SOCIETAL IMPACT OF PAIN
SIP TOOLKIT

How to establish and successfully manage SIP national platforms (NP)?

VERSION 1.0 | OCTOBER 2019

SIP
Societal Impact of Pain

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The scientific framework of the SIP platform is under the responsibility of the European Pain Federation EFIC®. Co-operation partners for SIP are Pain Alliance Europe and Active Citizenship Network. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support.

CONTENT

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1. INTRODUCTION

1.1. Objectives of the toolkit

This toolkit aims to be a practical step-by-step guide for national actors active in pain care – healthcare professionals, researchers, patients and industry - who wish to either set up a new Societal Impact of Pain National Platform (SIP NP) in countries where it does not yet exist or strengthen existing platforms. National stakeholders will find insights on how to launch the platform, build its legitimacy and recognition, ensure adequate representativeness, accountability as well as how to build its long-term sustainability. The toolkit also aims to encourage closer collaboration between national platforms and SIP Europe in order to increase capacity building as well as share knowledge and good practices.

Other stakeholders at national level such as decision-makers, private companies and trade associations or insurers might find this toolkit useful to improve their understanding of the role of national platforms as well as the synergies that may be drawn from supporting or partnering with them.

1.2. Why SIP is working on this

EU Institutions play an important role in driving public health policies in Europe. They identify common challenges, encourage cooperation between the EU Member States and, if necessary, lend support to their action. At the same time, united actions are only complementary to national policies, as it is Member States which retain full autonomy in the definition of their health policy and in the organisation and delivery of health services and medical care. With this in mind, Societal Impact of Pain Europe (SIP Europe) realizes that the best results can be obtained in close alignment with national stakeholders in a bottom-up and top-down approach, thereby ensuring optimal key stakeholder management on both national and EU level. Therefore, existence of robust National SIP Platforms (SIP NPs) is crucial for the successful creation and implementation of pain care policies in Europe. SIP NPs are best placed to monitor, understand and react to as well as to actively influence national pain care policies of their respective countries. They are a vital partner for SIP Europe, providing expertise on country-specific situations, and cascading SIP Europe messages from and to the national and regional levels. In other words, to be effective advocates at European level, there needs to be a strong voice in each of the European Union's member states.

Furthermore, thanks to its experience and knowledge, SIP Europe can support the building process by providing examples from other countries, acting as a bridge between national organisations and external stakeholders, and providing tools for the organisational development of the future platforms.

1.3. One size doesn't fit all

While there will be many similarities shared among various countries, it is also important to recognize that the processes of developing, establishing, and leading national platforms can vary greatly from one country to another. Our objective is not to deliver a "one-size-fits-all" solution, but rather to propose a pathway for organisations wishing to work together. Equally, given that many countries will be at various levels of development, any given chapter of this toolkit might be more useful for one platform than for the other. For this reason, this toolkit is supposed to be a menu of "a-la-carte" options that can be selected and used separately, in line with current needs of a given country. The toolkit is intended as a living document that can be updated with the experience of the existing SIP National Platforms, best practices and concrete examples of collaboration.

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2. SIP EUROPE BACKGROUND

2.1. History, partners, objectives and milestones

The "Societal Impact of Pain" (SIP) is an international platform created in 2009 as a joint initiative of the European Pain Federation EFIC and the pharmaceutical company Grünenthal GmbH. It aims at:

- Raising awareness of the relevance of the impact that pain has on our societies, health and economic systems
- Exchanging information and sharing best-practices across all member states of the European Union
- Developing and fostering European-wide policy strategies and activities for an improved pain care in Europe (Pain Policy).

As such, the platform provides opportunities for discussion for health care professionals, pain advocacy groups, politicians, healthcare insurance providers, representatives of health authorities, regulators and budget holders.

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Once a year politicians, budget holders, decision makers, health technology assessment bodies, health care professionals, pain advocacy groups, etc. gather for the annual SIP symposium to raise awareness of the societal impact of pain in Europe and to develop and foster Europe-wide policy strategies and activities for improved pain care in Europe.

Milestones of the SIP platform include:

- **2011: The Societal Impact of Pain A Road Map for Action**

  Signed at the Symposium "Societal Impact of Pain 2011", the road map sets out the call from the SIP Partners to European governments and EU Institutions to act and to put, as a priority, the societal impact of pain on their policy agenda.

- **2014: Informal Health Conclusions during the Italian Presidency, Informal Health Council**

  During the informal EU Health Ministers meeting in 2014, the Italian Presidency placed pain therapy and palliative care at the top of their agenda. This resulted in the 28 EU health ministers pledging to further promote the use of palliative care and pain therapy in the EU member states.

- **2016: 8 Policy Recommendations: Time for Action**

  Under the motto ‘Time for Action’, over 220 representatives of health care- and stakeholder-organisations from more than 28 countries met in the European Parliament and Concert Noble in Brussels to discuss the “Societal Impact of Pain” (SIP 2016). The objectives of the symposium SIP 2016 were endorsed by over 160 organisations active in the field of pain.

- **2017: Policy Recommendations 2017**

  Under the auspices of the 2017 Maltese Presidency the SIP platform formulated key recommendations directed at the institutions of the European Union and national governments building on the 2017 recommendations and the further input of over 300 European healthcare stakeholders from more than 20 countries.

- **2017: Maltese EU Council conclusion**

  Under the leadership of the Maltese Presidency, on 16th June in Brussels EU Health Ministers included chronic pain in the EU Council conclusions and agreed that it is time to evaluate access to treatment for patients with chronic pain, while recognising the need to maintain the balance between innovation, availability, accessibility and affordability

- **2017 SIP invited to join the EU Health Policy Platform (HPP)**

  EU HPP is an interactive tool managed by the European Commission to gather the input of relevant health stakeholders to boost discussions about public health concerns, share knowledge and best practices, pool stakeholder expertise in joint statements and disseminate actions among a wide audience.

- **2018: SIP Position Paper on the of the 9th EU Framework Program (FP9)**

  SIP responded to the European Commission public consultation on the next EU multiannual financial framework with a position paper outlining the specific needs for funding in pain research

- **2018/2019: SIP Thematic Network Joint Statement**

  2019 SIP continues the work of the SIP Thematic Network via a dedicated group hosted on the EU Health Policy Platform: SIP Stakeholder group

- **2019: SIP collaboration with CHRODIS+**

  Thanks to the connections made via the 2018 SIP Thematic Network, SIP is now collaborating with the Joint Action of the European Commission which aims to implement pilot projects and generate practical lessons in the area of chronic diseases.

2.2. The EU Presidencies as an opportunity to elevate SIP on the EU and national political agenda

An important milestone of the SIP Europe was the 7th symposium of the "Societal Impact of Pain" (SIP 2017, June 7-9 in Valletta, Malta) under the auspices of the 2017 Maltese Presidency of the Council of the EU. The symposium, entitled "Structured Cooperation between Health Care Systems tackling the societal impact of pain!" brought together about 300 international experts in the field of pain care, along with patient representatives, policy makers and other stakeholders in the field of pain policy and representing more than 200 international and national organisations.

Clear policy recommendations were formulated to improve pain care in the European Union and to alleviate the effect of pain on society.

As a major highlight at SIP 2017 - Martin Seychell, Deputy Director General in the European Commission (EC) responsible for Health and Food Safety', announced in his speech that the EC is following SIP's lead and has launched the "Expert Group on Social Impact of Pain" in the framework of the EU Health Policy Platform, to build a bridge between health systems and policy makers on the topic.

As a result of the Maltese initiative, under the leadership of the Maltese Presidency, on 16th June in Brussels EU Health Ministers included chronic pain in the EU Council conclusions and agreed that it is time to evaluate access to treatment for patients with chronic pain, while recognising the need to maintain the balance between innovation, availability, accessibility and affordability. The aim is to increase the effectiveness, accessibility and resilience of health systems across the European Union, and to identify priority areas where cooperation between health systems may add value.

Presidencies in the next five years are Finland (II 2019), Croatia (I 2020), Germany (II 2020), Portugal (I 2021), Slovenia (II 2021), France (I 2022), Czech Rep. (II 2022), Sweden (I 2023), Spain (II 2023), Belgium (I 2024) and Hungary (II 2024).

2.3. Health Policy Platform and Joint Statement

SIP platform was selected as one of three topics for the Thematic Networks program in 2018. The networks are hosted by the EU Health Policy Platform (HPP), an interactive tool run by EC (DG SANTE) to boost discussions about EU public health concerns, share knowledge and good practices. The HPP invites public health stakeholders to exchange with others, to pool expertise in joint statements and to disseminate actions among a wide audience. As such, it is a collaborative online tool to ease communication between the EC services and health-related interest groups. It has over 5200 users in 67 different networks actively promoting their initiatives.

The HPP has three pillars: the Web Platform, the EU Health Award and one physical meeting per year. The Web Platform hosts the “Agora network”, an open discussion area accessible to all registered stakeholders. Users can benefit from posting news, creating opinion polls, sharing upcoming events and storing documents, among other features. The Web Platforms also hosts other groups namely, Stakeholder Networks, Commission and Member States Led Networks, as well as Thematic Networks.

As part of the 2018 selected Thematic Network, SIP produced policy recommendations, based on an extensive dialogue with European pain community stakeholders, in the form of a Framing Paper and Joint Statement. The Statement includes concrete recommendations for policy action in the areas of:

1. Pain as an indicator: Develop instruments to assess the societal impact of pain

2. Pain in employment: Initiate policies addressing the impact of pain on employment and include pain in relevant existing initiatives

3. Pain research: Increase investment in research on the societal impact of pain

4. Pain education: Prioritise pain education for health care professionals, patients, policy makers, and the general public

Our priorities

- Indicators
- Employment
- Research
- Education

Framing Paper, which accompanies these Recommendations for Policy Action, was drafted by SIP in partnership with stakeholders and members of the EU Health Policy Platform. It presents the common position of these stakeholders and outlines existing policies and actions taken that are relevant to pain. It also lists examples by civil society of projects and activities which are running in the EU to address the societal impact of pain.

The Framing Paper and Joint Statement were formally endorsed by over 100 organizations and policy makers and were presented at the Annual Meeting of the HPP at EC, in November 2018.

After the closing of the Thematic Network Program in 2018, SIP has been transformed into a Stakeholder network group. Future collaboration will take place through these stakeholders' networks in the EU HPP. National Platforms are encouraged to publish their work there. You can register here. Guidelines on how to register can be found in section 8.8.

2.4. Pain related policies in Europe

Multiple existing policies demonstrate that pain poses a serious societal problem in Europe.

2.4.1. EU wide policies

The 2007 Eurobarometer used pain as an indicator, identifying that "one in four have experienced chronic pain of a magnitude sufficient to restrict daily activities" and "the problem of chronic pain, as with many other health problems, is reported more by women than by men (28% vs. 22%).

The EU has included reference to pain in its position ahead of the UN high-level meeting on the prevention and control of non-communicable diseases, which was launched in 2011, with a review in July 2014, and another in late 2018. The EU's position and commitment at/to the high-level meetings was made especially clear in a European Parliament Resolution ahead of the launch of the UN initiative, in September 2011, when a reference to pain was made for the first time.

Another important point of reference is Article 8(5) of the EU Directive on the application of patients' rights in cross-border healthcare (2011/24/EU) which states that an objective assessment of 'the degree of the patient's pain' must be used to assess the right to cross-border healthcare. Indicators are therefore needed in Member States to set criteria for granting access to cross-border healthcare and to compare the quality of healthcare services available to citizens, consumers, and patients. The implementation of the Directive is now under review by the EC, which opens a window of opportunity to raise debate within the EU institutions and expert organisations on the need to develop indicators for pain measurement as part of the implementation of the Directive.

The informal conclusions of the EU Health Ministers meeting in 2014, under the auspices of the Italian Presidency, pledged to further promote the use of palliative care and pain therapy in the EU member states

The 2017 Council Conclusions on 'Encouraging Member States-driven Voluntary Cooperation between Health Systems' called for evaluation of access to treatment for patients with chronic pain, while recognising the need to maintain the balance between innovation, availability, accessibility, and affordability.

As a result of the Maltese Presidency and Valletta SIP meeting, in 2018 EU Health Ministers included chronic pain in the EU Council conclusions (more details in section 2.2.).

On the topic of indicators, the EU funded BRIDGE-HEALTH project has provided a definition for the 37th indicator on ‘General musculoskeletal pain’, which falls under ‘Diseases and Mental Health’ in terms of policy areas and more specifically, under (Preventable) Burden of Disease (BoD) and health threats, communicable diseases. However, this indicator is still under development and no data is available in international databases. Therefore, further work has to be done and the Joint Action on Health Information (InfAct), which had its kick-off meeting in March 2018, is tackling the issue.

