

## Societal Impact of Pain – Model for the Future



The *European Pain Federation*, EFIC, has prepared this Template for the SIP National Platforms, to support them in defining their priorities and activities, which can also be useful when requesting funding from potential sponsors. It must be used in conjunction with the *SIP ToolKIT*.

[https://europeanpainfederation.eu/wp-content/uploads/2023/04/Toolkit\\_SIP\\_digital\\_compressed\\_compressed.pdf](https://europeanpainfederation.eu/wp-content/uploads/2023/04/Toolkit_SIP_digital_compressed_compressed.pdf)

Its objectives are to describe:

- The structure;
- Responsibilities;
- Governance;
- Collaboration with sponsors.

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### Background

The *Societal Impact of Pain* (SIP) platform <https://europeanpainfederation.eu/sip/> is a multi-stakeholder platform, which aims to raise awareness of pain and change pain policies. *Grünenthal*<sup>®</sup> and the *European Pain Federation* (EFIC), with *Pain Alliance Europe* (PAE) and *Active Citizenship Network* (ACN) joining as partners at a later stage, founded SIP (SIP Europe – SIP EU).

In 2019, *Grünenthal*<sup>®</sup> decided that it should step back from its role as a SIP partner, and instead take a sponsoring role. This implied that *Grünenthal*<sup>®</sup> must step back from direct interaction with authorities or active involvement in SIP projects and communication activities. From 2020 onwards, the other SIP partners took the lead on the strategic planning of activities, as well as the management of projects and communication for the national platforms.

Following the SIP EU model, where EFIC and PAE lead the platform, Portugal representatives took the lead in managing the platform (SIP PT), in a new model in 2018, with an Executive Committee, EC (*Comité Executivo, CE*), composed of a representative from *Associação Portuguesa para o Estudo da Dor* (APED) and four representatives of Patients Associations. The CE is responsible for the day-to-day management of the SIP PT platform, serving as its public face and being the point of contact for political decision-makers, sponsors, partners, constituent parties, other entities and organizations that make up the platform, managing institutional email [geral@sip-pt.pt](mailto:geral@sip-pt.pt) for communication between EC members, Patients Associations and SIP EU.

SIP PT defined: Members – “Membros” (APED and Patients Associations), Partners – “Parceiros” (Stakeholders) and as sponsors – “Patrocinadores” (Sponsors).

EC Delegates in 2024:

HCP Contact: **Carina Raposo** (APED - *Associação Portuguesa para o Estudo da Dor*);

Patients Contacts: **Isabel Pireza** (MIGRA Portugal - *Associação Portuguesa de Doentes com Enxaqueca e Cefaleias*); **Ivone Machado** (ADDCA - *Associação de Doentes de Dor Crónica dos Açores*); **Joana Vicente** (APJOF - *Associação Portuguesa de Fibromialgia*); **Mónica Rebelo** (LUPUS - *Associação de Doentes com Lúpus*); **Maria Teresa Flor-de-Lima** (AAADMJ - *Associação Atlântica de Apoio a Doentes de Machado-Joseph*) is a substitute member and, as ADDCA Vice-President, is a PAE representative.

EC members communicate via the following email [comite.executivo.sippt@gmail.com](mailto:comite.executivo.sippt@gmail.com)

The information below describes the SIP model as agreed by the National SIP Members.

## Objectives of SIP

The objectives of SIP are to:

- 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 national policy strategies & activities for an improved pain care in Europe.

## Principles

To maintain the integrity of the project, the SIP partners consider the following principles to be fundamental to the platform. All partners, sponsors and endorsers should adhere to these principles:

- SIP promotes the uptake of multimodal and multi-professional pain management and is not focused on one particular treatment approach;



- SIP raises awareness of the impact of all pain types, including both chronic and acute pain, and does not exist to promote specific conditions or symptoms;
- SIP values the voice of patients and aims to bring patients into policy decision making;
- SIP acts with transparency, in terms of declaring interests but also engaging with all relevant transparency measures of the EU Institutions and relevant sectoral codes.

The SIP national partners will not promote, recommend, endorse or procure products in the context of SIP. Under no circumstances will the SIP national partners inappropriately or unethically influence the decisions of health authorities, purchasing or prescribing bodies or individual healthcare professionals concerning specific medicinal products.

### **Governance and partners**

SIP PT became a project of voluntary partners, instead of having its own legal identity. SIP PT's economic resources, are allocated to the Portuguese Association for the Study of Pain (APED), with the EC managing the funding and providing transparent accounts on how the funding is used.

The project, has been governed by the following structure:

#### **Partners**

The EC serves as the manager of SIP PT, taking care of the ongoing management of the project, serving as the public face of SIP PT and being the point of contact for policymakers and other organizations. The platform's strategy is connected with SIP EU and is approved and implemented by national Members and Partners. Financial responsibility lies with the EC.

**Guidance of SIP National Platforms:** Since 2018, SIP EU has launched satellite national initiatives in various European countries. These platforms are maintained and coordinated with guidance, from the European SIP partners. SIP national platforms take a similar multi-stakeholder approach, including both clinicians and patients, following a template proposed by the European partners. Detailed guidance on establishing, growing and maintaining SIP national platforms can be found in the [SIP Toolkit](https://europeanpainfederation.eu/wp-content/uploads/2023/04/Toolkit_SIP_digital_compressed_compressed.pdf) published on the SIP EU website ([https://europeanpainfederation.eu/wp-content/uploads/2023/04/Toolkit\\_SIP\\_digital\\_compressed\\_compressed.pdf](https://europeanpainfederation.eu/wp-content/uploads/2023/04/Toolkit_SIP_digital_compressed_compressed.pdf))

and in the CE Functioning Document (SIP PT website <https://sip-pt.pt/Recursos>).

