SIP National Platform Meeting: 28th November 2023
Teams

Attendees

Patrice Forget (EFIC/SIP), Deirdre Ryan (PAE/SIP), Sam Kynman (EFIC/SIP), Emilia Kosińska (SIP/PAE), Angela Cano Palomares (EFIC/SIP), Paloma Verdegal (EFIC/SIP).

SIP National Platform Representatives.

Welcome and Introductions

- Angela Cano Palomares (ACP), SIP Advocacy and Projects Manager, opened the National Platform Call and explained the agenda of the day.
- Welcome and introductions from Patrice Forget (PF) and Deirdre Ryan (DR), SIP's Chair and Co-Chair and PAE President.
- Introduction of EFIC new Communications and Advocacy trainee, Paloma Verdegal.

SIP Stakeholder Forum De-Brief

On November 8th SIP held the SIP Stakeholder Forum Meeting. The Meeting brings together EU Stakeholders and SIP National Platforms, to discuss yearly and upcoming activities and policy objectives. However, since the SIP National Platforms, had the opportunity to meet in person during the EFIC Congress in Budapest in September 2023, and have an in-depth national status/needs discussion, the 2023 SIP Stakeholder Forum, was only attended by EU Stakeholders, in order to make it an EU in-depth discussion.

During the meeting SIP provided an overview of:

- 2022-2023 policy priorities,
- 2022-2023 events and,
- Aspirations for 2024 in relation to the upcoming EU Elections

ACP gave an overview of the results of the SIP Stakeholder Forum, pre-event survey results:

1. **EU priorities of relevance to SIP:**
    - Pain and Mental Health.
    - ICD-11 via the European Health Data Space.
    - Keep pain high on the EU Agenda.
2. **Perceptions of SIP from the Stakeholders:**
    - Good perceptions: Collaboration with Stakeholders on different advocacy topics.
    - Room for improvement: Guide SIP National Platforms even further with their national level activities.

Overall: SIP Stakeholders have been focusing on Mental Health in relation to and complementary to their own objectives and activities (i.e. MSDs, Cancer, etc.).

In conclusion: The common position moving forward into the new EU Mandate is to continue to work on the current points of focus and topics relevant in the long-term and once the new EU Policy Health Agenda is published, adapt accordingly.

SIP 2024 Objectives and Policy Priorities

- Digital Health and International Classification of Diseases (ICD-11)
- Pain and Mental Health

- Access to Treatment
- Closely monitor the new EU Mandate and Agenda and act in consequence.

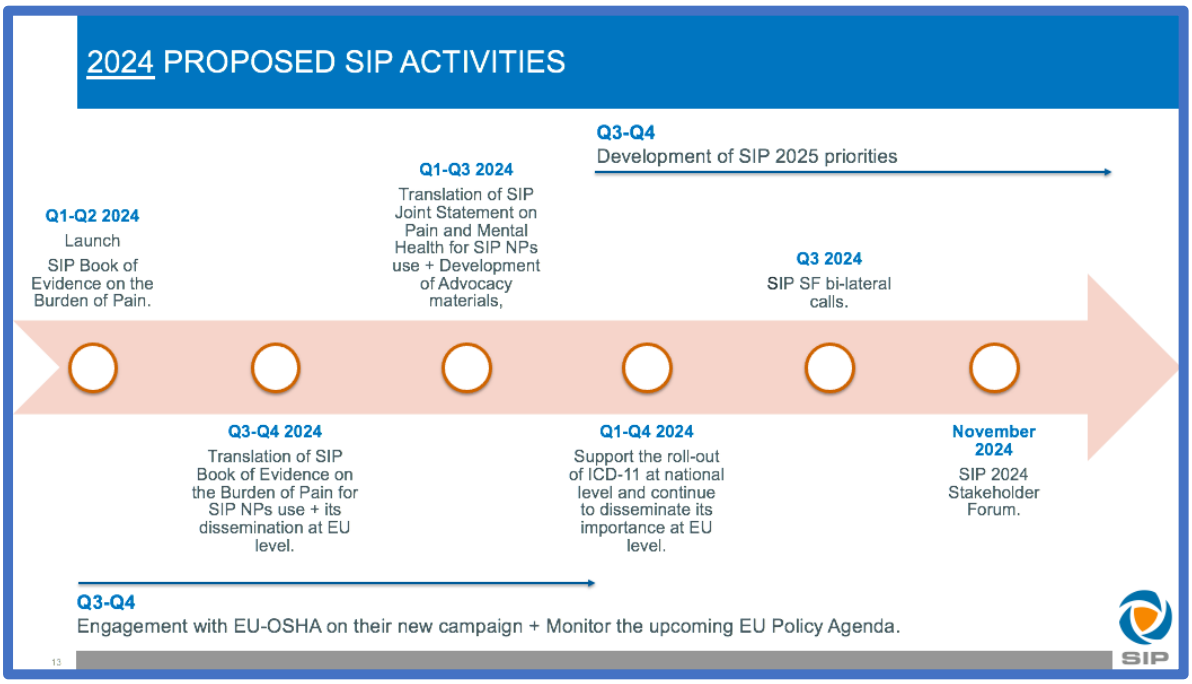
Moreover, to address the new EU Mandate, SIP has actively engaged in the following activities:

