



Flash sessions

July 9th, 2020, 15h CET / 9am EST

This online session is the great opportunity to address diverse but so important topic when it comes to Patient Engagement in medicines R&D. It will be done with short and interactive presentations (maximum 30 – 45 minutes maximum).

Sustainability roadmap for the patient engagement ecosystem

Patient engagement has increasingly gained attention in the past years, but it is not yet considered standard practice during the development of new medicines. The sustainability of patient engagement in the healthcare ecosystem, should be understood as a consistent and systematic approach taking into consideration the relationships existing among the relevant stakeholders and the interrelated processes. PARADIGM has co-created a sustainability roadmap that brings in all these elements and sets specific goals for the patient engagement community through changes in the culture, processes and resources of stakeholder organisations. This session will present the roadmap and highlight the essential role of the patient engagement community in achieving meaningful and sustainable patient engagement.

Patient engagement agreements explained

Collaboration between pharmaceutical companies and patient advocates should be based on contracts signed by both parties covering various types of activities such as consultancy, collaborations, speaking engagements and advisory boards. These contracts define the terms and conditions of the engagements, covering such matters as confidentiality, intellectual property, copyright, data protection, compensation and other responsibilities of both parties. They typically also contain provisions, mandated by the pharmaceutical industry or regulatory authority codes, designed to ensure an appropriate relationship between a patient and the engaging partner. In the past, the complexity of these agreements has often been challenging for the patient community and in particular patient advocates to work with due to the contracts being long, difficult to understand and sometimes containing ambiguous clauses. In PARADIGM, we developed a digital tool to support the patient community to understand the agreements they might need to review when collaborating with pharma.

The digital tool shows the reference agreements co-created by WECAN (under RAPP project) with additional explanations co-created and reviewed within a multi-stakeholder task force in PARADIGM. During this session, we will present the draft digital tool and we will, as part of the public consultation, welcome your feedback with an interactive tool.

<https://imi-paradigm.eu/petoolbox/contract-templates/>



Patient engagement in medicines R&D in the CEE region

On May 12th, PARADIGM organised 3 parallel workshops online to provide an opportunity for participants from the CEE countries to give feedback and shape the thinking about the patient engagement tools that PARADIGM is currently developing. The PARADIGM consortium has recognised that for the tools to stay sustainable and have a global impact, the insights coming from different regions are very much needed.

This flash session will allow us to give you a download of the feedback we have received through the workshops, putting this in the specific socio-economical and political context. Moreover, we'll have an interactive discussion about what concrete opportunities we can identify to help advance patient engagement in the region through PARADIGM and beyond.

Pre-reads: [CEE Patient Engagement Conference Part 1: Transferability workshops report](#)