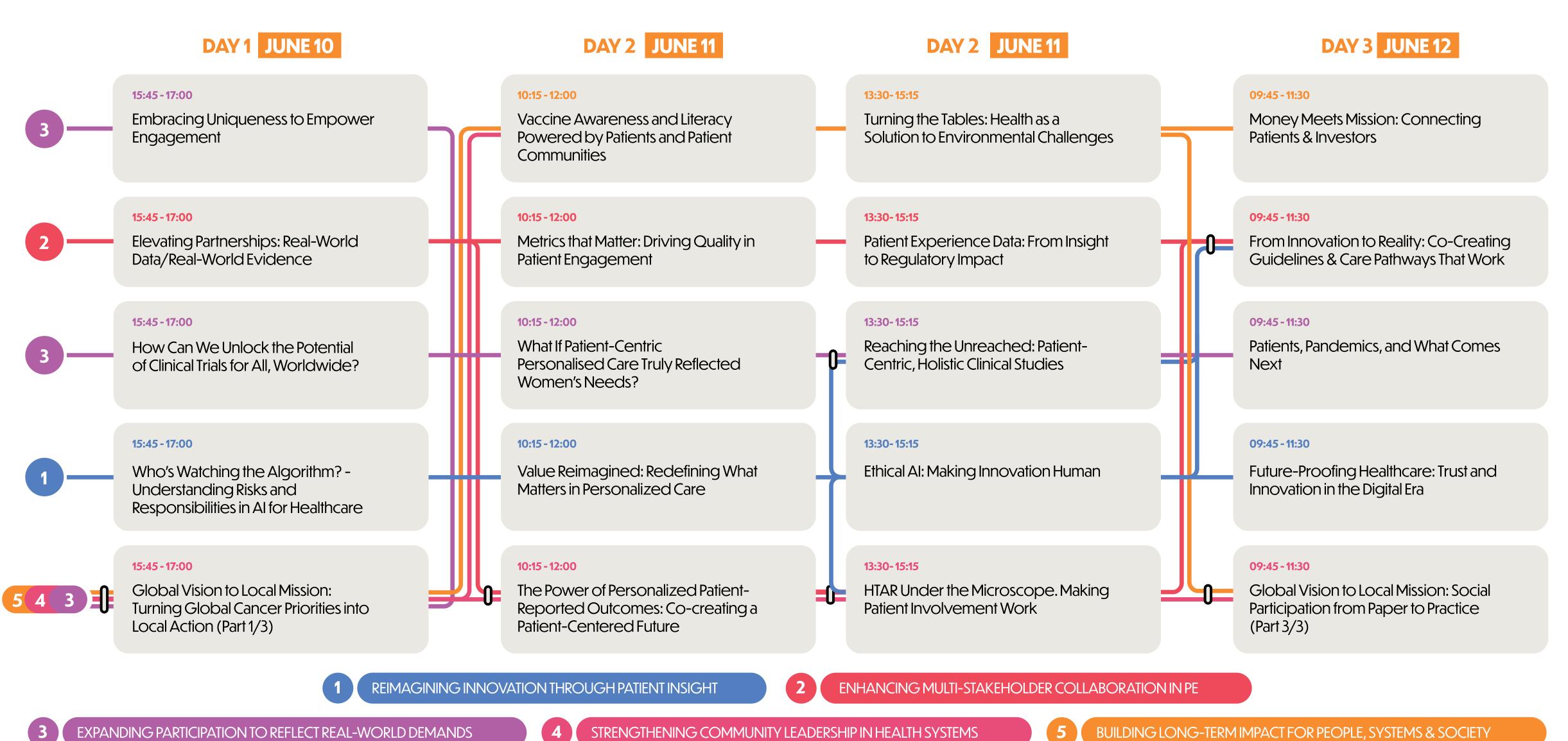


# 1 2 3 4 5 YOUR PATH.YOUR PACE.YOUR PEOF.









## **DAY 1** 10 JUNE 12:00-21:30 including lunch & dinner



11:00 - 13:00 CARLO 3

### Community Informal Meet-up

Are you already at the venue? Join this informal Patient Community Meet-up organized by the PEOF Program Committee!