- Participation in political parties Manifestos and meetings: ALDE, EPP, S&D.
- Joining EU organisations Manifestos: ECO.
- Tracking MEPs on their upcoming plans.

Upcoming:

- Engagement with the Spitzen candidates.
- Engagement with the EU Commission.

2024 Proposed SIP Activities

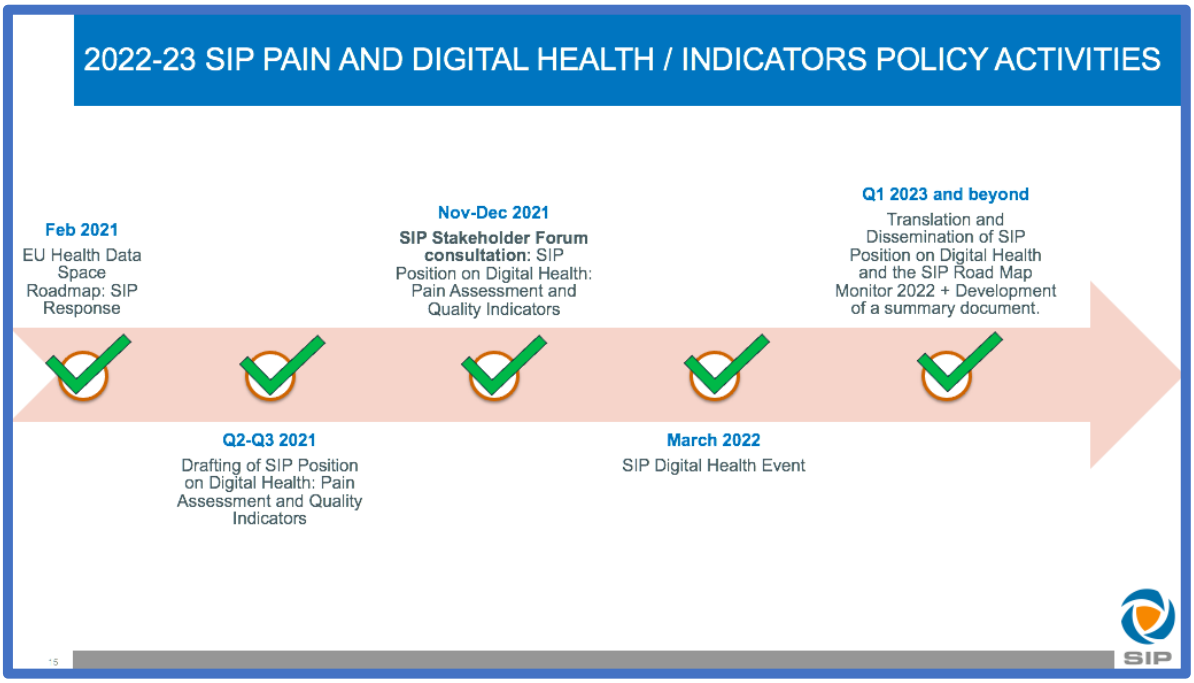


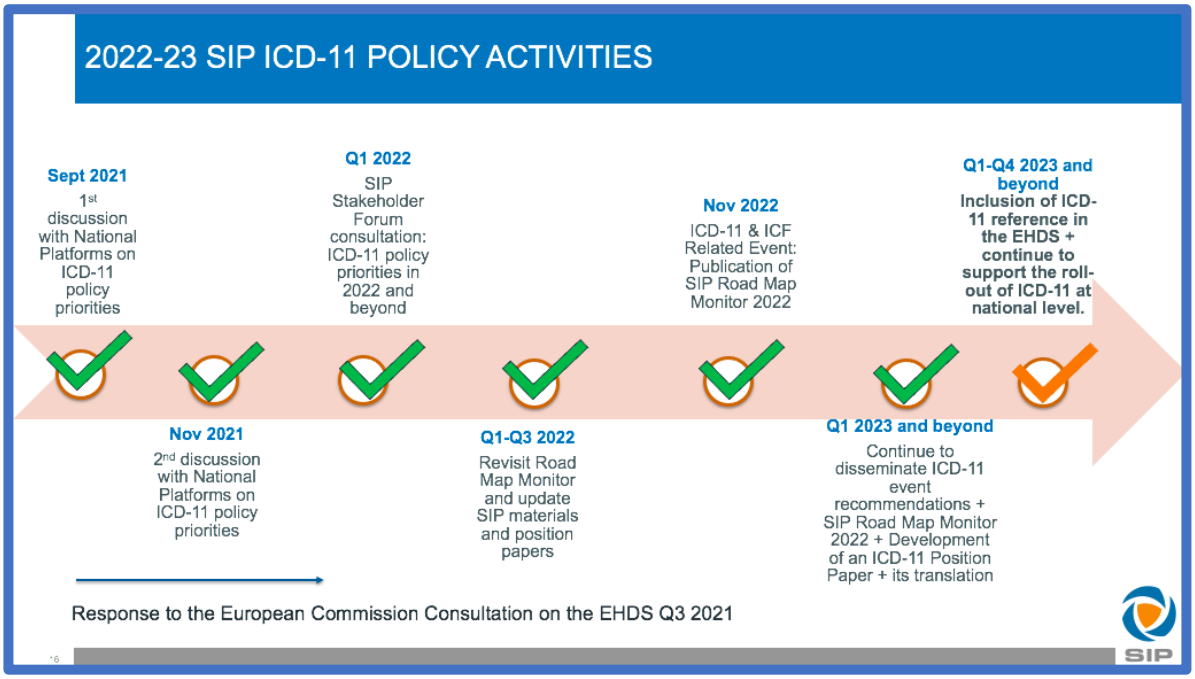
ACP highlighted that once the new EU Policy Health Agenda is published, SIP Objectives and activities will vary accordingly.

SIP Governance Model and SIP Bi-Lateral Calls

ACP kindly reminded attendees to update their SIP National Platform Governance document & plans for 2024 and that SIP Bilateral calls will continue to be scheduled for 2024.

