year 2023-2024. We have selected those which we believe are most indicative of quality work and real impact.

1. Number of Policy Papers / Positions / Resources Published:

This refers to SIP's multi-stakeholder, multidisciplinary, scientifically-based policy recommendations. These are the highest value substantial activities of the project. Additionally, SIP's contributions to other organisations' policy publications, and responses to public consultations are also listed.

- Response to the European Commission Public Consultation for the Upcoming EU Health Policy Agenda.

- Engagement with Political Parties to ensure SIP's priorities were included in their Manifestos: ALDE, EPP and S&D.
- Engagement with sibling organisations to ensure SIP's priorities were included in their Manifestos (i.e. ECO).
- SIP Joint Statement on Pain and Mental Health.
- Leaflet on the SIP Joint Statement on Pain and Mental Health.
- SIP Position Paper on ICD-11.
- Leaflet on the SIP Position Paper on ICD-11.
- Book of Evidence on the Burden of Pain.
- SIP Book of Evidence Case Studies.
- SIP Book of Evidence on the Burden of Pain Translations.
- SIP Book of Evidence Infographics and social media visuals.
- SIP Policy Framework on the Delivery of Pain Care.
- Leaflet on the SIP Policy Framework on the Delivery of Pain Care.

2. Number of Engagements with Political Stakeholders:

This refers to engagements with political representatives; renewing, strengthening, or establishing new relationships with key policy makers and institutions related to SIP's core objectives and positions.

- MEP Dolors MONTSERRAT (EPP, Spain)
- MEP Sipra PIETIKAINEN (EPP, Finland)
- MEP Alex AGIUS SALIBA (S&D, Malta)
- MEP Radka MAXOVÁ (S&D, Czechia)
- MEP Cyrus ENGERER (S&D, Malta)
- MEP Tomislav SOKOL (EPP, Croatia)
- MEP Bartosz ARLUKOWICZ (EPP, Poland)
- MEP Cristian-Silviu BUSOI (EPP, Romania)
- MEP Sara CERDAS (S&D, Portugal)
- MEP Stelios KYMPOUROPOULOS (EPP, Greece)
- MEP Peter LIESE (EPP, Germany)
- MEP Susana SOLÍS (Renew, Spain)
- MEP Deirdre CLUNE (EPP, Ireland)
- MEP András KULJA (EPP, Hungary)
- MEP Vytenis ANDRIUKAITIS (S&D, Lithuania)
- MEP Maria WALSH (EPP, Ireland)
- MEP Romana JERKOVIC (S&D, Croatia)
- European Commission DG SANTE – B4 Unit – Disease Prevention and Health Promotion
- PERM REPS: Slovenia (Health)
- PERM REP: Czech Republic (Health)
- PERM REP: Spain (Health)
- PERM REP: Belgium (Health)
- PERM REP: The Netherlands (Health)
- PERM REP: Hungary (Health)
- PERM REP: Malta (Health)
- EU-OSHA

3. Number of Engagements with other Key Stakeholders Relevant to Pain Policy:

This refers to engagements with other influential organisations in the Brussels policy-making sphere in 2023-2024:

- European Federation of Neurological Associations EFNA
- European Academy of Neurology EAN
- European Brain Council EBC
- Mental Health Europe MHE
- European Cancer Organisation ECO
- European Psychiatric Association EPA
- European Region of World Physiotherapy ERWCPT
- Active Citizens Network ACN
- European Connected Health Alliance ECHAlliance
- European Migraine and Headache Association EMHA
- European Headache Federation EHF
- GAMIAN-Europe
- Council of Occupational Therapists for the European Countries COTEC
- Euro Youth Mental Health EYMH
- European Federation of Psychologists Associations EFPA
- European Public Health Association EUPHA

4. Number of Subscribers to SIP Newsletter: 965 (Average unique open rate across all newsletters in 2024 is 36.6%) – (851 subscribers in 2023)

This refers to the subscribers on our mailing list, indicating the ‘circulation’ of SIP’s positions and recommendations, activities, and engagement opportunities.

5. Number of Views of the SIP Website and Relevant Pages in 2024: 13,990 – (1,366 in 2023)

This refers to the page views of SIP’s landing page and SIP’s relevant pages in 2024.

| 2023 | 2024 |
|--|-----------------------------------|
| Landing Page: 1,145 | Landing Page: 2,611 |
| SIP Current Projects: 241 | SIP Current Projects: 442 |
| SIP Access to Treatment: (Not yet available in 2023) | SIP Access to Treatment: 423 |
| SIP News on Book of Evidence: (Not yet available in 2023) | SIP News on Book of Evidence: 318 |
| SIP Upcoming Events: 139 | SIP Upcoming Events: 232 |
| About SIP: 98 | About SIP: 193 |

Top 10 Countries:

- Ireland
- Spain
- United Kingdom
- Belgium
- Germany
- Sweden
- Portugal
- The Netherlands
- Italy
- Malta

6. **Number of Followers on SIP Social Media Channels: 3, 43K – 5% increase from previous year (3.26K in 2023)**

This refers to the followers on each of our accounts, indicating the size of our audience and the strength of our voice in online discussions.