The State of Health in the EU is another significant reference point for the pain community. It is a separate, two-year cycle initiative between the EC and the OECD and provides policy makers, interest groups, and health practitioners with factual, comparative data and insights into health and health systems in EU countries. It tackles pain in the context of employment and lower productivity as well as pain in relation to patient-reported outcomes.

Health at a Glance: Europe 2018

State of Health in the EU Cycle

Chronic pain, along with several other types of pain, is included in the 11th revision of the International Classification of Diseases (ICD-11), as revised in June 2018. The implementation in all Member States will take time.

The inclusion of chronic pain conditions in the ICD-11 will further the recognition of chronic pain as a health problem in its own right and contribute to improved access to adequate pain treatment for persons with chronic pain worldwide.

The new ICD-11 classification is also expected to enhance pain management outcomes, in that it allows for inferences about unknown aspects of an individual who has been assigned a specific pain category. Given a pain (sub)category, clinicians and researchers can infer likely causes of symptoms, predict most likely consequences, estimate a timeline, the most likely future developments, and optimize treatment plans for that person.

The new classification of chronic pain will have to be shown to be reliable and clinically useful. The next step in the development of ICD-11 will be to encourage field trials to establish the psychometric properties of these codes and their utility.

2.4.2 Employment and pain

The EU Information Agency for Occupational Safety and Health (EU-OSHA) states that "musculoskeletal disorders (MSDs) are one of the most common work-related ailments. Throughout Europe they affect millions of workers and cost employers billions of euros. Tackling MSDs helps improve the lives of workers, but it also makes good business sense."

As musculoskeletal disorders are often work-related, Eurostat and other EU bodies collect data or report information on this issue. Under the heading of "Health and well-being at work", the European Foundation for the Improvement of Living and Working Conditions (Eurofound) has developed the European Working Conditions Survey which mentions that "musculoskeletal disorders are one of the most common work-related complaints, affecting millions of workers and costing billions of euros to employers."

In June 2018, the European Parliament Committee on Employment and Social Affairs unanimously adopted an own-initiative report on "Pathways for the reintegration of workers recovering from injury and illness into quality employment". It sets out measures that the EC and Member States should address to retain and reintegrate workers who suffer from chronic conditions or injuries into the workplace.

To address the issue at a broader level, the European Pillar of Social Rights was formally established by the EC in November 2017. The Pillar "reflects a joint commitment to providing a healthy, safe and well-adapted work environment for workers in the EU.

Since 2019, SIP is also formally collaborating with the CHRODIS PLUS - a high level response by the EU to support Member States by coming together and sharing best practices to alleviate the burden of chronic diseases. This three-year initiative (2017-2020) under the Third EU Health Programme (2014-2020) is funded by the European Commission and the participating partner organisations. SIP has become a collaborative partner involved in Work Package 8 on Employment and Chronic Diseases.

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2.4.3. Research on pain

In terms of research, the EC Framework Programmes for Research and Innovation funded a number of projects addressing pain such as the "EuroPain" focusing on understanding chronic pain and improving its treatment, "RELIEF" looking at the use of new technologies to assist chronic patients to self-manage their pain, and "DOLORisk which addresses personalised medicine and the better stratification of the patient to develop a risk model for neuropathic pain.

Further to this, since 2008, the Innovative Medicines Initiative (IMI), EU public-private partnership, has been working towards advancing medical research to overcome societal challenges and, as such, funded specific research on pain, "IMI Pain Care", to deliver on the project 'Improving the care of patients suffering from acute or chronic pain'.

Pain research will be continued in the upcoming EU Framework Programme "Horizon Europe" (2021 – 2027). Currently the Commission's proposal for this ambitious, nearly €100 billion research and innovation programme is being finalized by the EU Council and European Parliament.

2.4.4. Global resources

In 2007 WHO published a study "Neurological Disorders: Public Health Challenges". The document looks at the global public health importance of common neurological disorders. Chapter 3.7 "Pain associated with neurological disorders" discusses at length types of pain, pain disorders, assessment of pain, public health aspects of pain disorders, disability and burden, treatment and care, management of pain of neurological origin, service delivery, research and training.

September was officially recognised as International Pain Awareness Month at the 70th World Health Assembly in 2016. The campaign seeks to raise awareness of pain with patients, policy makers, healthcare professionals, as well as the general public.

As a result of the 2018 UN High Level meeting on Non-Communicable Diseases, in the UN Political Declaration has included mental health, including neurology as the so called 5th NCD (ahead of cancer, CVD, diabetes and respiratory disorders). This creates an opportunity for the pain community to be more present in the global NCDs portfolio as well as related Sustainable Development Goal 3.4.

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3. WHY THERE IS A NEED FOR SIP NATIONAL PLATFORMS?

3.1. Stronger by speaking in one voice

Poor management of chronic pain is a huge burden on society. However, when various groups of stakeholders advocate separately, their messages often fail to reach the ears of decision-makers. This is why creating a national coalition can benefit the pain care movement in your country:

- It improves the visibility of chronic pain: by joining forces, your voice is louder, and your actions have a bigger impact. You can attract media attention more easily

- Increased representativeness means more credibility: the fact that a national platform represents a big array of relevant stakeholders increases its credibility with decision-makers. Your advocacy work has more weight, as you represent more voters

- The national platform becomes the single point of contact for external stakeholders. You increase the chances for direct and regular contacts between pain community and a diverse set of stakeholders (decision-makers, media...). Ultimately, the national platform can be recognised as a partner by other stakeholders. The national platform can work on cross-cutting issues, enabling disease-specific organisations to focus on their area of specialisation.

- Speaking for your country on the international stage: a national platform is able to provide a country-specific consolidated pain experts' perspective at European and international level

- By pooling together the energy and human resources of the different member organisations, a national platform can ensure a continuous presence of pain-related issues in health and social policies and programmes. It also provides a forum for generating collaborative responses.

3.2. Smarter by sharing resources and knowledge

As well as raising visibility among decision-makers, the media and the wider public, forming a national platform of stakeholders interested in pain care means building on the expertise of others, increasing your knowledge and broadening your understanding of the chronic pain and its community.

- Seeing the big picture: a national platform can provide an overview of overarching patterns and complementary issues. This is beneficial both to the platform and its members, allowing thematic or disease-specific groups to focus on the specific challenges of their area

- Expanding your horizons: one of the added values of a national platform is that it gives all involved parties the opportunity to understand each other's competing and complementary needs and requirements. It broadens the consideration of issues to include differing values and facts

- Learning from each other: a forum provides the opportunity to share information, good practices and expertise. It also enables the development of more complete and satisfactory solutions

- Transcending institutional boundaries: professional and patients organizations often have to deal with different stakeholders and governmental agencies according to the condition they represent. Yet, problems that affect the entire community are best addressed by approaches that involve the resources of the entire community

- Individual gains: Being part of a national platform also means benefits for individual organisations and medical specialities that are a part of it. Thanks to this information exchange and common actions with other organisations, being part of a national platform results in more and quicker progress for the individual organisations in fulfilling their missions

- Use resources well: Through coordinated efforts, the associations involved also reduce the duplication of efforts and optimise the use of their own resources.

3.3. What is a National SIP Platform

A national SIP platform is an umbrella organisation grouping national or regional organizations and associations interested and active in pain care. These organisations come together and form a multidisciplinary coalition that should be representative of the collective interests of all involved parties.

Usually, the platform will be an informal body, as opposed to a more structured and labour-demanding legally constituted organization (that would require things such as general assembly, constitution and bank account).

A national platform will be aligned with and will closely collaborate with SIP EU.

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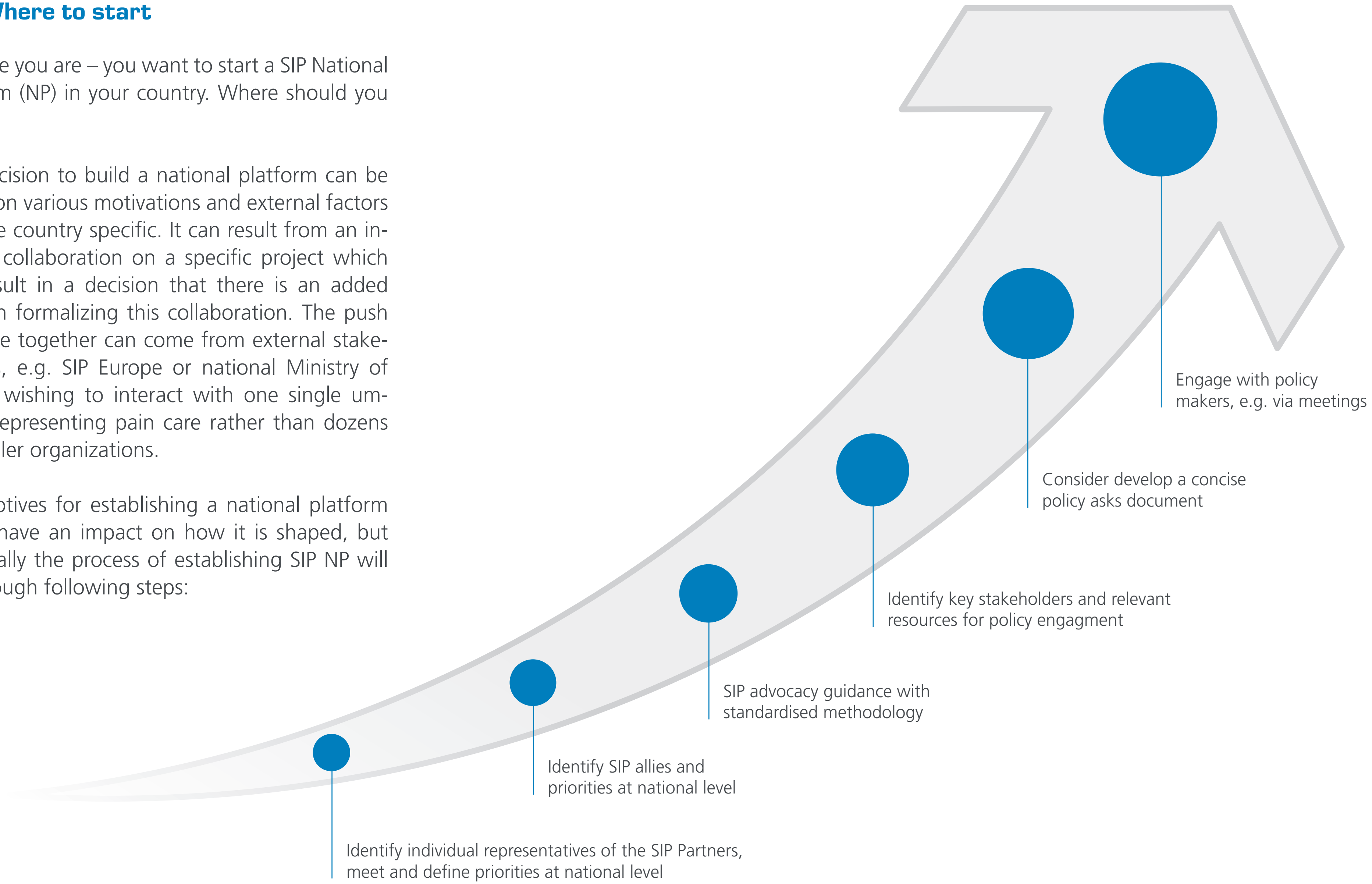
4. HOW TO SET UP A SIP NATIONAL PLATFORM

4.1. Where to start

So there you are – you want to start a SIP National Platform (NP) in your country. Where should you start?

The decision to build a national platform can be based on various motivations and external factors that are country specific. It can result from an informal collaboration on a specific project which can result in a decision that there is an added value in formalizing this collaboration. The push to come together can come from external stakeholders, e.g. SIP Europe or national Ministry of Health wishing to interact with one single umbrella representing pain care rather than dozens of smaller organizations.

The motives for establishing a national platform might have an impact on how it is shaped, but essentially the process of establishing SIP NP will go through following steps:



Identify individual representatives of the SIP Partners, meet and define priorities at national level

Identify SIP allies and priorities at national level

SIP advocacy guidance with standardised methodology

Identify key stakeholders and relevant resources for policy engagment

Consider develop a concise policy asks document

Engage with policy makers, e.g. via meetings

4.1.1. SIP National Platform core group

Start with a small group and build it from there. The nucleus of SIP NP will consist of your country member organizations of EFIC and PAE as well as Grünenthal national representative. For example in France these are: French Society for the Study and Treatment of Pain (SFETD), Association Francophone pour Vaincre les Douleurs (AFVD), Association Française de Lutte Anti-Rhumatismale (AFLAR) and Grünenthal S.A.S.