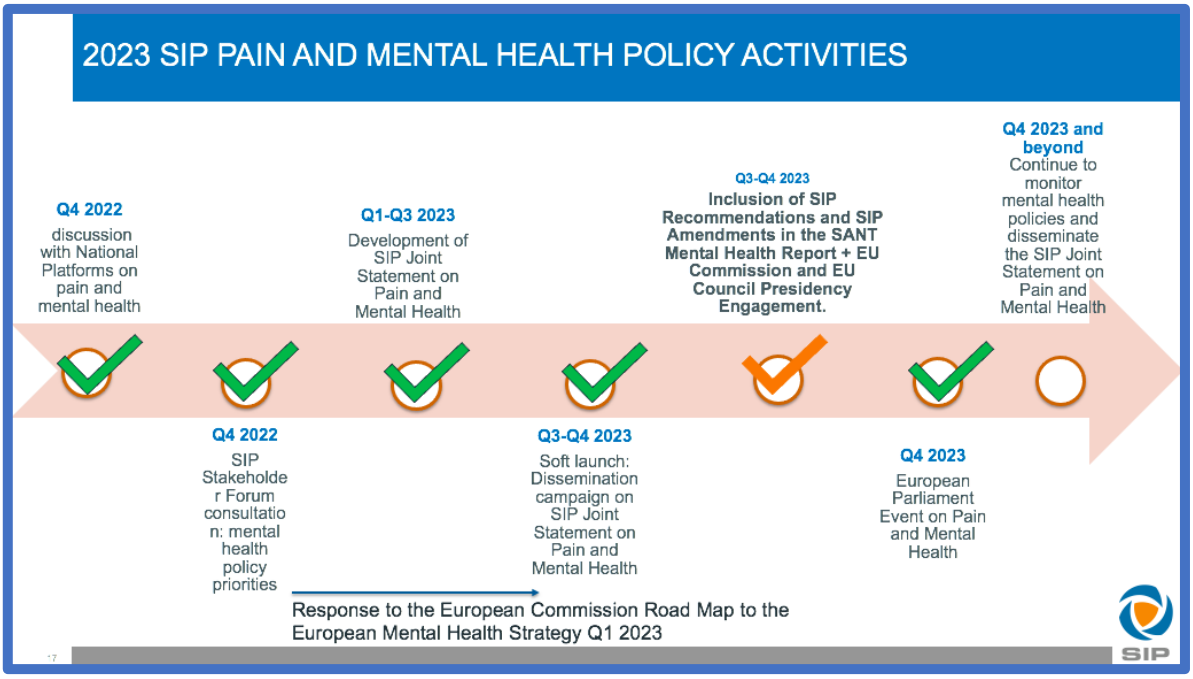
Progress Updates by Topic



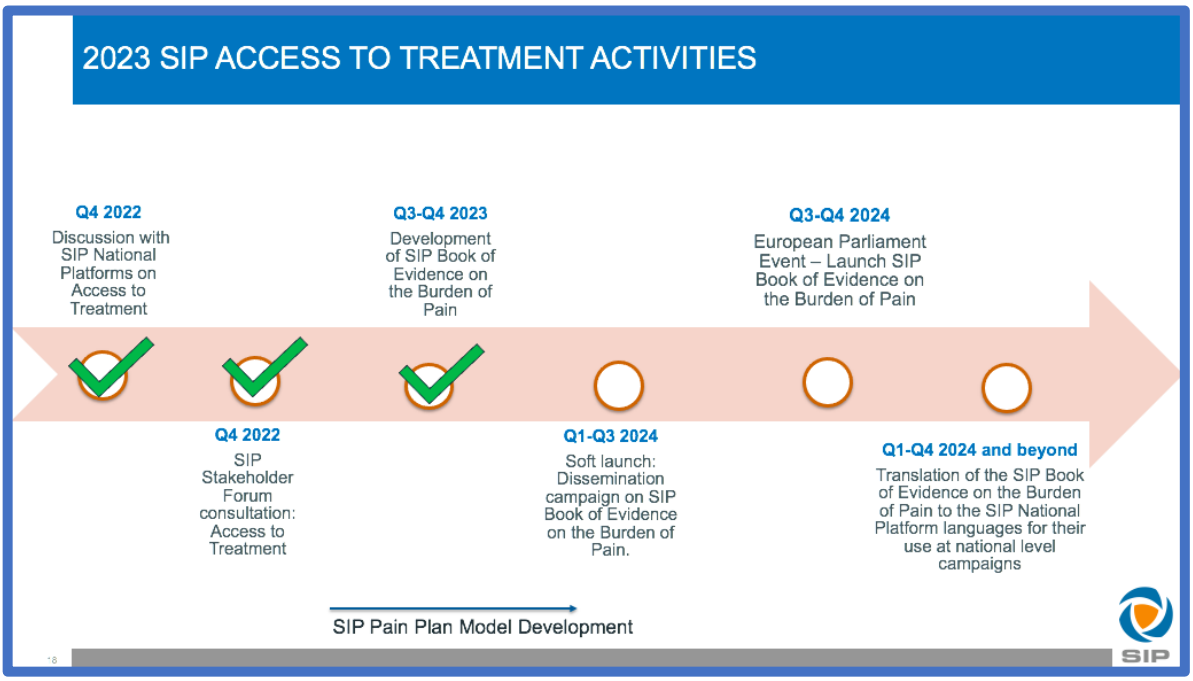


SIP Pain and Digital Health and ICD-11 important activities to flag:

- Inclusion of ICD-11 reference in the European Health Data Space (EHDS) – The Regulation is still being discussed at the European Parliament (Trialogues – negotiations between the European Commission, the European Council and the European Parliament – due to start shortly), however, one of the several Amendments proposed by SIP has passed the Compromise Amendments phase and an ICD-11 reference has been included in Article 5, where processed data in an electronic format is discussed. The rest of the Amendments to be confirmed shortly.
- SIP ICD-11 Position Paper launched.



