

Patient Engagement Open Forum 2023

DRAFT AGENDA

June 13-15, 2022 Milan, Italy

13 June, 13:00 - 21:00 (including dinner)

13:00 - 14:00	Lobby/Winter Garden	Welcome coffee & registration
14:15 - 15:15	Carlo 1	Welcome plenary Speakers including Derick Mitchell (IPPOSI), Elizabeth Priest (PFMD), Robyn Bent (FDA), Bronwyn Lewis (BI), Raquel Peck (Clarion I)
15:30 - 17:00 Parallel Sessions	Planetario 2	Building a Culture of Digital Health Literacy: Strategies for Engaging Patients and Other Stakeholders In this session, we aim to increase participants' understanding of the importance of digital health literacy and how it can help improve health outcomes for all. We will share good practices and discuss how citizens' priorities, needs, and expectations can be voiced and addressed in the development of digital health products and services. Speakers and moderators including Petra Hoogendoorn (Leiden University Medical Center), Birgit Bauer (Data Saves Lives), Nick Guldemond (Medical University of Gdańsk), Milana Trucl (EPF)
	Planetario 1	Unlocking the Power of Patient Engagement: Exploring PFMD Metrics for Impactful Measurement and Monitoring This session will dive into the Metrics Selector, a tool to help stakeholders select the most appropriate metrics to measure patient engagement and patient-centricity in healthcare initiatives. The session will also cover the outcomes of the piloting initiatives that have used the Metrics Selector, showcasing how it has helped to monitor and measure the impact of patient-centric initiatives. Participants will gain a deeper understanding of how to use the Metrics Selector and its potential impact on patient outcomes. Speakers including Eva Bretschneider (Bayer), Paula Wray (University of Oxford), Ghada Ibrahim (PACRT), Brian Goodman (PFMD)
	Planetario 3	Patient Education Towards Patient Empowerment Meaningful patient engagement creates expectations in terms of preparedness and knowledge among patients, patient representatives, and patient organizations. For efficient advocacy, in addition to the personal experience of living with a disease, patients require varied levels of diagnosis-specific knowledge, soft skills, knowledge about medicines R&D, the patient community, and their own role as agents of change. Consequently, the need for patient training and capacity building is expanding and diversifying. The objective of this session is to better understand the capacity-building needs of patients today, the different actors and offerings within patient education, and the existing gaps and challenges. Speakers and moderators including Tamas Bereczky (Patvocates), Claudia Egher (Maastricht University), Maria Dutarte (EUPATI), Anne-Pierre Pickaert (Myeloma Patients Europe), Derick Mitchell (IPPOSI), Paola Kruger (EUPATI), Amelia Hursey (Parkinson's Europe), Gözde Susuzlu (EPF)
	Carlo 1	The Power of Patient Engagement in Driving Sustainable Healthcare Practices: Driving Better Patient Outcomes through Investor Value Join us to explore how integrating patient engagement into sustainability strategies can drive socially responsible business practices in the healthcare industry, and deliver value to both patients and investors. In this session, we will dive into the purpose, measurements, skill building, management, and
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		other matters to explore what all stakeholders need to consider when engaging the patient community to meaningfully and effectively improve patient health outcomes, sustainability performance, and investor value. Speakers including Joep Muijrers (Gilde Healthcare), Rebecca Vermeulen (Roche), Graeme Johnston (Patient advocate), Hayley Chapman (PFMD)
17:00 - 17:30	Winter Garden	Coffee Break Including a EUPATIConnect demo
17:30 - 18:30 (Stakeholders Specific Sessions)	Carlo 1	Embedding patient involvement in global health systems architecture and decision—making to provoke lasting change During this session, we will collectively a) reflect on the united Call to Action from the last PEOF on embedding patient involvement more effectively in global health systems architecture and decision—making as both a right and an added value, b) understand the current scene and trends at European level and in the U.S.c.) Explore how we can transpose this expertise and know—how into a global context, and d) think innovatively about the resourcing of patient organizations and different levels and learnings from other movements. Speakers including Randall Rutta (NHC), Nicola Bedlington (Millwater Partners GmbH), Anca Toma (EPF), Derick Mitchell (IPPOSI), Raquel Peck (Clarion I)
	Planetario 2	Building a Community for Patient Engagement Industry Professionals Industry only session Join your industry colleagues attending PEOF as we reflect on shared experience implementing metrics for patient engagement and the collective needs of the industry community Speakers including Rebecca Vermeulen (Roche) & Marc Boutin (Novartis)
	Planetario 1	Building Evidence & Supporting Decision Making: Roundtables for HTA, Regulatory, Academia, and other PEOF stakeholder groups
18:30 - 19:00		Break
19:00 - 21:00	Royal Garden	Welcome dinner - Pizza Party