12:00 - 14:30 LOBBY / WINTER GARDEN

### Registration / Pre-event Coffee & Walking Lunch

12:00 - 14:00 LIVE FROM CARLO 1

### PEOF+ JPPaC&PFMD 8th PE Seminar

Join us from 12:00 to 14:00 for the PEOF+ JPPaC&PFMD 8th PE Seminar - Research Ethics from a Patient-Centered Perspective, live streamed at PEOF F2F.

14:30 - 15:30 CARLO 1

### Opening Plenary - The State of Patient Engagement in a Shifting World

In a world grappling with health crisis, conflicts, digital disruption, and restructuring, what's the role of patient engagement today? This session opens PEOF 2025 by anchoring us in the global policy and health systems context. We'll explore the forces shaping the ecosystem, and what's keeping patient engagement resilient, relevant, and responsive. Why must we double down on our shared work now?

**Speakers and moderators:** Amanda Bok (PFMD, The Synergist), Ilona Kickbusch (World Health Summit), Dani Motchi (IAPO), Jennifer Bright (ICHOM), Marc Boutin (independent PE expert), Andreas Christodoulou (Cyprus Federation of Patients' Associations).

15:45 - 17:30 CO-CREATION SESSIONS PLANETARIO 2 RIGHT

### **Embracing Uniqueness to Empower Engagement - Boost your Capacities!**

How do we build skills that don't just tick boxes but shift mindsets? This session explores how comprehensive, practical training can unlock broader, more representative engagement.

**Speakers and moderators:** Lara Bloom (Ehlers-Danlos Society) and Tamás Bereczky (Deutsche Aidshilfe)

15:45 - 17:30 CO-CREATION SESSIONS PLANETARIO 1

### **Elevating Partnerships: Real-World Data/Evidence - Boost your Capacities!**

More than just data, this session is about building the capacity and confidence to engage with RWD/RWE and apply it meaningfully to patient partnerships.

**Speakers and moderators:** Andreas Christodoulou (Cyprus Federation of Patients' Associations) and Daniel Weibel (VAC4EU)

15:45 - 17:30 CO-CREATION SESSIONS

PLANETARIO 2 LEFT

### How can we Unlock the Potential of Clinical Trials for All, Worldwide?

Clinical trials rarely reflect patients' lived experiences. This hands-on session tackles regional gaps in patient participation, including women's participation in the design and delivery of clinical trials, with a co-creative element to help unlock patient-centricity in the trial ecosystem across borders.

**Speakers and moderators:** Amanda Bok (PFMD, The Synergist), Rebecca Vermeulen (Roche), Bahija Gouimi (A.M.A.L), Jamie White (Independent Advocate), Nobutaka Yagi (YORIAILab), Mark Barone(Fórum CCNTs), Paloma Moraga Alapont (Hospital Universitario La Paz), Léa Proulx (Roche), Diogo Galvao (DNDI), Deon York (Haemophilia New Zeeland), Nicholas Brooke (PFMD, The Synergist), Ritu Jain (DEBRA International)

15:45 - 17:30 CO-CREATION SESSIONS

**PLANETARIO 3** 

## Who's Watching the Algorithm? - Understanding Risks and Responsibilities in Al for Healthcare - A Capacity Building Workshop

All is here, but patients aren't always in the room where decisions are made. This training empowers patients with knowledge and confidence to shape how All is used ethically and transparently. The session will feature a dynamic workshop on the critical role of human oversight in Al-driven healthcare.

**Speakers and moderators:** Milana Trucl (EPF), Mandy Melissa Jane Wittens (VUB)

15:45 - 17:30 CO-CREATION

SESSIONS CARLO 1

Global Vision to Local Mission: Turning Global Cancer Priorities into Local Action (Part 1/3)

Big goals mean little without local traction. This interactive session will explore how patient engagement can drive meaningful change by connecting global efforts to local realities. Through real-world insights and hands-on co-creation, participants will co-create practical strategies to translate global cancer care priorities at the national level, ensuring impact where it matters most.