The first meeting of this NP steering committee should be dedicated to a mapping process of the environment you find yourself in. You want to build on what is already there and avoid replicating work that has already been done or leaving out potential allies.

4.2. Define mission

A crucial step for any organisation is to define its ultimate purpose and ways to reach it. Developing a common understanding among the platform's members of who you are and what you stand for is essential to better present yourself to stakeholders, partners, and potential new members. Your mission and vision explain in a nutshell what problems your SIP NP intends to address in which way and for whom. Most importantly, they highlight the unique value of your coalition's approach.

The mission of an organisation should be stated in a few simple short sentences, free of jargon: easy to understand and easy to remember. It should be understandable by the organisation's staff, its members, and also by a wider audience.

An example of such a mission statement could be: By bringing together science and society to work towards decreasing the societal impact of pain in [COUNTRY NAME], with an ultimate goal of improving the quality of life of those affected by chronic pain.

4.3. Platform objectives

Examples:

To unite all [COUNTRY NAME] organisations and societies advocating for better pain care in order to jointly define and foster pain care policies

- To ensure access to adequate pain treatment for all [COUNTRY NAME] citizens
- To decrease the stigma of pain as an invisible disease
- To promote more research into pain

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This can be achieved by:

- Raising awareness of the relevance and impact that pain has on [COUNTRY NAME] society and its health and economic systems by demonstrating the socioeconomic burden of pain as well as the health gains of using best practice in pain management, as opposed to the cost burden of current care/non-treatment

- Exchanging information and sharing best-practices across all EU member states

- Contributing to development of Europe-wide policy strategies and activities for an improved pain care in Europe

Once you have defined your mission and objectives, you should consider sketching out the beginnings of an operational plan with key priority activities for the first couple of years. This can then be developed after the official launch of the coalition. Even if done in basic way due to limited resources, it can prove instrumental to your future success.

4.4. Key areas of focus

Each country should choose its focus and strategy on the basis of the specific policy landscape, gaps and challenges at national level. The SIP Joint Statement, building on 10 years of experience of the SIP Platform counted on the input and endorsement of national stakeholders from many countries across. The gaps identified via our SIP framing paper, informing the SIP Joint statement, were identified with the input of several national and European stakeholders. This process brought SIP Europe to cluster priority areas for policy engagement in pain in four areas. These broad policy domains can serve the national platform as starting points to flesh out their priorities.

- Pain as a quality indicator of healthcare systems
  Examples of policy areas on which to focus your asks in this domain:
  - o Advocate for the implementation of ICD 11
  - o Advocate for data to be collected on the socioeconomic burden of pain and pain impact on quality of lives
  - o Call for the establishment of pain registries and national plans for the prevention, treatment and management of pain

- Pain and Work
  Examples of policy areas on which to focus your asks in this domain:
  - o Adaptation and adjustments of the work environment such as part time and flex-time opportunities
  - o Re-integration policies such as vocational rehabilitation
  - o Build/gather evidence demonstrating economic benefits for businesses
  - o Monitor and encourage appropriate incentives for employers
  - o See work both as a preventive measure as well as support for a healing process

- Pain Research
  Examples of policy areas on which to focus your asks in this domain:
  - o Advocate for public funds to be allocated to research on the societal impact of pain
  - o Advocate for the inclusion of all relevant stakeholders in research development on pain (e.g. patient, citizens, clinicians, allied healthcare professionals) to ensure research outcomes are relevant
  - o Advocate for public funding to be allocated to the establishment of centers of excellence for multidisciplinary pain management
  - o Advocate for pain research strategies to be developed and implemented

- Education on pain
  Examples of policy areas on which to focus your asks in this domain:
  - o Raise awareness on societal burden of pain
  - o Increase access to pain education for health professionals and the general population
  - o Fight the associated stigma

4.5. Invite more members to the National Platform (NP)

Once the core of SIP NP is defined, invite more members in. Who are your potential members? NPs are usually composed of organisations active at national level only. However, according to your national reality, you may want to leave the door open to regional associations. Consider the role and criteria that each of these stakeholders must fulfil to become a member. What can be gained from a collaborative approach?

Remember that you want to be surrounded by people with motivation, vision and connections in the pain community, as well as leadership skills. They should be able to speak on behalf of wider pain care community rather than just their individual/speciality interests – in other words they are able to put the interest of the future NP first and work for the common good.

See what you have in common so as to identify what is the added value of your cooperation. Encourage participants to take these points back to their own organizations for feedback at the next meetings of the expanded NP steering group.

In the initial stage of formation, there might be a need to meet more frequently to stay engaged and work out any early difficulties that might arise. Make sure you have specific agendas, timings and anticipated outcomes to make the best use of everyone's time.

Before you move on to the next steps, be sure that all involved members share the same understanding about SIP NP. To this end you might consider developing an internal memorandum of understanding among those involved in the steering group.

SIP Europe partner can provide the founding partners of the NPs with guidance, background on the SIP work, methodology and examples from other platform to help them get started. SIP Europe will continue providing support with ongoing communication and engagement (see Relationship and cooperation with SIP EU - section 5.3).

4.6. Next steps

4.6.1. Identify Key Stakeholders

Define with whom your NP will be interacting, and in what manner. Write down the stakeholders you think are relevant for SIP NP and then consider dividing them into three groups: "Potential members" (this is covered in section 4.1.2.), "Allies and partners" and "Target audience". The SIP website "www.sip-platform.eu" is a good place to start looking for members and allies, check here "www.sip-platform.eu/sip-platform/endorsers-by-country" who are the endorsers of the SIP platform in your country and consider contacting them.

Who is your target audience? Whom are you trying to convince? You need to have a clear idea of the environment you will be evolving in. A good process to do this is to conduct a "PEST Analysis", looking at the political, economic, social and technological environment and its likely evolution in the foreseeable future. For this exercise to be most useful, assign a "score" based on the level of "criticality" of the factor at stake:

- Economic: e.g. financial crises, unemployment, reduced per capita income, reduced funding
- Political: e.g. elections, new legislation, changes to the health system
- Social: e.g. demographics (age of the population), increasing incidence of disease, press attitude, public opinion
- Technological: e.g. communication infrastructure, research and development of new medicines
- Other

To complete the picture, identify the greatest external opportunities and threats that may help or hinder the work of the coalition. Focus on outside factors that may help the coalition

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to do its work (opportunities) and the outside factors that may be unhelpful/hinder the work of your coalition (threats). Note that some factors/trends may be both an opportunity and a threat.

- Opportunities: e.g. health ministry acknowledgment of the role that civil society plays in policy discussions
- Threats: e.g. stigma affecting policy decisions or unfavourable legislation
- Both opportunity and threats: e.g. development of the new health system can be an opportunity if pain care stakeholders are involved or a threat if they are excluded from the process.

See also section 8.6.1 with Stakeholders Assessment Matrix.

4.6.2. Map existing national resources and gaps

It is vital that you have a solid understanding of current legislative framework and scientific data on pain care that are already available in your country. Carefully map existing studies, data, national plans etc. so that you are aware what the strengths are and where there are gaps.

4.6.3. Your pitch

Consider developing a document that captures the policy asks of the NP in a short and understandable way e.g. joint statement/white paper/manifesto. See also section 8.2.3. Joint Statement from Portugal.

4.6.4. Meetings with key politicians and other stakeholders

Among key objectives of your national platforms, you will be seeking to advocate on key policy issues and share policy recommendations and, as such, one of the SIP NP to exert influence over policy making process and, as such, one of SIP NP key components should be to establish and maintain relationships with national policy-makers. Therefore one of your first activities, after mapping potential stakeholders, should be requesting meetings with stakeholders such as key politicians from national ministries (e.g. health, research, employment), members of your parliament (especially those involved in relevant committees), other government bodies dealing with Health Technology Assessment, payers etc. It will be beneficial if you also establish relationships with some key Members of the European Parliament from your country – beside benefits that such contacts can offer to your SIP NP, they can be also helpful for SIP Europe.

See also section 8.6.2. with Introductory letter or email to stakeholders such as politicians

4.6.5. Organize events

Consider holding periodic events. While organizing events should not become the main focus of SIP NP, they can be a very effective tool to increase your visibility and get your messages heard among selected audiences. With this in mind, you should consider holding meetings such as periodic events to mark a specific occasion, e.g. annual Pain Awareness Day. Once your platform is up and running, you can also consider holding regular annual events bringing main national pain care stakeholders together along with other target groups.

4.6.6. Engage with media and journalists

Media can play an important role in creating awareness and provide a vital platform for accessing decision makers. Local, national, and EU politicians often receive dozens of letters, phone calls etc. but they are also members of the public and as such media coverage can be useful to catch their attention. For this purpose, media can be an effective tool. It is advisable to create an overview of the media in your country and split it into the relevant sectors e.g. broadcast/trade/consumer etc. and highlight the differences of each. This will enable your SIP NP to have a much more targeted approach when it comes to dealing with the media.

Media can also be used to create awareness and drive attendance to local conferences or event, through organizing round tables, participating in radio shows, contributing to articles and looking for the interview opportunities.

Cultivating a good network with journalists is an asset. On the one hand, you can ensure that your messages are heard, and communicated in an appropriate manner. On the other hand, it will increase the number of opportunities for being used as a source in the future, which will also add to your credibility. It is very important to be well prepared for a meeting with any representatives from the media. It is important to remember that when dealing with the media that nothing is off the record.

When creating a national event, consider hosting a press conference during the event, which could include a panel of speakers from the event. However, this approach is best used if you have some ground-breaking news which you want to share with the press.

See also section 8.3. - Approaching media/journalists

4.6.7. Use social media

Social media is now a critical part of the media landscape and in many cases stories develop and break online before they are covered in traditional media channels. Social media is interactive and fast moving – with content updated in a matter of minutes. Therefore, it is useful to have a social media plan in place to ensure you are maximizing the potential it has and using it in the right way.

The most important social media networks that you are probably already well aware of are:

- Facebook (@SIPPainPolicy)

  Almost everyone has a Facebook page, including businesses and organisations. It is not a place for debate in the same way as e.g. Twitter. Instead, it is a good place to share information and events that are important to ordinary people.

- Twitter (@SIP_PainPolicy)

  Media and politicians often use this media as a way to interact with their audience. Therefore, this is also a good place to catch these stakeholders’ attention and interact with them. The use of hashtags (#) makes it easy to track certain debates and events (e.g. #chronicpain, #impactofpain #pain policy)

- LinkedIn (SIP“SocietalImpactofPain”Group)

  The business oriented network mainly focuses on professional networking. However, LinkedIn can also be used to post more scientific articles and create discussions. Therefore, LinkedIn could be used to create interest and awareness among e.g. professionals working with the pain, but it should probably not be the first place to focus on when entering the social media stage.

- Youtube (@SIP YouTube)

  Can be used to share videos. When a person follows the channel (s)he will receive a notification about new uploads.

See also section 8.4. - Create and implement a social media strategy

5

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5. RELATIONSHIP AND COOPERATION WITH SIP EUROPE

5.1. Aligning strategy

SIP Europe and all national platforms are intrinsically connected and interlinked and should have their goals and strategies aligned in an effort to reinforce one another.

5.2. Regular communication channels

SIP Europe provides regular communication channels that include:

- Periodic online meetings organised and moderated by SIP Europe with all SIP NP representatives
- Newsletter and website featuring relevant information for the Platforms and with dedicated space for each platform to provide updates (you can subscribe here)
- Dedicated group on the EU Health Policy Platform. You can register here and here are guidelines on how to register.
- In addition to this, SIP Europe will strive to organize annual meetings that bring SIP NP representatives together to discuss good practices, common challenges as well as joint work.

5.3. Joint policy initiatives

SIP Europe can help building bridges between national and EU policy engagement. The following can serve as examples:

- Engagement with rotating presidency of the EU from the national platform countries
- Joint work to approach Members of the European Parliament to further both European and national goals.

6

6. TRANSPARENCY AND DISCLAIMER

Ethics and transparency are an absolute priority for organisations involved in public health advocacy. This applies to every aspect of an organisation's structure and activities and is especially crucial when it comes to funding. For this reason, the following SIP Europe disclaimer has to be included/adapted for the national context:

SIP Europe disclaimer

The scientific framework of the SIP platform is under the responsibility of the European Pain Federation EFIC®. Co-operation partners for SIP are Pain Alliance Europe and Active Citizenship Network. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support

Below is a template example that you can adapt in your language.