14 June, 09:00 - 21:00 (including lunch & dinner)

07:00 - 09:00	Hotel Restaurant	Breakfast
09:00 - 10:00	Carlo 1	Day 2 plenary: Key Outcomes from the Stakeholder-Specific Sessions Reporting back on the previous day's sessions and highlights from the stakeholder-specific sessions. Speakers including Rebecca Vermeulen (Roche), Randall Ruta (NHC), Neil Bertelsen (HTAi), Dr Stuart Faulkner (University of Oxford)
10:15 - 11:45 Parallel Sessions	Carlo 1	System Change Leadership: How to achieve lasting change together to embed true patient engagement in healthcare For most, patient engagement has become a no-brainer, but the practice remains fragmented and scattered. Many new tools and guidelines have come out in the last few years, and new ones are still developed every day. The session will explore how we can complement tools or guidances to provoke actual lasting change, what else needs to happen to generalize adoption & what are the leverage points to make those tools and good practices even more actionable within an organization and beyond. Speakers including Marc Boutin (Novartis), Robyn Bent (FDA), Nicola Bedlington (Millwater Partners)

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GmbH), Quentin Clermont (PFMD) Planetario 2 Unleashing the Power of Collaborative Efforts for a Patient-Centric Clinical Trial Distribution Network Join us at this workshop to contribute to the design of an innovative platform that aims to enhance the accessibility of clinical trials for patients. The platform will provide structured and enriched data for clinical protocols, connecting existing stakeholders in the ecosystem. By participating, you'll gain insights into our demo pilot and collaborate on scaling it up to create a more inclusive and accessible clinical trial ecosystem. Speakers and moderators including, Rebecca Vermeulen (Roche), Daniel De Schryver (Janssen), Brian Goodman (PFMD), Jan Geissler (Patvocates), Nicole Wicki (PFMD), Silvia Bornengo (PFMD) Closing the Loop: Maximizing the Impact of Patient Engagement Monitoring through Effective Planetario 3 **Feedback Loops** This session will focus on the importance of effective feedback loops in patient engagement (PE) monitoring. By creating a closed-loop system that allows for continuous feedback and improvement, stakeholders can optimize the impact of their PE initiatives and improve patient outcomes. The session will explore various strategies and tools that can be used to establish an effective feedback loop. Join us in defining the baseline of how to leverage feedback loops to improve patient engagement outcomes! Speakers including Robert Joyce (Patient advocate), Christel Paganoni (Sobi), Paula Wray (University of Oxford), Hayley Chapman (PFMD) Planetario 1 Getting our act together for access – working together for better HTA In this session, the participants will co-create strategies, actions, and ideas to improve patient involvement in HTA building from recommendations made in the HTAi 360 project - a partnership between HTAi, EUPATI, and EPF aimed at identifying improvements to patient involvement in HTA. Speakers including Anke-Peggy Holtorf (Health Outcomes Strategies GmbH), Neil Bertelsen (HTAi) Coffee Break & Networking time - Organize your side meetings! Winter 11:45 - 12:30 Garden Introduction to the From Testing to Targeted Treatments (FT3) Program Carlo 1 **Buffet Lunch** Hotel 12:30 - 14:00 Restaurant Planetario 2 Enriching Healthcare Evidence Generation and Decision-Making: Integrating Patient Experience Data and Patient Engagement Join us for an insightful session that will consider the intersection of patient engagement, patient experience data, and larger system integration in healthcare. We will delve into some of the challenges and examine the critical components of patient engagement and patient experience data that are important and necessary to all stakeholders to drive meaningful change and improve patient outcomes. Through collaborative dialogue, we will explore areas of mutual agreement for all stakeholders and strive to establish a more intelligent and cohesive system that prioritizes patient 14:30 - 16:00 needs, and fosters improved health outcomes. Parallel Speakers including Robyn Bent (FDA), Juan García Burgos (EMA), Denis Costello (CML Advocates Sessions Network), Neil Bertelsen (HTAi), Rebecca Vermeulen (Roche), Hayley Chapman (PFMD) Planetario 1 Breaking Barriers: Educating all Healthcare Stakeholders through Patient Engagement Training During this session, we aim to equip participants with the necessary resources to enhance patient engagement by providing stakeholders with tailored training. We will also explore patient engagement resources that participants can leverage to extend this training across the healthcare ecosystem. Join us to help co-create an inclusive environment where all stakeholders engage patients throughout the patient journey. Together, we can improve the quality of care and outcomes for patients.