**Speakers and moderators:** Abigail Simon-Hart (The Bricon Foundation), Thesandree (Tess) Padayachee (WHO), Carolyn Taylor (Global Focus on Cancer), Heba AlSawahli (WHO EMRO)

17:30 - 18:30 WINTER GARDEN

**Networking Coffee Break** 

17:30 - 18:30

**PLANETARIO 1** 

## **Documentary Premiere: Blood In My Stool**

Want to have a different coffee break? Grab a snack & a drink and join us for the Documentary Premiere: Blood In My Stool - a heart-stopping, true-life story of survival and triumph. "Blood in my Stool" is an example of how PEOF brings diverse stakeholders together to spark lasting change, as the idea for this documentary was born at PEOF 2023. Curious to find out more? Join us!

**SESSION MAIN THEMES:** 

1 REIMAGINING INNOVATION THROUGH PATIENT INSIGHT

2

ENHANCING MULTI-STAKEHOLDER COLLABORATION IN PE

3

EXPANDING PARTICIPATION TO REFLECT REAL-WORLD DEMANDS

4 STRENGTHENING COMMUNITY LEADERSHIP IN HEALTH SYSTEMS

5

5 BUILDING LONG-TERM IMPACT FOR PEOPLE, SYSTEMS & SOCIETY

## **DAY 1** 10 JUNE 12:00-21:30 including lunch & dinner



18:30 - 20:00

CARLO 1 & MARGHERITA GARDEN

### **Engagement Unplugged ;)**

A collective engagement activity, with a twist! Expect reflection, music, and connection.

20:00 - 21:30 HOTEL RESTAURANT

Dinner

22:00 - 22:30 CARLO 1

### **Documentary: The Patient Journey**

A different evening at PEOF this year with an optional after-dinner movie night. The powerful documentary called "The Patient Journey" by Voices for Women exposes the constant challenges in ensuring women's health needs are met, revealing how many women face misdiagnosis and inadequate care due to system's barriers.













## **DAY 2** 11 JUNE 9:00-21:30 including lunch & dinner



07:00 - 09:00 HOTEL RESTAURANT

#### **Breakfast**

09:00 - 10:00 CARLO 1

### Day 2 Plenary - Leadership in Patient Engagement: Who's Stepping Up?

Let's get honest: As the patient engagement community, how are we showing up in response to today's challenges? Are we making space for all patients, not just usual voices? Are we sharing power, shifting systems, and backing words with action? This plenary explores what real leadership looks like in PE now, spotlighting bold actions that move beyond tokenism toward meaningful collaboration.

**Speakers and moderators:** Rebecca Vermeulen (Roche), Konstantina Boumaki (EPF Youth Group), Juan Garcia (EMA), Mark Barone (ForumCCNTs) and Jennifer Austin (GlobalSkin)

10:15 - 12:00 **CO-CREATION** SESSIONS **PLANETARIO 2** LEFT

### **Vaccine Awareness and Literacy Powered by Patients** and Patient Communities

Patient communities are shaping vaccine uptake and trust. This session maps real-world insights, gaps, and strategies for more patient-driven vaccine approaches.

**Speakers and moderators:** Maria Dutarte (EUPATI), Charlotte Vernhes (Vaccines Europe), Mariano Votta (Active Citizenship Network) and Daniel Weibel (VAC4EU)

10:15 - 12:00 **CO-CREATION** SESSIONS CARLO 1

### **Metrics that Matter: Driving Quality in Patient Engagement**

Patient engagement isn't something that should just be measured after the fact—it should evolve in real-time, continuously shaping the work as it unfolds. In this session, we'll explore how to create a dynamic feedback loop that not only measures the impact of patient engagement but also provides actionable insights that drive improvements. We'll discuss how to identify and collect key metrics that give us true patient engagement intelligence in a multi-stakeholder setting to ensure that the quality of care and patient involvement keep improving every step of the way.

**Speakers and moderators:** Liz Clark (King's College London), Jennifer Austin (GlobalSkin), Daniel De Schryver (Johnson & Johnson), Michaela Dinboeck (Novartis), Derick Mitchell (The Synergist)

10:15 - 12:00 **CO-CREATION** SESSIONS **PLANETARIO 3** 

## What If Patient-Centric Personalised Care Truly Reflected Women's Needs?

From Tailored Approaches in Shared Decision-Making to System Change - Participants will explore real-world experiences from the patient community, recognizing that evidence shows that different women have unique needs and challenges. This recognition will enable progress in patient engagement which offers valuable lessons that can drive more personalized care and better health, societal, and economic outcomes for all. Attendees will learn more about the emerging Synergist Women's Health Catalyst and other aligned initiatives, such as the Global Alliance for Women's Health and ViiV Healthcare.