The scientific framework of the SIP [country] platform is under the responsibility of the [National Chapter of the European Pain Federation EFIC®]. Co-operation partners for SIP are [National member of Pain Alliance Europe/ relevant national patient group] and [relevant national citizen organisation]. The pharmaceutical company Grünenthal [National entity of Grünenthal] is responsible for funding and non-financial support (as applicable).

All activities of SIP must be non-promotional and not related to any specific treatment option. The standard SIP disclaimer must be included in any material or communication. All applicable regulations including codes of practices must be followed to ensure that SIP is respected as a platform with high ethical standards and collaborates in a transparent way.

7

7. SUSTAINABILITY

Your national platform is set up. Congratulations! Now you need to ensure its sustainability, to develop the capacity to grow and adapt to a changing environment. Only in this way you can have a real impact and reach your goals that go beyond the initial period of enthusiasm. Sustainability can be seen as consisting of following elements: strong structure + clear and long-term planning + sound and diverse funding base + effective communication + ownership. These are some of the things to keep in mind:

7.1. Plan strategically

Develop your first strategic and action plans. It's hard to accomplish anything without a plan, even if your plan is basic at first, due to limited resources. By writing your SIP NP strategic and operational plans, you translate your mission and vision into concrete actions. A strategic plan looks at all the things your organisation could do and narrows it down to the things that you can realistically achieve, and where there is most added value for the SIP NP to intervene. A strategic plan also helps the platform's leadership to determine where to spend its resources.

7.2. Communicate effectively

To grow your membership and your impact and to build your legitimacy, you need to communicate on your national platform.

Know your target audience: You do not use the same arguments or the same tone to invite a patient organisation to join the national platform or to convince the Ministry of Health to meet with you. Segment your audience, adapt your messages and develop specific material for each of your targets.

Streamline your communication: Each of the people involved with your organisation may have a different reason why they are doing this, and all of them might speak about your organisation and the work you do with third parties, be it in an informal context, at a networking event or when making a speech at a conference. You also need to make sure that the persons who are going to speak about your SIP NP to external stakeholders will give the same view of your organisation. Indeed, when promoting the work of your organisation, you should be speaking with a unique voice.

7.2.1. 5 key messages about your organisation

During a meeting with your NPs members, list the most important things you want other people to know about your SIP NP. It may be the vision of your umbrella, the current topics you cover, and/or what it can offer to other people. Reduce the list to five pieces of information and create short and realistic messages that summarise your work and will grab people's attention. Make sure you disseminate these five key messages throughout and review them if necessary. See also section 8.1. – Key messages

7.2.2. Create an elevator pitch for people who will represent the NP in public

An elevator pitch answers the question: "If you only have a minute to talk about your platform, what would you say?" See an example in section 8.1.3.

This tool prevents you from going into every detail of what your organisation does and to get the attention of an audience in a very limited time and should be learnt by individuals who are going to represent your platform externally. Develop a short story that will make your platform's work come alive and demonstrate your impact. Make sure your pitch is clear, concise, credible, concrete and conversational enough.

7.2.3. Don't forget about internal communication

A great mistake would be to invest all of your efforts in external communication. Open and transparent communication with members is key to ensure the NP's transparency and democracy. In order to ensure ownership and commitment, you need to put in place user-friendly communication tools that facilitate the internal information flow.

Examples of internal communication tools include websites, intranet, social media groups (Facebook group), printed or online newsletters for NP members only, physical meetings, training events, emails, phone calls, teleconferences.

The journey towards sustainable organisations is a long one. We know that with this toolkit we cover only one of the many steps to becoming a strong and credible SIP partner. As part of our commitment to capacity building, SIP Europe will continue to develop and share resources with National SIP Platforms members and will address new topics in the years to come.

8

8. USEFUL RESOURCES

8.1. Key messages

8.1.1. Short key messages

- Of the 750 million people in Europe, 20% of them, or the population of Germany and France combined, will experience chronic persistent pain at some point in their lives (Eccleston, Wells, & Morlion, 2017).

- Experts estimate that half of all citizens living in the EU at some point in their lives suffer from back pain. Approximately 15 percent of these citizens with back pain are on sick leave for over one month (Bevan et al., 2009).

- Chronic pain causes unmeasurable suffering to those affected.

- The estimated direct and indirect healthcare costs for chronic pain disorders vary between two and three percent of GDP across the EU (Bevan, Stephen. 2013) (Breivik et al. 2013.). For 2016, this would result in up to 441 billion Euros annually (EuroStat 3 30, 2017.)

- Pain remains the major source of disability worldwide, and is the main reason people seek to health care, from general practice to emergency care. This increases the risks of other health problems, social exclusion and poverty (Eccleston, Wells, & Morlion, 2017).

- Stigma and lack of public knowledge worsen the burden on patients and families by preventing people in pain from seeking treatment (Brain, Mind and Pain, The Book of Evidence, 2019).

- Large health inequalities persist in the EU as many patients do not have access to adequate pain treatment (Barnett, et al., 2012).

- Pain-related conditions result in an increasing part of the workforce retiring too early. Musculoskeletal pain causes almost 50% of all absences from work lasting at least three days in the EU and 60% of permanent work incapacity (Breivik et al. 2013).

- Chronic pain is also one of the major reasons why people exit the labour market prematurely and it contributes significantly to disability retirement (Saastamoinen et al., 2012).

- In [country name] alone annual cost/prevalence etc. (please list here any data that you have for your country) of chronic pain amounts to [figure]

- To address this, under the umbrella of the European SIP platform, SIP [country name] was established to improve pain care policies

- SIP NP [your country] brings together representatives from [country name] organisations having an interest in pain care like: healthcare professionals, pain advocacy groups, health care authorities and industry.

SIP [country name] aims at:

- Raising awareness of the relevance of the impact that pain has on our society, health and economic system

- Exchanging information and sharing of best-practices

- Developing and fostering policy strategies & activities for an improved pain care.

8.1.2. Key messages - expanded

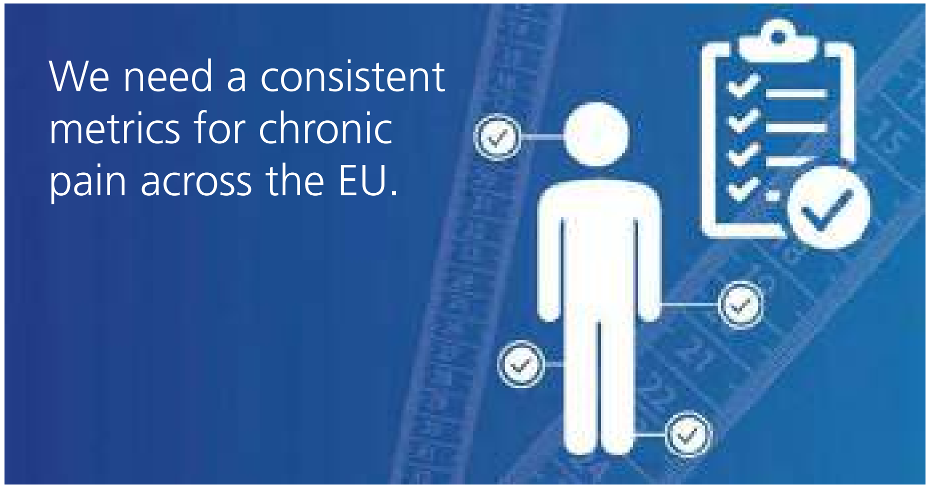
What is pain?

Pain is an "unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."(IASP, 2017).

Acute pain is pain of recent onset and limited duration due to injuries, illness, or as a result of surgical interventions, e.g. post-operative pain, acute headaches, strain trauma and burns, fractures, activated arthrosis, and dental pain. (Ready and Edwards, 1992).

However, acute pain which persists for longer than three months, is generally classified as chronic pain (Treede et al, 2015).. The process of which is known as 'chronification'. "Biologic factors involved in this transition include central sensitization, neuroplastic changes, altered pain modulation, and changes to the "neuromatrix." Chronic pain may involve irreversible pathophysiologic changes, so interrupting the cascade of events that allows acute pain to advance to chronic pain is of crucial importance.

Pain can also arise due to other illnesses (known as "co-morbidity") and can result in palliative care. Further, pain is commonly connected with numerous chronic health conditions, such as cancer and musculoskeletal diseases. (Roberto, et al., 2016) (Majithia, Loprinzi, & Smith, 2016) (IASP, 2009) (Mieritz, Forman, Mieritz, Hartvigsen, & Christensen, 2016). Indeed, chronic pain often accompanies other long-term illnesses.



Burden of pain at European level

In Europe the population is approximately 740 million people (United Nations Population division). Most of these people experience an episode of severe pain at some point in their life. For approximately 20 percent, that pain is chronic – episodic, persistent, or variable. In other words, today there are 150 million people in Europe experiencing pain. That number is approximately equal to the populations of Germany and France combined. (Eccleston, Wells, & Morlion, 2017).

Pain can interfere with a person's quality of life and general functioning. People in pain can experience impairments in attention, control, working memory, mental flexibility, problem solving and information processing speed (Hart, Wade, & Martelli, 2003). In the presence of chronic pain, other aspects of health (physical, psychological, social) are severely reduced (Elliott, Smith, Penny, Chambers, & Smith, 1999) (Smith, et al., 2001). Additionally, pain is associated with increased depression, anxiety, fear, and anger (Bruehl, Burns, Chung, & Chont, 2009).

Pain complaints cause a large proportion of physician visits (Gureje, Simon, & Von Korff, 2001) (Mäntyselkä, et al., 2001) (Koleva, 2005), placing a large burden on clinics and healthcare professionals to treat the increased number of patients in an appropriate manner. As a result, pain places an enormous economic burden on healthcare systems (Eccleston, Wells & Morlion, 2017).

Pain related conditions result in an increasing part of the workforce retiring too early. With more than 500 million sick days per year in Europe, musculoskeletal pain causes almost 50 percent of all absences from work lasting at least three days in the EU and 60 percent of permanent work incapacity (Bevan, 2013). Unsurprisingly chronic pain is one of the major reasons why people exit the labour market prematurely and it contributes significantly to disability retirement (Saastamoinen, et al., 2012).

This is where it will be important that one of the first activities of your SIP NP be mapping of country specific data on pain that you will be using in your advocacy work. If there is no data or it is outdated, you should consider coordinating collection of the most recent national data.

8.1.3. Elevator pitch

Ideally an elevator pitch (30-60 seconds long) should only come at someone else's prompting. If you're spontaneously reciting it to random people, you're not doing yourself any favours. But if they ask, you want to be prepared with an interesting, well-crafted pitch.

Below are a few paragraphs that you could use in the elevator pitch but you will be most convincing if you adapt it to your circumstances and wrap it in a short story that is relevant for you.

Briefly introduce yourself by saying who are you and what your connection to pain care is.

Relate to a person you are talking to by mentioning that with a high degree of probability he or she experienced in their life at least one episode of more or less severe pain. As the person to imagine how it would feel to have such pain persisting for day, weeks or longer.

Chronic pain is neurological issue and not a psychological problem. It is a "programming" process. Just like an artist, athlete, or musician, pain lays down reproducible pathways - with repetition such chronic pain pathways are created in a similar manner. Pain pathways hit the brain much faster and are very often linked with anxiety and anger. Once a neurological circuit is created it is permanent. Is it possible to unlearn to ride a bicycle?

Although there is no medical test to measure chronic pain levels, all pain is real. This may seem obvious, but people with chronic pain are sometimes treated as if their chronic pain is either imaginary or exaggerated. In some cases, they feel they have to prove their chronic pain to their friends, family, and doctors.

Depending on who you talk to, it might be a good idea to select a couple of statistics from key messages (section 8.1.1.) demonstrating the burden that pain has on society.

Finish with a take home message that will depend on who you are speaking to. It can be asking for a meeting, referring to a particular resource, giving an invitation to an event, making a referral to a specific piece of legislation that you are hoping to influence, or even inviting the person to think if he/she knows someone with chronic pain and could use what he/she just learnt to offer more understanding and support.

8.2. Good practice examples

SIP
Societal Impact of Pain
FRANCE

8.2.1. France: detailed case study with full list of activities

SIP France was officially created on May 2018, however many initiatives were carried out before its formal constitution (more details below).

Currently France SIP focuses on two themes:

1. Care pathway for patients in pain
2. Pain and disability

> Only 22% of medical schools in the EU offer a dedicated pain medicine module.

To improve patients’ experience under these two themes, the following steps have being taken so far:

Position paper (White Book on Pain)

In 2017 the French Pain Society SFETD published the “White Book on Pain”. More than 60 authors participated in the project, including medical doctors from numerous specialties, nurses, psychologists, physiotherapists and also patients representatives, pharmacists, and veterinarians. This was built in the context of presidential elections in France in 2017, with a new government, as health was a central question of the presidential programme.