		Speakers and facilitators including Victoria Siegrist (Roche), Holger Bartos (Boehringer Ingelheim), Steve Bourke (PersonalPulse), Maria Dutarte (EUPATI), Brian Goodman (PFMD)
	Carlo 1	The importance of patient engagement in enabling cross-border access to clinical trials Borders are high barriers to participation in a clinical trial in another country. Initiatives such as the multi-stakeholder EU-X-CT Initiative are being put in place to improve the situation for patients in need of trial participation. This session will discuss the role of patients and patient organizations in enabling cross-border participation in clinical trials today and in the future. Speakers including Ingrid Klingmann (EFGCP), Susan Bhatti (Merck BV), Lisbeth Oxholm Snede (EUPATI)
	Planetario 3	Advancing PE in Digital Health - What do stakeholders in digital health expect and need from each other to ensure better health outcomes Join us for an interactive session where we will find out what stakeholders in digital health expect and need from each other. The objective of the session is to present the results of PFMD's stakeholder expectations matrix in digital health, the outcomes of dozens of interviews with global digital health experts, and see how we can truly leverage the richness of information in order to support PE in digital health at a global level. Speakers including Leanne West (iCAN), Derick Mitchell (IPPOSI), Valerie Storms (Roche), Nicholas Brooke (PFMD)
16:00 - 17:30	Winter Garden	Break Check out the EUPATI Connect demo
17:30 - 18:30	Carlo 1	Made with Patients Awards Ceremony
18:30 - 19:30	Margherita Garden	Made with Patients Celebration cocktail
19:30 - 21:00	Hotel Restaurant	Dinner

15 June, 09:00 - 14:30 (including lunch)

07:00 - 09:00	Hotel Restaurant	Breakfast
09:00 - 10:00	Carlo 1	Day 3 Plenary - Going Global & Going Together: Not Leaving Anyone Behind Includes reporting back from the previous day's sessions and outcomes. Speakers including Tony Hoos (SOBI), Nidhi Swarup (Crohn's & Colitis Society of Singapore, CCSS), & Runcie Chidebe (Project PINK BLUE)
10:15 - 11:45 Parallel Sessions	Carlo 1	Exploring the Concept of "Patient Experience Data Dossiers": What is their role in streamlining the generation and use of PED for meaningful healthcare decision—making with the patient community? During this session, participants will hear from several speakers and participate in small group discussions exploring interest among global stakeholders, the feasibility, resources needed, and potential alternative solutions to PED Dossiers as a solution to connect researchers and healthcare decision—makers and ultimately streamline the generation and use of PED for and with patients. Speakers including Elisabeth Oehrlein (Applied Patient Experience, LLC), Omar Escontrías (NHC), Carole Scrafton (FibroFlutters), Hayley Chapman (PFMD)