- **Pain and Mental Health important activities to flag**:
  - Inclusion of SIP Amendments in the SANT Committee Mental Health Report – Over 40 Amendments inspired by SIP, 24 of which were SIP's exact wording. All 24 Amendments where included within the Compromised Amendments and passed. The Report will soon be published.
  - SIP Joint Statement on Pain and Mental Health launched.



- **Access to Treatment important activities to flag**:
  - Launch Book of Evidence on the Burden of Pain in early 2024.

- Soft Launch: Dissemination campaign on the SIP Book of Evidence on the Burden of Pain + online event/webinar in Q2-Q3 2023.
- Political launch: In person, multistakeholder event at the European Parliament
- Translation of the SIP Book of Evidence on the Burden of Pain to the SIP National Platform languages for their use at national level campaigns.

Activities by SIP Europe Involving SIP National Platforms:

- Translation of the SIP Digital Health Position Paper: Done
- Translation of the SIP ICD-11 Position Paper: Done
- Translation of SIP Joint Statement on Pain and Mental Health: To start shortly
- Providing input and testimonials for the SIP Book of Evidence: Ongoing
- Translation of SIP Book of Evidence: To start shortly
- Translation of the Letter to policymakers: Done
- Translation of the Agenda for policymakers meeting: Done
- Outreach to policymakers with all relevant materials: To start shortly
- Letter to the Editor of relevant scientific journals on:
  - ICD-11: Done
  - cancer pain & pain: Done
  - mental health: Ongoing
- SIP National Platform surveys: Done
- SIP National Platform bi-lateral calls: Done
- SIP National Platform quarterly calls: Done
- SIP National Pain Plan model: To start shortly

SIP National Platform Round-Table

Country Presentations:

- Swedish National Pain Plan: Monika Löfgren and Gunilla Göran
- Portugal National Pain Plan: Maria Teresa Flor de Lima
- Danish National Health Plan: Lars Bye Møller
- The Netherlands Multidisciplinary Pain Care Plan: André Wolff - Recording (Available in the slides)

Monika Löfgren initiated the round-table by presenting the Swedish National Pain Plan and care pathway.

The National System for Knowledge-driven Management within the Swedish Healthcare leads the overall work on developing person-centred and coherent healthcare pathways. The pathway for chronic pain, entitled 'Vårdförlopp Smärta - långvarig hos vuxna', has been developed within the framework of the National Programme Area of Diseases of the Nervous System.

The document was developed by a national task force which started its activity back in 2019. The national task force represented patient organisations, different health professions, different regions and different levels of care.

The National Programme Area of Diseases of the Nervous System approved the pathway for chronic pain in October 2022. Currently, work is ongoing to implement such pathway in all the different Swedish regions.

The healthcare pathway initiates due to pain lasting at least 3 months or at risk of developing into chronic pain, and ends when the patient is able to handle the situation without additional healthcare.

The main aim of the care pathway is to support healthcare professionals to provide an adequate level of care and offer evidence-based treatments when dealing with adult patients with chronic pain.

The goal of the pathway is to achieve:

- Improved quality of life for patients.
- Increased continuity and safety for patients during and between care contact as well as between health professionals.
- Increase the proportion of patients who are able to manage their pain early on without further care measures.
- Increased collaboration within and between levels of care, where the care is requested by the referrer in consultation with the patient.
- Increased knowledge among healthcare professionals and patients in the field of chronic pain, where knowledge is based on evidence and proven experience.
- Reduced costs for the individual, the healthcare system and society.

