SIP Advocacy Toolkit Training - Minutes

15/10/2025 – 09:30-12:00

Attendees

Ángela Cano Palomares **(ÁCP)**, Hannah Kampos-Green **(HKG),** Marzia Ley **(ML)**, Sam Kynman **(SK),** Patrice Forget **(PF),** Nadia Malliou **(NM),** Brian McGuire **(BM),** Gertrude Buttigieg **(GB),** Liisa Jutila **(LJ),** Jo Brown **(JB),** Françoise Alliot Launois **(FAL),** Mario Grixti **(MG),** Maria Teresa Flor-de-Lima **(MTFdL),** Muna Sidarus **(MS),** Gunilla Göran **(GG),** Sophie Goddaert **(SG),** Ellen Gepts **(EG)**, Eddy Claes **(EC).**

Purpose of the training

The Advocacy Toolkit Training brought together representatives from national SIP platforms, EFIC, and partner organisations to exchange experiences on advocacy practice, communication, and policy engagement. Participants discussed how SIP materials and tools can be used more effectively at national level and how to adapt them to different political and cultural contexts.

Q&A

Adapting and Translating SIP Materials

The session began with a discussion on the translation and localisation of SIP materials. Several participants expressed interest in producing national versions, particularly in Dutch, to support local advocacy efforts. The group agreed that translations should maintain the design quality and visual consistency of the original materials. It was suggested that teams contact the original designer for support in adapting visuals for new languages.

LJ noted that flyers, billboards, and other accessible communication formats are especially effective in reaching wider audiences. Participants agreed that the existing SIP infographics and communication materials have been well received and highly useful in meetings with stakeholders and policymakers.

Clarifying the SIP Structure

MS raised a question about the structure of SIP and how many independent organisations are involved. **SK** clarified that SIP functions as an informal network and a collaborative platform, rather than a legally registered entity. It operates as a shared philosophy of cooperation, uniting diverse partners under common goals rather than through formal administration.

Advocacy Experiences and Political Engagement

SK invited participants to share their experiences in engaging with policymakers.

LJ explained that in her country, discussions with politicians often focus on the Burden of Pain, and that linking national advocacy to EU-level initiatives strengthens credibility. She highlighted the value of SIP materials in these conversations, providing concrete evidence and messaging frameworks.

MS reported that referencing SIP policy documents had significantly increased their organisation's visibility. Following a government change, her team was invited to present their recommendations directly to policymakers — a major step forward.

NM reflected on the balance between professional and patient-led advocacy, noting that the patient voice remains underrepresented in some countries, such as Greece. She suggested that the SIP platform could help unite and empower patient communities that currently lack strong representation.

GG agreed that patients play a vital role in advocacy, sharing their lived experiences to strengthen the collective message. MTFdL added that while collaboration is key, there can sometimes be tension when professional organisations dominate advocacy spaces.

PF reminded participants that effective advocacy must be multidisciplinary, combining the perspectives of clinicians, patients, and researchers. He also emphasised the importance of addressing gender bias in health and pain care.

LJ shared that the SIP Joint Statement on Pain and Mental Health had been successfully used in Sweden to guide national discussions, although debates around medication availability remain sensitive.

PF provided insights from Belgium, where the government is planning new reforms for people with chronic conditions. While this initiative is promising, he cautioned that there is a risk of premature return-to-work pressures on patients. **EG** added that some national platforms still lack formal government stakeholders for pain, raising the question of whether registering as a separate legal entity could facilitate progress.

FAL noted that patient engagement remains strong in her country and that SIP has motivated collaboration across sectors.

Adapting Advocacy to a Changing Political Context

SK highlighted that Europe's political landscape is evolving, and advocacy strategies must be flexible. The SIP toolkit, while effective, cannot be applied uniformly across countries. Political instability and shifting health priorities can both hinder and create opportunities for engagement.

LJ cautioned that international examples, such as the United States, show how quickly scientific freedom and advocacy space can narrow, particularly on sensitive topics like gender or health equity. She urged participants to remain alert and protect existing advocacy frameworks.

SK reaffirmed that SIP remains politically neutral, operating from the centre and collaborating with a broad range of stakeholders — including socialists, greens, and moderates. While occasional outreach from political parties during elections can be challenging, SIP's non-partisan stance ensures credibility and long-term partnerships.

SK underlined the importance of creative and didactic advocacy, giving a memorable example of visual campaigning within the European Parliament to capture policymakers' attention.

Funding, Resources, and Advocacy Skills

GB asked about funding opportunities for national advocacy. **SK** explained that EU funding is typically short-term and project-based, requiring focused proposals. While this structure limits continuity, it encourages clear, measurable outcomes. He also noted that research projects can apply for specific grants.

The group discussed employment and pain as an emerging advocacy priority. **GB** noted that in Malta, individuals unable to work full-time often lose employment entirely, a challenge that will likely intensify in coming years. **SK** confirmed that employment and pain will be a central advocacy theme for 2026.

NM agreed, highlighting the stigma and marginalisation that people living with chronic pain continue to face. **MS** requested practical etiquette guidelines for advocacy meetings, while **MG** reflected that healthcare professionals are often not trained for political advocacy.

Participants shared that meetings with politicians can be unpredictable and require persistence, preparation, and empathy. **SK** reminded attendees that policymakers are human, and effective communication depends on understanding their perspective. Several participants observed that economic arguments — particularly cost-effectiveness and productivity impacts — often resonate most strongly with decision-makers.

LJ advised advocates to keep personal stories concise when speaking to policymakers, focusing on three to five sentences about their background before moving on to clear policy recommendations.

Action Points

Translate SIP materials (including Dutch and other languages) and adapt visuals for local use.

Support national platforms in applying SIP tools and data (e.g. Burden of Pain) during advocacy meetings.

Strengthen coordination between SIP and national platforms through organisational mapping and shared planning.

Offer advocacy and communication training to enhance national representatives' effectiveness with policymakers.

Prioritise employment and pain as a key advocacy focus for 2026.