- Facebook: 639 followers
- Twitter: 1.63K followers
- LinkedIn (page): 1,16K followers
- LinkedIn (group): 6.840K members

Top countries:

- United Kingdom
- Spain
- Netherlands
- Italy
- Belgium
- Portugal
- Germany
- United States
- Denmark
- Ireland
- France
- Switzerland
- Greece
- Malta
- Sweden
- Brazil
- Finland

7. **Number of SIP National Platforms in Operation: 13 + 1 in Development**

This refers to the number of active platforms in existence, demonstrating national level reach and amplification of SIP positions and recommendations, and links to national policymakers and stakeholders.

- Belgium
- Finland
- France
- Germany
- Ireland
- Malta
- Netherlands
- Portugal
- Slovenia
- Spain
- Switzerland
- Sweden
- Denmark

- UK (Platform in development)

8. SIP National Platform Upcoming/Milestones

This refers to the SIP national platforms milestones or upcoming milestones with a public and multi-stakeholder nature.

- Belgium
 - Convening the first Stakeholder Meeting in 2024.
 - Establishing a coordinated network involving specialists and primary healthcare providers.
 - Driving awareness and education initiatives focusing on the societal impact of pain.
- Finland
 - Translation of the ICD-11 materials and implementation by January 2026, as part of the Government Task Force on the topic.
 - Continuation of the Pain and Migraine Task Force outreach efforts.
 - Organisation of a National Seminar in autumn 2025.
- France
 - Meetings with the Senate, and Ministry of Health on new health pathways for healthcare professionals and patients and palliative care and chronic pain.
 - Member of the National Health Agency Committees on regional pain, musculoskeletal, rheumatological and neurological conditions.
 - National campaign in collaboration with the Senate on World Pain Day.
- Germany
 - Annual Pain Forum in 2024.
 - Hold regular meetings with the Parliament.
 - Campaign during the German National Action Day Against Pain.
 - Establishing working programmes on ICD-11.
- Ireland
 - Development of a National Model of Care.
 - Utilisation of the SIP Book of Evidence.
 - Establishing new platform priorities and an advocacy planning strategy.
- Malta
 - Supporting the Erasmus+ project by raising awareness of chronic pain challenges in workplaces.
 - Developing video for healthcare professionals and patients on chronic pain.
 - Foster collaboration with local organisations to further inclusion efforts.
- Netherlands
 - Hosting a multidisciplinary congress in 2024.
 - Implementing the Pain Care Standard – a programme that looks at implementing chronic pain care pathways at national level – and developing chronic pain care guidelines.
- Portugal
 - Finalising and launching the ‘SIP PT Reflection’ by the end of 2024 to engage with policymakers.
 - Completing the ‘Pain in Employment’ research project and enhancing advocacy efforts.
 - Translating all SIP materials to increase research and impact.
 - Webinar to celebrate the 25th anniversary of National Day to Combat Pain; Translation of Consensus Documents, May in 2024.
- Slovenia
 - SIP Slovenia is currently going through a challenging phase of human resources. More

news to follow soon.

- Spain
 - Actively participating in scientific events in 2025, while also promoting ICD-11 resources.
 - Participating in IASP's Scientific Symposia and Spanish Pain Congress in 2025.
 - Enhance collaboration with PAE and related patient organisation.
 - Engaging with policymakers at national level on the different SIP priorities.
- Switzerland
 - Including patient representatives in the Platform: The Rheumatology Patient Organisation in Switzerland had little interest in chronic pain, up until now, as they recently created a chronic pain group. André will get in touch with them, in order to involve the group in the Platform.
 - ICD-11: André will aim to get in touch with policymakers to discuss ICD-11 implementation in the country, where not even ICD-10 is yet established as a norm. Only hospitals are forced to use ICD-11 when a patient leaves the hospital in order for them to get reimbursed. Further, the Swiss Pain Society recently established a working group on ICD-11, and André will try to engage them in SIP's work on the topic.
 - 2024 multi-stakeholder meeting: André will strive to organise another multi-stakeholder meeting/event, which gathers, healthcare professionals, patients, policymakers (i.e. ministry of health and public health authorities, the federal bureau of statistics, who is responsible for ICD-11) and insurance companies.
- Sweden
 - Establishing a steering committee and goals for SIP Sweden in November 2024.
 - Hosting an education day and public kick-off event in March 2025.
 - Identifying and securing potential sponsors for ongoing initiatives.
- Denmark
 - 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.