**Speakers and moderators:** Mirjam Kaijer (Voices for Women), Nneka Nwokolo (ViiV Healthcare/Chelsea and Westminster Hospital), Eleanor Nwadinobi (MWIA), Marta Bragagnolo (Global Heart Hub), Jamie White (Independent women's health advocate), Vanessa Apea (Barts Health NHS Trust)

10:15 - 12:00 **CO-CREATION** 

**PLANETARIO 2** RIGHT

SESSIONS

### Value Reimagined: Redefining What Matters in Personalized Care

As health systems shift toward personalized care, we need new ways to define and assess value, especially of innovative health technologies. In this session, participants will unpack emerging value drivers and co-create strategies to embed them into health policy and Health Technology Assessment (HTA). The goal: to advance patient-centered innovation and broaden access for better patient outcomes.

Speakers and moderators: Alan Balch (PAF), Cat Koola Fisher (ICER), Clarissa Cooblall (ISPOR) & Jamie O'Hara (Independent Expert)

10:15 - 12:00 **CO-CREATION** 

**PLANETARIO 1** 

SESSIONS

### The Power of Personalized Patient-Reported Outcomes: Co-creating a **Patient-Centered Future**

This interactive session will explore how personalized patient-reported outcomes (PROs) can better reflect real patient priorities. Using the Health Outcomes Observatory (H2O) results sets and digital PRO tools as a starting point, participants will co-create solutions to overcome adoption challenges and generate actionable recommendations for more meaningful use in care, research, and policy.

**Speakers and moderators:** Bianca Pop (EPF); Judith Lancaster (Acumen); Alizé Rogge (Charité - Universitätsmedizin Berlin); Evelyn Gross (ÖMCCV); Andreas Christodoulou (Cyprus Federation of Patients' Associations, Board Member of EPF and Treasurer of the Pan-European Observatory of EU-funded H2O project) of Patients' Associations, Board Member of EPF and Treasurer of the Pan-European Observatory of EU-funded H2O project)

12:00 - 13:30

HOTEL RESTAURANT

### Lunch

13:30 - 15:15 **CO-CREATION** SESSIONS

**PLANETARIO 2** LEFT

### Turning the Tables: Health as a Solution to Environmental Challenges

What if healthcare could lead the climate agenda? As climate and environmental conditions worsen health outcomes, patients and communities must be at the center of solutions. This interactive session flips the narrative, focusing on how regenerative health systems can power climate resilience. Through real-world examples, collaboration, and strategy mapping, participants will co-create an action roadmap to build regenerative health systems that benefit both people and the planet.

**Speakers and moderators:** Ilona Kickbusch (World Health Summit), Helena Harnik (The Synergist)

13:30 - 15:15

**SESSIONS** CARLO 1

**CO-CREATION** 

## Patient Experience Data: From Insight to Regulatory Impact

As the European Medicines Agency (EMA) prepares its upcoming reflection paper on the role of Patient Experience Data (PED) in regulatory decision-making, this session offers a unique opportunity to collaborate with global regulatory experts. Join us as we get straight to what matters: how Patient Experience Data can drive more patient-centered, evidence-based regulatory decisions. This candid, hands-on co-creation session will focus on PEDs' value, real-world applications, and integration into regulatory frameworks – contributing to shaping its future in policy and practice.

**Speakers and moderators:** Juan Garcia Burgos (European Medicines Agency, EMA), Robyn Bent (FDA), Shun Tezuka (PMDA), and Hayley Chapman (PFMD, The Synergist)

### **SESSION MAIN THEMES:**

REIMAGINING INNOVATION THROUGH PATIENT INSIGHT





## **DAY 2** 11 JUNE 9:00-21:30 INCLUDING LUNCH & DINNER



13:30 - 15:15 **CO-CREATION** SESSIONS **PLANETARIO 2** 

RIGHT

### **Reaching the Unreachable: Patient-Centric, Holistic Clinical Studies**

Too many populations, including young people and women, face systemic challenges in how they can engage with and in clinical studies, leading to deep data and scientific gaps. Through co-creation and focused conversations, participants will develop actionable strategies to make research more comprehensive, balanced, and truly fit for the real-world reality of patients everywhere.