The proposed outcome indicators are linked to the domains recommended for scientific monitoring of this patient group, such as IMMPACT's and VAPAIN's. Follow-up forms are available for several of these. Important domains in the clinical context include pain intensity, physical function, sleep disturbance, anxiety, depression, fatigue, and ability to participate in social activities and have social roles, establishing a rehabilitation plan and a contact person early during the pathway. The indicators are primarily chosen to be collected from the Swedish Quality Registry of Pain Rehabilitation (SQRP), however, some data can also be collected from Regional registries.

Consequences for implementation:

- The pathway implies large consequences for primary care and partly for specialised care.
- Developed working methods, changes of healthcare organisation and development of knowledge is needed. This will on the short term increase costs and needs of resources.
- Non-valuable healthcare will be avoided and the right level of care will be easier to define.
- On the long-term (within 5 years) early measures and an improved structure lead to fewer healthcare visits and lower costs for the individual, health care and society. A probable saving of costs will be seen on the longer term.
- The calculations are not including ongoing projects of digitalisation of parts of the pathway. Implementation of these initiatives might decrease costs for health care.

Benefits for patients:

- Continuity for the patients who often are in need of multiple measures from different professionals and often in cooperation with the employer and authorities.
- Support beneficial healthcare meetings by decreasing the number of unnecessary revisits and increase cooperation between levels of care and healthcare professionals.
- Increase healthcare professionals' and patients' knowledge of chronic pain with the aim to improve the quality of healthcare meetings.
- Support patients without taking over his/her own responsibility, by creating a rehabilitation plan in dialogue between the healthcare professionals and the patients and by offering the patient both support and guidance in contacts, measures and own care.

Maria Teresa Flor de Lima presented the initiatives and plans against pain in Portugal.

She began discussing that in the late 1990s, the Health General Directorate (DGS) in Portugal recognised the imperative to enhance the approach to pain management. Collaborating with the Portuguese Association for the Study of Pain

(APED), this collaboration resulted in the inception of the first strategic document, the National Plan for the Fight against Pain (PNLCD), officially approved by ministerial order on March 26, 2001. This initiative followed the launch of the National Day against Pain in 1999, making Portugal the first country in the world to establish a dedicated national day for pain awareness.

The National Plan for the Fight against Pain (PNLCD) was founded on the principles of Multidisciplinary Teams and Multimodal Treatment.

In 2008, an update introduced the National Pain Control Program (PNCD). This program established organization and classification standards for Chronic Pain Units, aligning with the IASP classification. Over the following decade, new objectives and strategies aimed to enhance the organizational capacity of healthcare services and improve models of good practice in addressing pain. Simultaneously, the DGS released guidelines covering pain evaluation (as the 5th Vital Sign), diagnosis (fibromyalgia), treatment in children and the elderly, opioid use, among others. Educational programs for health professionals, such as the one in the Azores in 2009, were implemented.

In 2012, the National Strategic Plan for Pain Prevention and Control (PENPCDor) was introduced.

The National Health Program 30, an essential health governance instrument at the national level, guides and facilitates the construction of a social commitment to achieve improvements in the health status of the population within the framework of the United Nations 2030 Agenda for Sustainable Development. The PNS is the outcome of a highly participative process, involving technical and scientific expertise, engagement from over 100 organisations both within and outside the health sector, and input from 114 entities and citizens who participated in the public consultation.

The slogan is "Giving Voice to Patients" and integrating patients, families, and caregivers into the clinical decision-making team, guiding patients in the centre of care.

Lars Bye Møller joined the conversation, sharing some recent updates on the Danish National Health Plan.

He noted that part of the Danish national health plan was rounded off at an event on the 27th November. The Danish Health Authority hold a themed day for healthcare professionals, health authorities and patient representatives to support the dissemination and implementation of the new Recommendations for people with chronic pain.