Over 300 pages the White Book summarizes all aspects of pain in France: epidemiology, healthcare professionals, education for all professionals, pain management in all settings (hospital and private practice and all specific care centres), current licensed drugs and difficulties for new approvals and complementary medicines, safety issues. Building on this, it offers relevant solutions and approaches for a new policy on pain, for the whole country and all patients, with innovative aspects.

The book is an example on how to analyze all aspects of pain medicine, not only at the hospital and university levels but also at all levels where pain can be a problem: in emergency rooms, in psychiatry care, in long term dependency care and in pediatric care.

The paper calls upon policy makers for mobilization against Pain in France. Its key messages are:

- Pain has to be recognized as a crucial health issue, requiring a stronger care trajectory
- To reach this objective, it is essential to implement concrete measures, focusing on five aspects

1. Integration:

a. Enhance pain assessment and care training for all involved healthcare professionals, notably regarding vulnerable population

b. Understand the importance of medical visits dedicated to pain

c. Strengthen the role and function of care networks, interprofessional coordination and coordination between hospital and ambulatory care

2. Prevention

a. Improve pain prevention strategies for patients receiving specific cares, such as surgical procedures

b. Improve the involvement of front-line health care professionals, including occupational therapists, and medico-social workers in pain prevention strategies

c. Develop research to better understand pain related mechanisms and enhance the effectiveness of prevention and care

3. Patient participation

a. Systematically use assessment tools, notably for « silent pain » and vulnerable patients

b. Help patients to understand pain mechanism and to take responsibility for their own care

c. Improve patient access to tailored analgesics, in respect of recommendations and good practices aiming at ensuring proper use of medicinal products.

4. Patient protection

a. Improve recognition of disability status for patient in pain (for the most severe cases)

b. Strengthen the modalities of pain care for the most vulnerable populations, disabled people (physically and mentally), elderly people, disabled, cognitively impaired.

5. Mobilization

a. Recognize the fight against pain as a priority of the French health policy for a five-year term and beyond

The White Book on Pain (in French) can be downloaded here.

National conference (October 2018)

Think Pain, Treat Pain

- A meeting under the high patronage of the Minister in Charge of Solidarity and Health
- Hosted by the Solidarity and Health Ministry
- Gathered around 90 participants: patients, representatives of healthcare professional organizations and learned societies, Members of Parliament, public authorities

SFETD

Livre blanc
de la douleur 2017

État des lieux et propositions pour un système de santé éthique, moderne et citoyen

Société Française d'Étude
et de Traitement de la Douleur (SFETD)

- The following themes where discussed:

  1. Does chronic pain cause disabilities?

  2. Pain care: what are the issues for the French health system?

- Speakers included representatives from SFETD, Grünenthal, members of the scientific committee, a Member of Parliament, a philosopher and a psychanalyst and the General Secretary of the Inter-ministerial Committee for Disability

A regional roundtable (February 2019)

- Lunch-time debate on the course of care of the patient with pain

- 50 participants representing public authorities, health professionals, social activists, and patients - this promoted the position paper and its recommendations

- Spread of the national debate initiated last October at the 1st National Forum against Pain around the region

- Exchanges on the challenges of the pain care pathway in the district and on the initiatives that could be developed to address them, especially in the most vulnerable populations in order to improve the diagnosis, assessment and management of the pain patient in his or her health pathway

- Discuss the daily difficulties in taking care of patients with pain and the initiatives implemented by their organizations to address them

Other initiatives of the SIP NP include:

Meetings with key policy makers

Discuss the proposals of the position paper (ongoing)

A comic book

It shows the complicated care pathway of the pain patient

Open Letter to the future French President

Back in 2016, in anticipation of the French Presidential election in May in 2017, doctors and patients called upon the future President to “open a new chapter in the fight again pain”.

8.2.2. Malta - video

In 2017, with the support of SIP Malta, national organisations Malta Health Network (MHN) and No Pain Foundation (NPF) started a research project to provide data on the extent of chronic pain in Malta and its impact on the day-to-day activities of affected individuals, including social and economic repercussions.

One of the results of this research is a short video explaining the outcome and importance of pain in Malta.

8.2.3. Portugal – Joint Statement

Patient associations and scientific societies from SIP Portugal signed a Joint Statement recommending the urgent implementation of measures to promote the employability of people with pain. The statement was subsequently discussed at a meeting with companies from different sectors of activity to present measures to promote the maintenance of work or professional reintegration of the person with chronic pain, in order to reduce absenteeism and presentism, as well as early retirement due to disability.

8.3. Approaching media/journalists

- Identify the target group for a specific event/issue; some events might be relevant to national media, while others will only be relevant to local or specific (e.g. scientific journal) media

- Content of the invitations:

    - Be specific in your invitation: “Dear ‘Local News’…”
    - Avoid sending the same invitation to several media at the same time (offer exclusivity)
    - Include details in the invitation that show the media why this is relevant to this specific paper/news channel etc. E.g. have a case history from the local area, numbers/data from the region etc.
    - If possible, relate the story to something that the media already has covered

- Get attention

    - Call the media –they will probably tell you that you will have to send an email to a certain person. Make sure you are prepared with ‘pitch points’ so you can ‘sell’ your story quickly and effectively. Calling the media in advance to learn whom to speak to will;

Joint Declaration of the Platform for the Social Impact of Pain in Portugal
Recommendations for Action

Preamble

1. Ensure that you get in contact with the right person from the start
2. Create more attention from the start, if the email starts with “as agreed with XX, I hereby send you…”

  - o Write to the journalist personally
  - o Do not send an invitation to both the journalist and the editorial office, if you are in doubt who you should send the invitation to, it is better only to send it to the editorial office
  - o Send a physical invitation, if the invitation stands out it will also create more attention. It is recommended that you send via email and if this can be an HTML email – so the invitation can be viewed in the body of the email rather than a separate attachment – this is usually preferred
  - o Journalists receive many stories every day, just because they do not use your story the first time you contact them, does not mean that you should not contact them again next time you have a story for them
  - o Send out press releases to create attention

8.4. Create and implement a social media strategy

- Consider which social media networks fit your organisation and if you have the right competences in your organisation or will need external advice.

- Create the content decided upon in your social media strategy on your social media page before going live and ensure that it is carefully aligned with the information on your website. When you add people on e.g. twitter, they will often look at who you are – this is a great opportunity to get followers. The more content you have on your profile, the more likely it is that people will recognize and/or find you interesting and worth following

- Add a recognisable profile picture (and background picture) and a brief paragraph about your SIP NP including a link to your website as well as a reference to the other social medias in which you are present

- Invite your network to follow/like your profile

- Ask individuals in your network to recommend your NP on social media. It is recommended that you write an email to some of your contacts making them aware that you now have a profile on XX social media and/or mention it via your other communication channels i.e. other social media, newsletter etc.

How to maintain your social media activities

- Keep up interest through regular updates. However, know your media: if you make too many updates on Facebook, it will tend to be perceived negatively by your audience. On Twitter, on the other hand, it is almost impossible to create too many updates

- To increase tweet views and attention, you can also add photos (or infographics) to tweets as often as possible

- A key action here for your SIP NP to consider would be to follow SIP Europe and where possible to re-tweet SIP Europe tweets etc. not only to further your reach but also to create additional content for your own pages. SIP NP thus invites you to join by “liking”, “share”, “re-tweet” or “follow”.

8.5. Ambassadors

Ambassadors can be a very good tool to increase visibility of your SIP NP. They could be politicians, highly profiled scientists or celebrities. The use of ambassadors will help you get the attention of the politicians and more importantly, the media. However, it is important that this is done in careful consideration of the audience that you wish to get attention from.

You also need to be realistic about what you will ask of them since most likely they will be busy people who will be reluctant to make new commitments. A great way to get their involvement can be to ask them to provide a short quote.

In looking for an ambassador use your personal contacts and also ask your networks to make recommendations for suitable persons.

When approaching potential ambassadors you can follow the steps below:

Letter 1
Request to potential Ambassador/ Endorsing organisations

Introduce SIP NP:

As part of this initiative, we are looking to engage with high profile individuals from all walks of life to lend their support and I would like to invite you to become one of our esteemed ambassadors. All we seek is a few lines about what it means to society to improve pain care in [your country]. Please be assured that we do not require any further input from you; it is your written support that will be so valuable to us.

All endorsements are added to our website which you can view at:

www.sip-platform.eu (find endorser on SIP Website)

We would be most honored if you feel able to accept our invitation as your name will add gravitas to this important initiative.

Letter 2
If you receive agreement to act as an Ambassador

Thank you so much for coming back to me so quickly. I am absolutely delighted and honored you are willing to become one of our esteemed Ambassadors.

We really appreciate your support in lending your name to such an important initiative. It would be an enormous privilege for us if you could prepare a few words about the importance of reducing the burden of chronic pain. All quotes will be uploaded on our website.

Again, my very sincere thanks for your participation in our campaign; it is highly valued and I look forward to hearing from you.

Letter 3
Thank you for giving us a quote

My very grateful thanks to you for sparing the time to give us a few words of support. It is enormously appreciated.

Again, my sincere thanks to you for lending your name to our important campaign.

8.6. Other templates

8.6.1. Stakeholder Assessment Matrix

Fill in the table below listing specific organisations/individuals, considering why they would be interested in chronic pain and whether they may be a good contributor of a national SIP platform.

Stakeholder Category e.g. NGO, Academia, Policy	**Potential Members**	**Allies and Partners**	**Target Audience**	**Current Interest in Pain** (Rate 1 to 5)					**Impact/ Power** (Rate 1 to 5)					**Partner Structure** (organisation/individual, legal, informal movement	**Keep Informed about Platform Work**	
				1	2	3	4	5	1	2	3	4	5		Yes	No

8.6.2. Introductory letter or email to stakeholders such as politicians

- "Dear Mr./Mrs./Dr. XXX": Take the time to find the full name and title of a person to whom you are writing
- Introduce yourself and your SIP NP
- If you have met the person before, you will of course need less introduction, however, keep in mind that politicians meet many people every day and might not remember you. Therefore, start with a short introduction of yourself and the SIP NP as well as a reminder of where you met
- State your reason for approaching this particular politician, e.g. is it to get the person sign a petition, participate in an event, to set up a meeting, etc.
- Conclusion
- Kind regards: insert title, your name and name of your organization
- Include SIP disclaimer

Template – Thank you note

- After having had a meeting with a politician, it is import to keep in contact. First step is to send a thank you letter after your meeting.

  "Dear Mr./Mrs./Dr. XXX

  On behalf of SIP NP, we would to thank you for your participation in (name of event) on (date)/ thank you for taking the time to meet with us"

  Other points to cover in the letter, cf. below;
- Short summary (reminder) of the meeting/event
- If it was a round table or similar; shortly describe the conclusions
- Any other important information/what has happened since the meeting
- A quick reminder of the actions/asks from the original letter
- (Further actions)
- Kind regards: insert title, your name and name of your organization

8.7. Key documents from SIP Europe

Key websites:
SIP Europe www.sip-platform.eu

Pain Alliance Europe
www.pae-eu.eu

European Pain Federation EFIC
www.europeanpainfederation.eu

The scientific framework of the SIP platform is under the responsibility of the European Pain Federation EFIC®. Co-operation partners for SIP are Pain Alliance Europe and Active Citizenship Network. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support.

Active Citizenship Network

www.activecitizenship.net

JOB OPPORTUNITY AT ACN

13th European Patients' Rights Day

Activities of SIP National Platforms

- Website with national news, initiatives and main contacts

SIP Stakeholders Group under EU Health Platform

SIP platform was selected as one of three topics for the Thematic Networks program in 2018. The networks are hosted by the EU Health Policy Platform, an interactive tool run by the European Commission (DG SANTE).