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	Planetario 1	Informed Consent in Precision Medicine Clinical Practice Join us for an interactive 90-minute workshop on informed consent in precision medicine clinical practice and biomarker testing. Every patient has the right to get information and ask questions before procedures and treatments, yet patients often report that they are unaware of whether their healthcare team has ordered biomarker testing. In this session, you will learn about precision medicine and how empowering patients with information might mitigate clinical practice hurdles. We'll explore how informed consent may support Shared Decision Making and navigating the best care pathway for each patient, and outline where it is essential to involve patients and their representatives in developing information-sharing or consent procedures. Speakers and moderators including Nicole Sheahan (Global Colon Cancer Association), Denis Costello (CML Advocates Network), Marianna Vitaloni (DiCE), Alan Balch (Patient Advocates Foundation), Charles Steward (Genomics England), Ivica Belina (KUZ Croatia), Bahija Gouimi (AMAL), Helena Harnik (FT3, The Synergist)
	Planetario 3	Is matchmaking still a challenge for patient engagement? Effective patient engagement requires matching the right patient(s) with the right activity throughout the medicines' development life cycle. The IMI-PARADIGM project (2018-2020) identified challenges in the selection of participants and adequate representation. While progress is being made in how patients and their representatives are selected prior to an engagement activity, e.g. via tools like EUPATIConnect, challenges still remain. This session will take stock of the current developments and challenges in the area, by looking into e.g. patient group databases, registries, social networking tools, and platforms, as well as the evolving selection criteria for co-design with the patient community, standard practices, and published case studies. Speakers including Ebony Anchelle Buehler (Healthcare professional), Allison FitzGerald (GlobalSkin), Victoria Siegrist (Roche), Maya Zlatanova (FindMeCure)
	Planetario 2	Driving Patient Engagement: Co-Creating a Patient Engagement Campaign to Promote Health Outcome Data Sharing This session will delve into how patient engagement can be leveraged to collect and generate valuable health outcome data. Participants will brainstorm and co-create a campaign that encourages patients to share their data, providing insights into patient needs, preferences, and expectations. Gain a deeper understanding of how patient engagement and health outcome data can work together to drive more collaborative, patient-centric healthcare practices. Speakers and moderators including Cristian Andriciuc (H2O Patient Advisory Board), Viorica Cursaru (H2O Patient Advisory Board), Gözde Susuzlu (EPF, Data Saves Lives), Judith Schilling (Acumen)
11:45 - 12:00	Winter Garden	Coffee Break
12:00 - 13:00	Carlo 1	Closing Plenary: The Future of Patient Engagement Speakers including Juan García Burgos (EMA), Robyn Bent (FDA), Marc Boutin (Novartis), Julia Jenkins (EveryLife Foundation), Hayley Chapman (PFMD)
13:00 - 14:30	Hotel Restaurant	Goodbye Lunch & Departure

































Ongoing Activities:



EUPATI Lounge (Winter Garden)



Synapse Area (Winter Garden)



Made with Patients Awards Ceremony

(Margherita Garden)

Sit and chat with the EUPATI team and learn how we provide patient engagement through education. Explore the EUPATI Open Classroom & Toolbox with demo sessions. Get to know EUPATConnect, the National Platforms & our patient engagement training with us!

Visit the Synapse Area to chat with the team and upgrade your presence online. Mini-workshops and demo sessions will also give an in-depth look at how you can make the most out of specific Synapse features and tools, including the Metrics Selector, the latest Fair PE Planner & more. Come engage with the team for live co-creation and exchange of feedback

This year we will be celebrating our inspiring patient engagement champions and initiatives during an award ceremony and cocktail on Day 2 of PEOF. Building on some of last year's PEOF co-creation activities, the awards will shine a light on those who help advance global PE. The winners and jury members of the award will be called on stage to receive their awards and congratulations and the ceremony will continue with a short cocktail.



EATRIS - Patient Engagement Resource Centre (Lobby - Next to Carlo I)



(Lobby - Next to Carlo I)



Other Ongoing Activities (Winter Garden)

EATRIS invites you to come and explore their new user-friendly website for researchers getting started with PE.

Find us daily at the PEOF Info Desk to get information about: Agenda & Ongoing Activities, On-site contacts & support, and COVID safety updates

- **PE plane** Join us as we scan the horizon looking for trends, upcoming policy changes and pending obstacles for patient engagement.
- Feedback wall Your space to let us know how we did and what else can we do to make PEOF better next time.
- **Professional photo booth** Need a new portrait or looking at updating your LinkedIn / Synapse profile picture? Say no more as you will be able to do that at PEOF with a professional photographer.
- INSTA Wall Bring your energy into focus at the interactive photo booth with a vibrant backdrop, fun props & more to click that perfect group picture and share it on social media (with #PEOF of course!).
- Stakeholder Matrix Share your provocative thoughts and help map what various stakeholders expect from each other to inform the change of the future

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