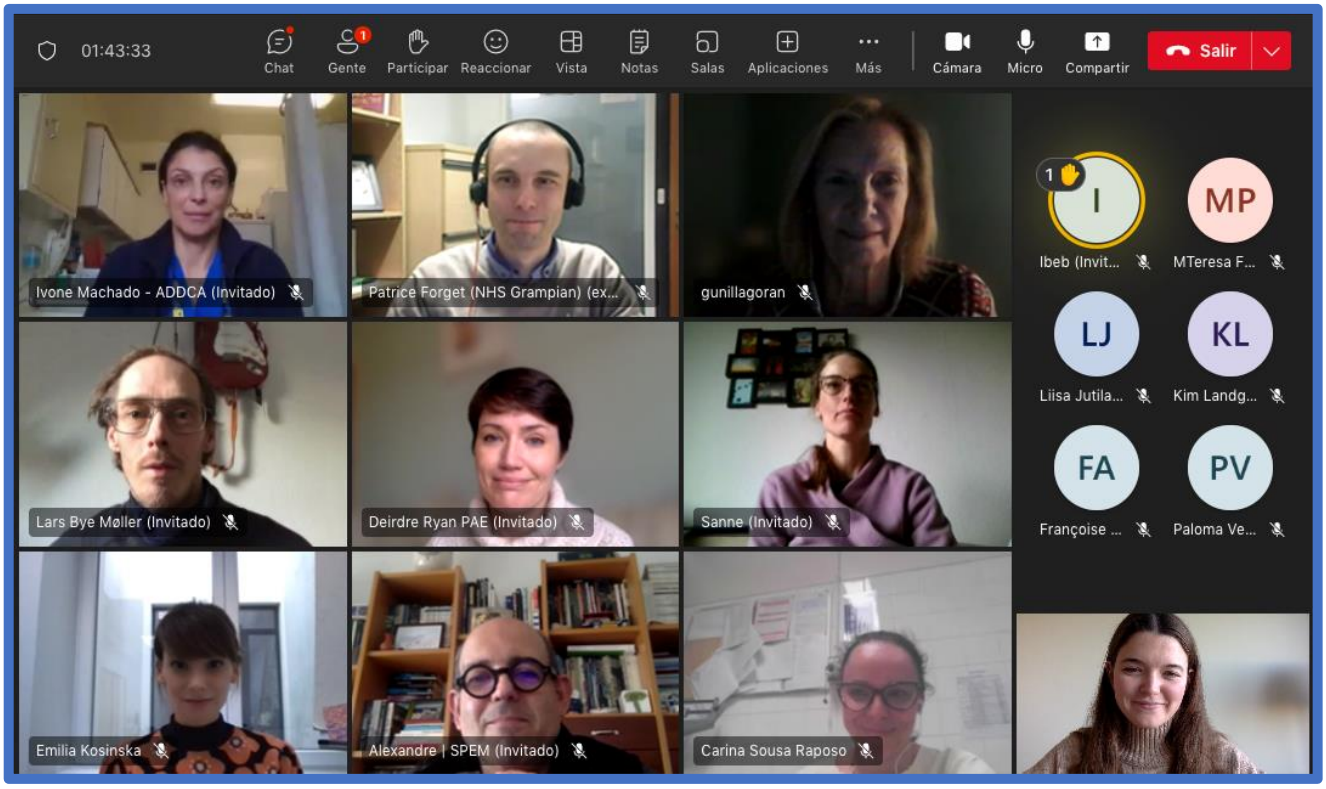
The ambition is to provide a framework for cooperation and discussion on how the Danish Health Authority's Recommendations on cross sectional organisation and identification and management of people with chronic pain in general practice, can be implemented in practice. Lars Bye mentioned that it seems the biggest challenge is to provide resources, both human and economical, to make the implementation across Denmark a reality.

Finally, ACP stated that following the SIP Road Map Monitor launch in 2022, and the advancements at national level on the different National Pain Plan, SIP has just started a new ad-hoc activity entitled 'SIP National Pain Plan Model'. A document that aims to provide a clear guidance and pathway for national Governments to follow. The SIP National Platforms and partners will be able to provide their input and feedback directly to the document and will hopefully be a valuable resource for national raising awareness campaigns. The document will be shared for feedback as soon as the first draft is ready.

SIP Communications Channels

DR and PF invited attendees to send SIP their activities to be disseminated through its communication channels and newsletter. SIP National Platforms have until 8th December to share their news, for them to be included in the next SIP Newsletter (15th December).

Next Steps, Date of Next Call and Closure

- The next SIP National Platform meeting will take place on 14th February 2024.
- ACP will send all links for the 2024 meetings shortly.

Patrice Forget and Deirdre Ryan thanked everyone and closed the meeting at 15h30 CET.