- See section 8.8. detailing steps to register

Members of the European Parliament (MEP) Interest Group on Brain, Mind and Pain

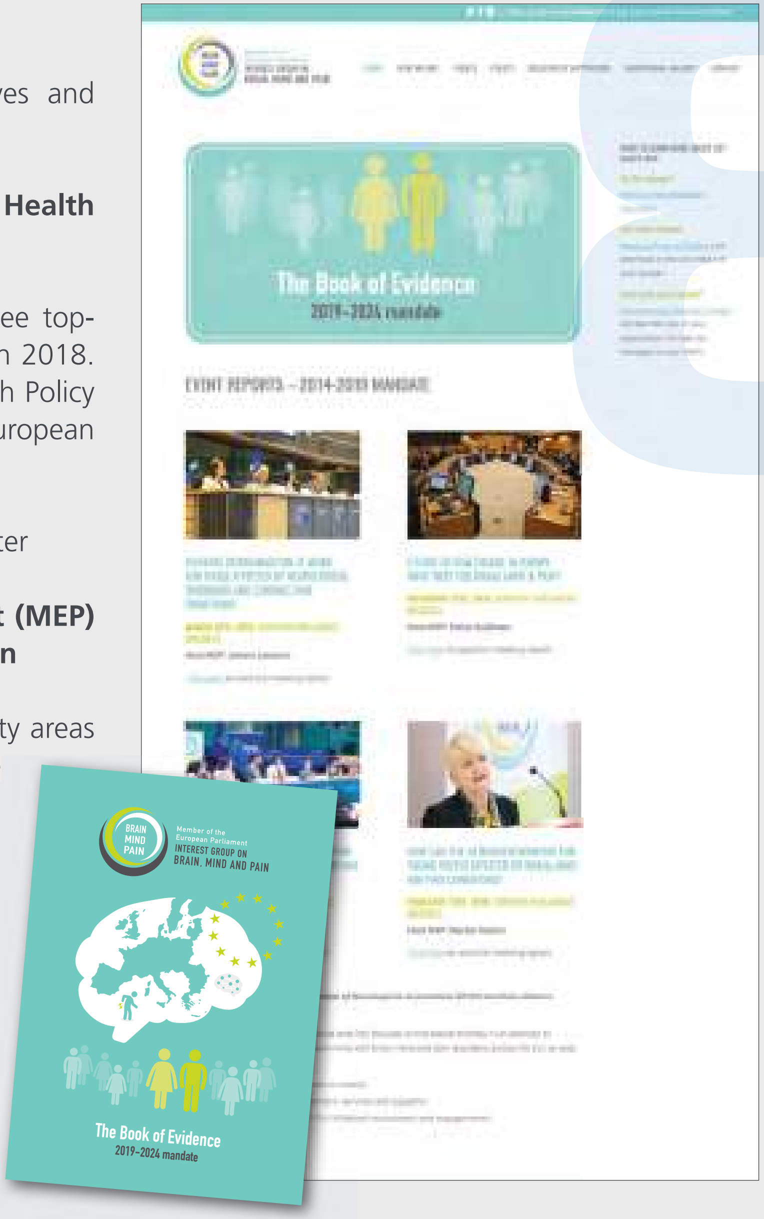
The MEP interest group focuses on priority areas in an attempt to improve the quality of life of all those living with brain, mind and pain disorders across the EU, as well as their families and carers:

The Book of Evidence 2019 – 2024

This Book of Evidence (BoE) sets a strategic vision on policy action to deliver better care for people with neurological and chronic pain disorders in the EU.

Brain, Mind and Pain

www.brainmindpain.eu



The Book of Evidence 2019–2024 mandate

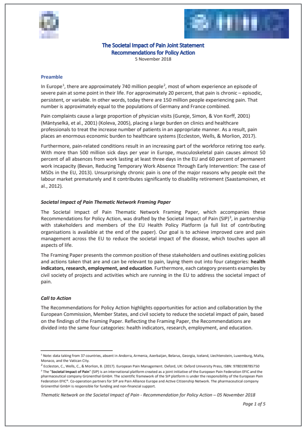
EVENT REPORTS – 2014-2019 MANDATE

SIP Thematic Network 2018 - Joint Statement

Below is the final Joint Statement and the related Framing Paper of the SIP Thematic Network on the EU Health Policy Platform which has been presented to the European Commission on November 12th 2018.

- Joint Statement
- Framing Paper
- Infographic

http://bit.ly/SIP-joint-statement



The Societal Impact of Pain Joint Statement
Recommendations for Policy Action
5 November 2018

Preamble

In Europe[1], there are approximately 740 million people[2], most of whom experience an episode of severe pain at some point in their life. For approximately 20 percent, that pain is chronic – episodic, persistent, or variable. In other words, today there are 150 million people experiencing pain. That number is approximately equal to the populations of Germany and France combined.

Pain complaints cause a large proportion of physician visits (Gureje, Simon, & Von Korff, 2001) (Mäntyselkä, et al., 2001) (Koleva, 2005), placing a large burden on clinics and healthcare professionals to treat the increase number of patients in an appropriate manner. As a result, pain places an enormous economic burden to healthcare systems (Eccleston, Wells, & Morlion, 2017).

Furthermore, pain-related conditions result in an increasing part of the workforce retiring too early. With more than 500 million sick days per year in Europe, musculoskeletal pain causes almost 50 percent of all absences from work lasting at least three days in the EU and 60 percent of permanent work incapacity (Bevan, Reducing Temporary Work Absence Through Early Intervention: The case of MSDs in the EU, 2013). Unsurprisingly chronic pain is one of the major reasons why people exit the labour market prematurely and it contributes significantly to disability retirement (Saastamoinen, et al., 2012).

Societal Impact of Pain Thematic Network Framing Paper

The Societal Impact of Pain Thematic Network Framing Paper, which accompanies these Recommendations for Policy Action, was drafted by the Societal Impact of Pain (SIP)[3], in partnership with stakeholders and members of the EU Health Policy Platform (a full list of contributing organisations is available at the end of the paper). Our goal is to achieve improved care and pain management across the EU to reduce the societal impact of the disease, which touches upon all aspects of life.

The Framing Paper presents the common position of these stakeholders and outlines existing policies and actions taken that are and can be relevant to pain, laying them out into four categories: **health indicators, research, employment, and education**. Furthermore, each category presents examples by civil society of projects and activities which are running in the EU to address the societal impact of pain.

Call to Action

The Recommendations for Policy Action highlights opportunities for action and collaboration by the European Commission, Member States, and civil society to reduce the societal impact of pain, based on the findings of the Framing Paper. Reflecting the Framing Paper, the Recommendations are divided into the same four categories: health indicators, research, employment, and education.

---

[1] Note: data taking from 37 countries, absent in Andorra, Armenia, Azerbaijan, Belarus, Georgia, Iceland, Liechtenstein, Luxemburg, Malta, Monaco, and the Vatican City.

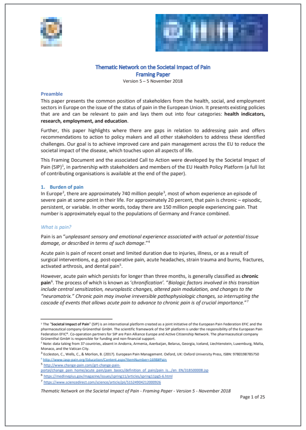
[2] Eccleston, C., Wells, C., & Morlion, B. (2017). European Pain Management. Oxford, UK: Oxford University Press, ISBN: 9780198785750

[3] The "**Societal Impact of Pain**" (SIP) is an international platform created as a joint initiative of the European Pain Federation EFIC and the pharmaceutical company Grünenthal GmbH. The scientific framework of the SIP platform is under the responsibility of the European Pain Federation EFIC®. Co-operation partners for SIP are Pain Alliance Europe and Active Citizenship Network. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support.

Thematic Network on the Societal Impact of Pain - Recommendation for Policy Action – 05 November 2018

Page 1 of 5

Joint Statement



Thematic Network on the Societal Impact of Pain
Framing Paper
Version 5 – 5 November 2018

Preamble

This paper presents the common position of stakeholders from the health, social, and employment sectors in Europe on the issue of the status of pain in the European Union. It presents existing policies that are and can be relevant to pain and lays them out into four categories: **health indicators, research, employment, and education**.

Further, this paper highlights where there are gaps in relation to addressing pain and offers recommendations to action to policy makers and all other stakeholders to address these identified challenges. Our goal is to achieve improved care and pain management across the EU to reduce the societal impact of the disease, which touches upon all aspects of life.

This Framing Document and the associated Call to Action were developed by the Societal Impact of Pain (SIP)[1], in partnership with stakeholders and members of the EU Health Policy Platform (a full list of contributing organisations is available at the end of the paper).

1. Burden of pain

In Europe[2], there are approximately 740 million people[3], most of whom experience an episode of severe pain at some point in their life. For approximately 20 percent, that pain is chronic – episodic, persistent, or variable. In other words, today there are 150 million people experiencing pain. That number is approximately equal to the populations of Germany and France combined.

What is pain?

Pain is an "*unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*."[4]

Acute pain is pain of recent onset and limited duration due to injuries, illness, or as a result of surgical interventions, e.g. post-operative pain, acute headaches, strain trauma and burns, fractures, activated arthrosis, and dental pain[5].

However, acute pain which persists for longer than three months, is generally classified as **chronic pain**[6]. The process of which is known as '*chronification*'. "*Biologic factors involved in this transition include central sensitization, neuroplastic changes, altered pain modulation, and changes to the "neuromatrix." Chronic pain may involve irreversible pathophysiologic changes, so interrupting the cascade of events that allows acute pain to advance to chronic pain is of crucial importance.*"[7]

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[1] The "**Societal Impact of Pain**" (SIP) is an international platform created as a joint initiative of the European Pain Federation EFIC and the pharmaceutical company Grünenthal GmbH. The scientific framework of the SIP platform is under the responsibility of the European Pain Federation EFIC®. Co-operation partners for SIP are Pain Alliance Europe and Active Citizenship Network. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support.

[2] Note: data taking from 37 countries, absent in Andorra, Armenia, Azerbaijan, Belarus, Georgia, Iceland, Liechtenstein, Luxemburg, Malta, Monaco, and the Vatican City.

[3] Eccleston, C., Wells, C., & Morlion, B. (2017). European Pain Management. Oxford, UK: Oxford University Press, ISBN: 9780198785750

[4] http://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698#Pain

[5] http://www.change-pain.com/grt-change-pain-portal/change_pain_home/acute_pain/pain_basics/definition_of_pain/pain_is.../en_EN/318500008.jsp

[6] https://medlineplus.gov/magazine/issues/spring11/articles/spring11pg5-6.html

[7] https://www.sciencedirect.com/science/article/pii/S1524904212000926

Thematic Network on the Societal Impact of Pain - Framing Paper - Version 5 - November 2018

Page 1 of 25

Framing Paper

White Book for the worldwide promotion of palliative care

The Pontifical Academy for Life presented on May 2019 in Berlin the "PAL-LIFE - White Book for the worldwide promotion of palliative care.

- White Paper
- White Book

10th Anniversary of Societal Impact of Pain

- Read more

http://bit.ly/10-years-SIP

SIP 2019 strategy as defined in the 2018 SIP Steering Committee meeting

On 25 October 2018, the Societal Impact of Pain (SIP) Steering Committee met in Brussels to discuss the next SIP strategy for 2019 while identifying how to advance SIP.

- Report

http://bit.ly/steering-committee-report

SOCIETAL IMPACT OF PAIN

FRAMING PAPER SUMMARY

It is the goal of the Societal Impact of Pain (SIP) group to achieve improved care and pain management across the EU to reduce the societal impact of the disease, which touches upon all aspects of life.

1 in 5 people experience chronic pain

In Europe, more than 150 million people suffer from chronic pain

That´s more than the population of Germany and France combined.

Chronic pain costs the EU €240 billion a year

Infographic

SIP 2018 Steering Committee Meeting Report

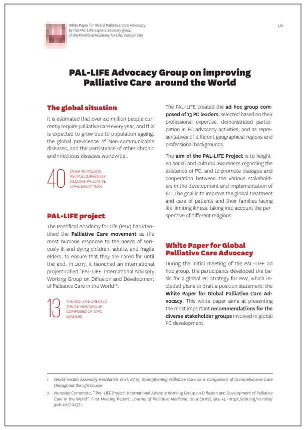
25 October 2018, 10:00 – 17:00
Fondation Universitaire,
Rue d'Egmont 11,
1000 Bruxelles, Belgium

1 The scientific framework of the "Societal Impact of Pain" (SIP) platform is under the responsibility of the European Pain Federation, EFIC®. Cooperation partners are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). In the past the scientific aims of the SIP symposia have been endorsed by over 300 international and national pain advocacy groups, scientific organisations and authorities.

Report

Social Impact of Pain (SIP) Stakeholder Group on the EU Health Policy Platform (EU HPP)

In 2017, the European Commission's has taken the decision to dedicate an Expert Group to the 'social impact of pain', and communicated this during the SIP Symposium in Malta, June 2017 and in October the Social Impact of Pain (SIP) Expert Group has been launched. In 2018 it has been renamed into SIP Stakeholder Group. SIP news are published there and shared on a regular basis with the AGORA community of the EU HPP. Administrators of the SIP Stakeholder Group are Anca Pop (Pain Alliance Europe) and Vittoria Carraro (EFIC).