**Stakeholder Forum** SIP PT will establish a Stakeholder Forum, bringing together organisations with an interest in pain from various sectors. These are likely to, primarily, be scientific or patient-led organisations, but other interested organisations will be considered. The Stakeholder Forum will meet at least annually, with the purpose to co-develop the strategy of SIP, and to identify specific objectives and policy goals.

**A wider network of experts and endorsers:** SIP PT will seek to include a wide range of stakeholders within SIP as speakers at events, contributors to publications and endorsing organisations. These could include employers, trade unions, academics, research institutions, think tanks and health systems managers.

**Sponsors:** Sponsors would be invited to participate in the Stakeholder Forum as observers, be invited to an annual meeting or receive annual reports to give their feedback on the national platform activities and their suggestions for policy objectives. Sponsors will also, be invited to SIP PT public events, remembering that Portuguese Law is followed.

### **Management responsibilities**

The management of SIP PT's national activities is led by the EC and the decisions are presented in a bimonthly General Meeting, which includes all Members, to fulfil the responsibilities described.

Responsibilities are:

- Monitoring of national policy opportunities;
- Regular information on the key partners;
- Liaison with sponsors;
- Arrangement of meetings;
- Liaison with SIP Europe;
- Dissemination of SIP national activities;
- Management of specific projects;
- Attracting more partners;
- Fund-raising.

The management of SIP PT planned national activities is assigned to the EC

### **Long-term priorities of SIP**

In 2018, SIP Europe, was invited by the European Commission to organise a Thematic Network on the Commission's Health Policy Platform. The Thematic Network brought together a large number of health stakeholders to work on a Joint Statement on the societal impact of pain. The Joint Statement was the most comprehensive piece of policy advocacy that the partners had committed to the project. Therefore, it serves as the underlying basis for most of its work going forward. The Joint Statement covered the following areas:

1. **Pain as an indicator:** Develop instruments to assess the societal impact of pain (pain as a quality indicator);
2. **Pain education:** Prioritize pain education for health care professionals, patients, policymakers, and the general public;

3. **Pain in employment:** Facilitate policies addressing the impact of pain on employment and include pain in relevant existing initiatives;
4. **Pain research:** Increase investment in research on the societal impact of pain.

These policy areas will most likely remain relevant for years to come and will serve as the underlying basis for much of the work of SIP for the foreseeable future. They will also serve as a template for SIP national platforms.

### **Priorities for 2024**

SIP PT describe the planned priorities, events, and activities as well as key milestones in 2024. Further guidance is available from the SIP Europe office. One can see the 8<sup>th</sup> chapter (“Useful Resources”) of the [SIP Toolkit](#).

### **Strategy and planning models**

#### **SPONSORS**

When started, SIP PT was financially supported only by *Grünenthal*<sup>PT</sup>.

To increase the sustainability of the initiative, platform members have sought to find multiple sponsors since 2022, exclusively from the pharmaceutical industry:

- For website and Webinar: *Grunenthal*<sup>PT</sup>, *Tilray*, *Angelini*, *Medtronic*;
- For specific projects:
  - First Consultation Guide – *Technimede*
  - Interactive Manual – *Pfizer*

#### **ACTIVITIES PLAN 2024**

The activities planned are based on two fundamental axes:

- 1 - Alignment with SIP Europe guidelines and proposals;
- 2- Disclosure of SIP PT activities among political decision-makers and entities linked to health.

### **Priorities**

- Promotion of SIP PT activities to political decision-makers and entities linked to health;

- Organization of meetings with SIP PT Members and Partners;
- Captivate new Members and Partners;
- Disclosure of SIP EU Position Documents.

### **Activities/Events**

- Monthly EC meetings;
- Bimonthly General Meetings;
- Monthly newsletters or leaflets: Dissemination of newsletters from SIP PT Members and Partners on the SIP PT website and dissemination of them to other Members/Partners.
- Scheduling meetings with:
  - o Members of the National Health Ministry and of Autonomous Governments of Madeira and the Azores ;
  - o Health Committee of the Assembly of the Republic;
  - o General Directorate of Health (DGS);
  - o Portuguese deputies elected to the European Parliament;
  - o Sponsors
  - o New Members and Partners
- Organization of a Webinar to celebrate the 25th anniversary of the first National Day to Fight Pain - **“The Pain Voice”** - “A Voz da Dor”;
  - o Date: June 14, 2024
  - o Format: Online debate
  - o Organization: SIP PT
- Preparation and dissemination of the **“Questionnaire on Pain and Work Activity”**
  - o Deadline: Dec. 2024
- Celebration of National Day to Fight Pain 2024
  - o Date: October 18<sup>th</sup> 2024
- Provide the collection of ideas for the preparation of the Next Consultation Manual (continuation of the First Consultation Guide)
  - o Deadline: Dec. 2024



## **KEY MILESTONES**

- Collaboration in the dissemination of translated Position Documents (SIP EU Documents);
- Promotion of SIP PT activities;
- Captivate new Members, Partners and Sponsors.

**Date:** April 17<sup>th</sup> 2024

### **Executive Committee 2024:**

Carina Raposo  
Isabel Pireza  
Ivone Machado  
Joana Vicente  
Mónica Rebelo  
Maria Teresa Flor de Lima (substitute EC Delegate)

**Approved in General Meeting** the May 8<sup>th</sup>2024