White Paper for Global Palliative Care Advocacy.
By the PAL-LIFE experts advisory group
of the Pontifical Academy for Life, Vatican City

1/2

PAL-LIFE Advocacy Group on improving Palliative Care around the World

The global situation

It is estimated that over 40 million people currently require palliative care every year, and this is expected to grow due to population ageing, the global prevalence of Non-communicable diseases, and the persistence of other chronic and infectious diseases worldwide[1].

40 OVER 40 MILLION PEOPLE CURRENTLY REQUIRE PALLIATIVE CARE EVERY YEAR

PAL-LIFE project

The Pontifical Academy for Life (PAV) has identified the **Palliative Care movement** as the most humane response to the needs of seriously ill and dying children, adults, and fragile elders, to ensure that they are cared for until the end. In 2017, it launched an international project called "PAL-LIFE: International Advisory Working Group on Diffusion and Development of Palliative Care in the World"[2].

13 THE PAL-LIFE CREATED THE AD HOC GROUP COMPOSED OF 13 PC LEADERS

The PAL-LIFE created the **ad hoc group composed of 13 PC leaders**, selected based on their professional expertise, demonstrated participation in PC advocacy activities, and as representatives of different geographical regions and professional backgrounds.

The **aim of the PAL-LIFE Project** is to heighten social and cultural awareness regarding the existence of PC, and to promote dialogue and cooperation between the various stakeholders in the development and implementation of PC. The goal is to improve the global treatment and care of patients and their families facing life-limiting illness, taking into account the perspective of different religions.

White Paper for Global Palliative Care Advocacy

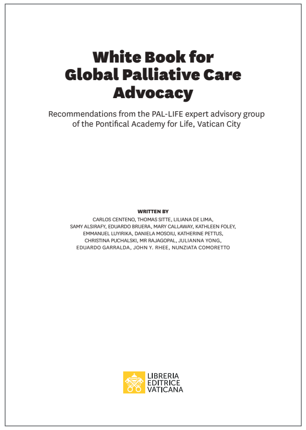
During the initial meeting of the PAL-LIFE ad hoc group, the participants developed the basis for a global PC strategy for PAV, which included plans to draft a position statement: the **White Paper for Global Palliative Care Advocacy**. This white paper aims at presenting the most important **recommendations for the diverse stakeholder groups** involved in global PC development.

---

[1] *World Health Assembly Resolution WHA 67.19. Strengthening Palliative Care as a Component of Comprehensive Care throughout the Life Course.*

[2] Nunziata Comoretto, '"PAL-LIFE Project: International Advisory Working Group on Diffusion and Development of Palliative Care in the World": First Meeting Report', *Journal of Palliative Medicine*, 20.9 (2017), 913–14 <https://doi.org/10.1089/jpm.2017.0237>.

White Paper



White Book for Global Palliative Care Advocacy

Recommendations from the PAL-LIFE expert advisory group
of the Pontifical Academy for Life, Vatican City

WRITTEN BY
CARLOS CENTENO, THOMAS SITTE, LILIANA DE LIMA,
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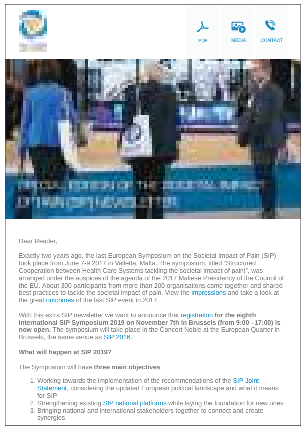
White Book



Dear Reader,

Exactly two years ago, the last European Symposium on the Societal Impact of Pain (SIP) took place from June 7-9 2017 in Valletta, Malta. The symposium, titled "Structured Cooperation between Health Care Systems tackling the societal impact of pain!", was arranged under the auspices of the agenda of the 2017 Maltese Presidency of the Council of the EU. About 300 participants from more than 200 organisations came together and shared best practices to tackle the societal impact of pain. View the impressions and take a look at the great outcomes of the last SIP event in 2017.

With this extra SIP newsletter we want to announce that registration **for the eighth international SIP Symposium 2019 on November 7th in Brussels (from 9:00 –17:00) is now open.** The symposium will take place in the Concert Noble at the European Quarter in Brussels, the same venue as SIP 2016.

What will happen at SIP 2019?

The Symposium will have **three main objectives**

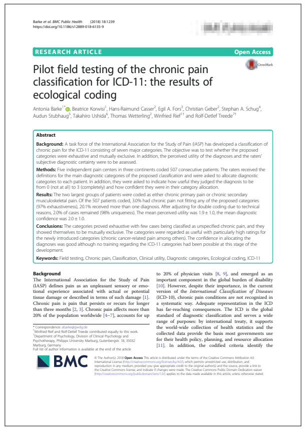
1. Working towards the implementation of the recommendations of the SIP Joint Statement, considering the updated European political landscape and what it means for SIP
2. Strengthening existing SIP national platforms while laying the foundation for new ones
3. Bringing national and international stakeholders together to connect and create synergies

Newsletter

SIP Europe analysis

10th Anniversary of Societal Impact of Pain

Social Impact of Pain (SIP) Stakeholder Group



Barke *et al. BMC Public Health* (2018) 18:1239
https://doi.org/10.1186/s12889-018-6135-9

RESEARCH ARTICLE Open Access

Pilot field testing of the chronic pain classification for ICD-11: the results of ecological coding

Antonia Barke[1*], Beatrice Korwisi[1], Hans-Raimund Casser[2], Egil A. Fors[3], Christian Geber[2], Stephan A. Schug[4], Audun Stubhaug[5], Takahiro Ushida[6], Thomas Wetterling[2], Winfried Rief[1†] and Rolf-Detlef Treede[7†]

Abstract

Background: A task force of the International Association for the Study of Pain (IASP) has developed a classification of chronic pain for the ICD-11 consisting of seven major categories. The objective was to test whether the proposed categories were exhaustive and mutually exclusive. In addition, the perceived utility of the diagnoses and the raters' subjective diagnostic certainty were to be assessed.

Methods: Five independent pain centers in three continents coded 507 consecutive patients. The raters received the definitions for the main diagnostic categories of the proposed classification and were asked to allocate diagnostic categories to each patient. In addition, they were asked to indicate how useful they judged the diagnosis to be from 0 (not at all) to 3 (completely) and how confident they were in their category allocation.

Results: The two largest groups of patients were coded as either chronic primary pain or chronic secondary musculoskeletal pain. Of the 507 patients coded, 3.0% had chronic pain not fitting any of the proposed categories (97% exhaustiveness), 20.1% received more than one diagnosis. After adjusting for double coding due to technical reasons, 2.0% of cases remained (98% uniqueness). The mean perceived utility was 1.9 ± 1.0, the mean diagnostic confidence was 2.0 ± 1.0.

Conclusions: The categories proved exhaustive with few cases being classified as unspecified chronic pain, and they showed themselves to be mutually exclusive. The categories were regarded as useful with particularly high ratings for the newly introduced categories (chronic cancer-related pain among others). The confidence in allocating the diagnoses was good although no training regarding the ICD-11 categories had been possible at this stage of the development.

Keywords: Field testing, Chronic pain, Classification, Clinical utility, Diagnostic categories, Ecological coding, ICD-11

Background

The International Association for the Study of Pain (IASP) defines pain as an unpleasant sensory or emotional experience associated with actual or potential tissue damage or described in terms of such damage [1]. Chronic pain is pain that persists or recurs for longer than three months [2, 3]. Chronic pain affects more than 20% of the population worldwide [4–7], accounts for up to 20% of physician visits [8, 9], and emerged as an important component in the global burden of disability [10]. However, despite their importance, in the current version of the *International Classification of Diseases* (ICD-10), chronic pain conditions are not recognized in a systematic way. Adequate representation in the ICD has far-reaching consequences. The ICD is the global standard of diagnostic classification and serves a wide range of purposes: by international treaty, it supports the world-wide collection of health statistics and the collected data provide the basis most governments use for their health policy, planning, and resource allocation [11]. In addition, the codified criteria identify the

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Full list of author information is available at the end of the article

BMC

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Report BMC Public Health

SURVEY OF YOUNG EUROPEANS
WITH NEUROLOGICAL
CONDITIONS

JULY 2018

EFNA

Report of the survey

- Social Impact of Pain (SIP) Stakeholder Group instruction
  https://www.sip-platform.eu/resources/details/social-impact-of-pain-sip-stakeholder-group

Pilot field testing of the chronic pain classification for ICD-11: the results of ecological coding

A task force of the International Association for the Study of Pain (IASP) has developed a classification of chronic pain for the ICD-11 consisting of seven major categories.

- Report
  https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-018-6135-9

EFNA survey of young Europeans with neurological conditions

The European Federation of Neurological Associations (EFNA) has published a report of findings from the recent Survey of Young Europeans with Neurological Conditions.

- Read the full report of the survey

PAE Survey 2018 on Chronic Pain and Work Life

Pain Alliance Europe performed a European online survey to identify the economic and work-related problems of chronic pain patients.

- Report

SIP position paper on inclusion of pain research in the 9th EU framework program: what´s next?

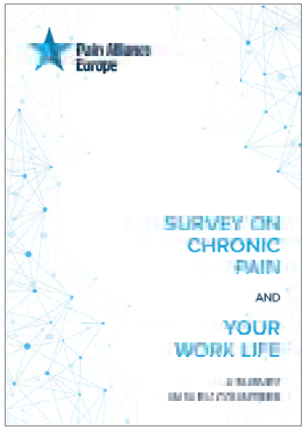
The SIP platform drafted a position paper to highlight the importance of strengthening pain research (basic science, clinical science, epidemiological research) as a priority in the EU 9th Framework Program (FP9) to the Commission.

- Position Paper

PAE Survey on Chronic Pain 2017

The 2017 report is a result of a survey on chronic pain performed in 17 countries.

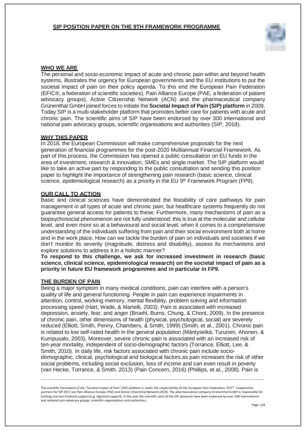
- Report


SURVEY ON CHRONIC PAIN

AND

YOUR WORK LIFE

PAE Survey 2018


SIP POSITION PAPER ON THE 9TH FRAMEWORK PROGRAMME

WHO WE ARE
The personal and socio-economic impact of acute and chronic pain within and beyond health systems, illustrates the urgency for European governments and the EU institutions to put the societal impact of pain on their policy agenda. To this end the European Pain Federation (EFIC®, a federation of scientific societies), Pain Alliance Europe (PAE, a federation of patient advocacy groups), Active Citizenship Network (ACN) and the pharmaceutical company Grünenthal GmbH joined forces to initiate the **Societal Impact of Pain (SIP) platform** in 2009. Today SIP is a multi-stakeholder platform that promotes better care for patients with acute and chronic pain. The scientific aims of SIP have been endorsed by over 300 international and national pain advocacy groups, scientific organisations and authorities (SIP, 2018).

WHY THIS PAPER
In 2018, the European Commission will make comprehensive proposals for the next generation of financial programmes for the post-2020 Multiannual Financial Framework. As part of this process, the Commission has opened a public consultation on EU funds in the area of investment, research & innovation, SMEs and single market. The SIP platform would like to take an active part by responding to the public consultation and sending this position paper to highlight the importance of strengthening pain research (basic science, clinical science, epidemiological research) as a priority in the EU 9th Framework Program (FP9).

OUR CALL TO ACTION
Basic and clinical sciences have demonstrated the feasibility of care pathways for pain management in all types of acute and chronic pain, but healthcare systems frequently do not guarantee general access for patients to these. Furthermore, many mechanisms of pain as a biopsychosocial phenomenon are not fully understood: this is true at the molecular and cellular level, and even more so at a behavioural and social level, when it comes to a comprehensive understanding of the individuals suffering from pain and their social environment both at home and in the work place. How can we tackle the burden of pain on individuals and societies if we don't monitor its severity (magnitude, distress and disability), assess its mechanisms and explore solutions to address it in a holistic manner?
To respond to this challenge, we ask for increased investment in research (basic science, clinical science, epidemiological research) on the societal impact of pain as a priority in future EU framework programmes and in particular in FP9.

THE BURDEN OF PAIN
Being a major symptom in many medical conditions, pain can interfere with a person's quality of life and general functioning. People in pain can experience impairments in attention, control, working memory, mental flexibility, problem solving and information processing speed (Hart, Wade, & Martelli, 2003). Pain is associated with increased depression, anxiety, fear, and anger (Bruehl, Burns, Chung, & Chont, 2009). In the presence of chronic pain, other dimensions of health (physical, psychological, social) are severely reduced (Elliott, Smith, Penny, Chambers, & Smith, 1999) (Smith, et al., 2001). Chronic pain is related to low self-rated health in the general population (Mäntyselkä, Turunen, Ahonen, & Kumpusalo, 2003). Moreover, severe chronic pain is associated with an increased risk of ten-year mortality, independent of socio-demographic factors (Torrance, Elliott, Lee, & Smith, 2010). In daily life, risk factors associated with chronic pain include socio-demographic, clinical, psychological and biological factors.as pain increases the risk of other social problems, including social exclusion, loss of income and can even result in poverty (van Hecke, Torrance, & Smith, 2013) (Pain Concern, 2016) (Phillips, et al., 2008). Pain is

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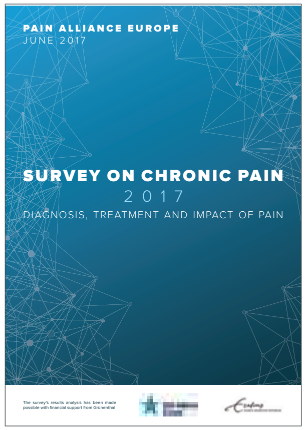
The scientific framework of the "Societal Impact of Pain" (SIP) platform is under the responsibility of the European Pain Federation, EFIC®. Cooperation partners for SIP 2017 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). In the past the scientific aims of the SIP symposia have been endorsed by over 300 international and national pain advocacy groups, scientific organisations and authorities.

Page: 1/8

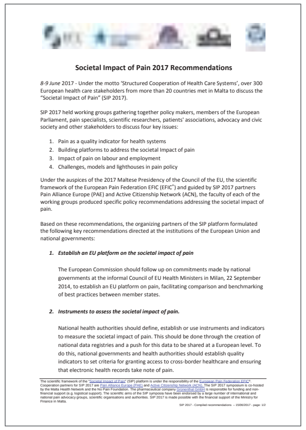
Position Paper


PAIN ALLIANCE EUROPE
JUNE 2017

SURVEY ON CHRONIC PAIN
2017
DIAGNOSIS, TREATMENT AND IMPACT OF PAIN

The survey's results analysis has been made possible with financial support from Grünenthal

PAE Survey on Chronic Pain


Societal Impact of Pain 2017 Recommendations

8-9 June 2017 - Under the motto 'Structured Cooperation of Health Care Systems', over 300 European health care stakeholders from more than 20 countries met in Malta to discuss the "Societal Impact of Pain" (SIP 2017).

SIP 2017 held working groups gathering together policy makers, members of the European Parliament, pain specialists, scientific researchers, patients' associations, advocacy and civic society and other stakeholders to discuss four key issues:

1. Pain as a quality indicator for health systems
2. Building platforms to address the societal Impact of pain
3. Impact of pain on labour and employment
4. Challenges, models and lighthouses in pain policy

Under the auspices of the 2017 Maltese Presidency of the Council of the EU, the scientific framework of the European Pain Federation EFIC (EFIC®) and guided by SIP 2017 partners Pain Alliance Europe (PAE) and Active Citizenship Network (ACN), the faculty of each of the working groups produced specific policy recommendations addressing the societal impact of pain.

Based on these recommendations, the organizing partners of the SIP platform formulated the following key recommendations directed at the institutions of the European Union and national governments:

1. ***Establish an EU platform on the societal impact of pain***

   The European Commission should follow up on commitments made by national governments at the informal Council of EU Health Ministers in Milan, 22 September 2014, to establish an EU platform on pain, facilitating comparison and benchmarking of best practices between member states.

2. ***Instruments to assess the societal impact of pain.***

   National health authorities should define, establish or use instruments and indicators to measure the societal impact of pain. This should be done through the creation of national data registries and a push for this data to be shared at a European level. To do this, national governments and health authorities should establish quality indicators to set criteria for granting access to cross-border healthcare and ensuring that electronic health records take note of pain.

The scientific framework of the "Societal Impact of Pain" (SIP) platform is under the responsibility of the European Pain Federation EFIC®. Cooperation partners for SIP 2017 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The SIP 2017 symposium is co-hosted by the Malta Health Network and the No Pain Foundation. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP symposia have been endorsed by a large number of international and national pain advocacy groups, scientific organisations and authorities. SIP 2017 is made possible with the financial support of the Ministry for Finance in Malta.

SIP 2017 - Compiled recommendations – 15/06/2017 - page: 1/2

SIP 2017 Compiled Recommendations

SIP 2017 Policy Recommendations

Under the motto 'Structured Cooperation of Health Care Systems', over 300 European health care stakeholders from more than 20 countries met in Malta to discuss the "Societal Impact of Pain" (SIP 2017).

- SIP 2017 Compiled Recommendations
- SIP 2017 Recommendations


SIP
2017
Structured Cooperation between Health Care Systems tackling the societal impact of pain!

Key Recommendations from the SIP Working Groups

Main findings & recommendations

SIP 2017 Recommendations

8.8. How to register and become a member of the EU Health Policy Platform's "Stakeholder Group on the Societal Impact of Pain"

To access the Stakeholder Group on the Social Impact of Pain, you first need to register on the EU Health Policy Platform. As health stakeholder, you need to meet the EU Health Policy Platform criteria in order to register. (Please see the eligibility criteria in Annex 1).

Registration Procedure
Please proceed to the registration as follows:

STEP 1: Follow the link to the IT Platform:
https://webgate.ec.europa.eu/hpf/
Follow the instruction to create an ECAS account clicking on ''NOT REGISTERED YET'

STEP 2: Create an account in the European Commission Authentication System (ECAS) using a personalised email address related to the organisation that you represent/work for (not your personal email e.g. Gmail, Hotmail). If you already have an ECAS account, please proceed to STEP 3.

Once you created the account, you will receive an email with further instructions.

STEP 3: Log in with your EU Login (ECAS) username and password. This will take you to the home page of the Platform where you can request access to various networks.

STEP 4: Once you are logged in, your webpage will look like the figure below. Now you need to request access to **Agora network** and to your **Stakeholder Group on the Social Impact of Pain**; the moderator will grant you access as soon as possible.

You will find the Agora network at the top of the page. To find the **Stakeholder Group on the Social Impact of Pain**, please scroll down to the bottom of the page and you will find the preview of our group as per the image below.

STEP 5: You will receive a confirmation email once your profile is approved.

STEP 6: You can start uploading and navigating in the Platform. There is space for you to upload publications, documentation on national best practices, events in your home country and even your personal story.

Disclaimer: All postings in this group should be related to the "Social Impact of Pain" (SIP) and not contain any commercial advertising. Adverts, promotion and self-promotion will be removed. Impolite or offending postings will be deleted. Do not reveal any identifiable patient information. All postings should be free of copyright (meaning that we cannot cut and paste from other publications without permission and reference).

STEP 7: Once you are registered and you want to come back on the EU health platform to access the SIP group, you can find it in the scroll down menu 'select a network' on the right of your page.

STEP 8: Visit regularly the Expert Group and keep up to date!

If you would like to propose areas for discussion, please contact:

- Vittoria Carraro, External Relation Manager
  European Federation EFIC
  Vittoria.carraro@efic.org
- Joop Van Griensven, President
  Pain Alliance Europe
  president@pae-eu.eu

You will receive a regular (monthly) progress report of the platform. We will analyse the content of the platform and propose new topics.

ELIGIBILITY CRITERIA

There are 3 kinds of users in the EU Health Policy Platform:

- The European Commission staff;
- The members of already established EU Expert and Stakeholder Groups of DG Health and Food Safety;

- Any health stakeholders meeting the EU Health Policy Platform criteria.

In order to be accepted as Platform users, health stakeholders must meet the following criteria

They must:

1. Represent an organisation with an operative email;
2. Be a European, national, regional or local entity, registered legally in an EU Member State, EEA-country or a country participating in the funding of the 3rd Health Programme.
3. Organisations from third countries may also register on the EU Health Policy Platform as long as their contribution helps to achieve higher levels of public health in the EU. Their requests will be considered on an ad hoc – basis.
4. Be registered in the EU Transparency Registry and must directly and exclusively represent their own interests (meaning consultancies and law firms may not participate on behalf of clients);
5. Respect the guiding principles with regard to transparency, present in the annex;
6. Be one of the following entities:
   - Public health non-governmental organisations;
   - Organisations representing patients;
   - Organisations representing health professionals;
   - Health service providers;
   - Health insurance bodies;
   - Research organisations, universities and academic institutions;
   - Business associations with a clear commitment to health promotion; protection or prevention of diseases in Europe.
7. Have an interest in health; work in public health or in health-related fields.

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Pain Alliance Europe and Active Citizenship Network. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support.

Endorser

The Framing Paper and Joint Statement were drafted by the Societal Impact of Pain (SIP) group, in partnership with various stakeholders and as part of the 2018 Thematic Network Program on the EU Health Policy Platform of the European Commission.

Members of European Parliament:
Alfred Sant, Heinz K. Becker, Jeroen Lenaers, José Inácio Faria, Marek Plura, Marian Harkin, Merja Kyllönen, Miriam Dalli, Nicola Caputo, Roberta Metsola, Sabine Verheyen, Sirpa Pietikäinen, Sofia Ribeiro

8.9. Where to find information and materials on the SIP website?

Visit the SIP website www.sip-platform.eu to find SIP related materials and initiatives to make use of them on your SIP National Platform.

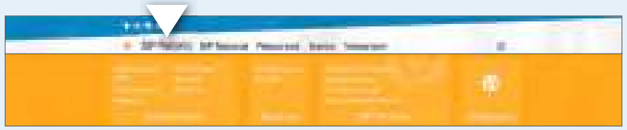
The header of the SIP website shows current highlights and relevant SIP news at a first glance.

On the homepage you can find the most relevant news articles, events and SIP initiatives.

The SIP homepage is available in five languages while the detailed information is mainly published in English.

The side-bar menu guides you to subscribe for the SIP newsletter and to find the various SIP Social Media and other communication channels.

The primary navigation of the SIP website presents the main structure of the website which will be described in detail below.



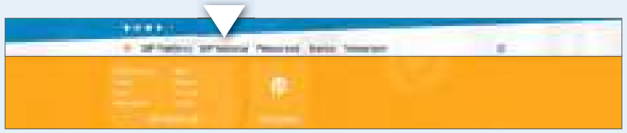
8.9.1. SIP Platform

Achievements: Here you can find all milestone achievements of SIP since its launch in 2009

About Us: Find the most relevant information about the SIP platform

SIP Partners: Read more about the four partners of the SIP platform

Endorser: Identify the SIP endorsing organisations from your country to liaise and collaborate with them with your SIP national platform

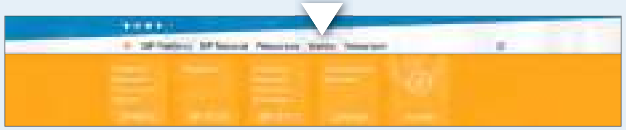


8.9.2. SIP National

Here you can find news, materials and contact persons for each SIP National Platform. Other national pain related information can be found per country under "Initiatives".

8.9.3. Resources

Here you can search in the database for existing materials by topic, by name of the author or by type of document. More than 1,000 entries have been made where you can find information by using tags, by entering a name or a specific topic.

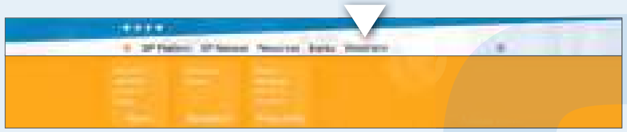


8.9.4. Events

The most recent SIP events or upcoming symposia are shown in a well-structured format.

Calendar: Every year more than 60 national and international SIP related meetings and congresses can be found in the calendar with a brief introduction and a link to the congress website.

In the archive you can find the program and outcome of all SIP Symposia since the first event in 2010.



8.9.5. Newsroom

Here you can find all published SIP News from the SIP website by year of publication as well as all editions of the SIP Newsletter.

Press related articles and materials are filed in the Press Area which can be used also for national journalists.

8.10. Contact details from SIP NPs representatives

The contact details from the representatives of the existing SIP national platforms can be found on the SIP website together with further information and news about each platform.

If you want to know more about the Societal Impact of Pain platform, please contact:

- secretary@efic.org
- sip-platform@grunenthal.com

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SOCIETAL IMPACT OF PAIN

SIP TOOLKIT

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