**Speakers and moderators:** Amanda Bok (PFMD, The Synergist) Maria Dutarte (EUPATI), Léa Proulx (Roche), Paloma Moraga Alapont (SERMAS), Nadine Boesten (EPF), Valentina Strammiello (EPF), Mitchell Silva (Patient Centrics and Esperity), Begonya Nafria Escalera (San Joan de Déu Children's Hospital), Nersey Rastan (The Synergist)

13:30 - 15:15 **CO-CREATION** SESSIONS **PLANETARIO 1** 

### **Ethical AI: Making Innovation Human**

An interactive session with expert insights, focused on addressing AI's challenges and opportunities in healthcare. Building on last year's PEOF co-creation insights and aligning with AI training on day 1, the session will involve co-creating guidelines for patient engagement in AI development, with tangible takeaways for improving the ethical application of AI in healthcare.

**Speakers and moderators:** Laura Kavanagh (IPPOSI), Aneta Tyszkiewicz (EFPIA), Bianca Cucoș (Ino.Med), Lara Bloom (Ehlers-Danlos Society), Leanne West (iCAN), Derick Mitchell (The Synergist)

13:30 - 15:15

**CO-CREATION** SESSIONS

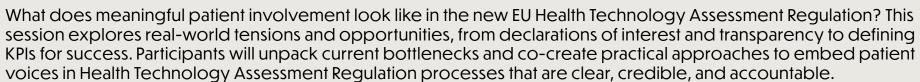
**PLANETARIO 3** 

15:15 - 15:45 WINTER GARDEN

15:45 - 17:15 **STAKEHOLDER** SPECIFIC SESSIONS

**PLANETARIO 1** 

## **Health Technology Assessment Regulation (HTAR) Under the Microscope. Making Patient Involvement Work**



**Speakers and moderators:** Finn McCartney (EUPATI), Valentina Strammiello (EPF), Cat Koola Fischer (Institute for Clinical and Economic Review - ICER) & Jörg Ruof (European Access Academy)

#### **Coffee Break**

### Industry-only Session hosted by PEPs -The Industry Voice for Patient Engagement Professionals

A dedicated pre-competitive space for industry peers to have honest, forward-looking conversations to further professionalize PE, share best practices and systematic PE deployment.

Moderators: Rebecca Vermeulen (Roche) and Roslyn Schneider (Independent PE Expert), Kersten Sharrock (Sanofi) - Industry only

### **Patient Community-only Session - Global Vision to Local Mission:** Social Participation Starts Now (Part 2/3)

15:45 - 17:15 STAKEHOLDER SPECIFIC SESSIONS CARLO 1

The WHA Resolution on social participation is a potential accelerator for patients' existing advocacy work, but how can it best support current and future strategies? This session brings patient and community leaders together to translate global pathways into local realities. Participants will surface opportunities and identify practical ways to reinforce their own partnership strategies through the use of social participation in health systems. This session links into a second co-creation session on Thursday.

**Speakers and moderators:** Mark Barone (Intersectoral Forum to Fight NCDs, Brazil), Deon York (Former Director of Consumer Engagement, Health Quality and Safety Commission), Gabriele Pastorino (WHO), Caroline Wong (Centre of Excellence on Partnership with Patients and the Public), Lara Bloom (Ehlers-Danlos Society), Jennifer Austin (GlobalSkin) and Marc Boutin (Independent PE Expert) - Patient Community only

15:45 - 17:15 **STAKEHOLDER** 

**SPECIFIC** 

**SESSIONS** 

WINTER GARDEN **GAZEBO** 

### PE Enthusiasts Exchange (HCPs, Academia, Regulators, ..)

An informal space for regulators, healthcare professionals, researchers, academics, and others passionate about patient engagement to connect beyond their usual circles. This session will feature a speed-dating format designed to spark fresh conversations, challenge assumptions, and encourage cross-sector exchange.

**Speakers and moderators:** Derick Mitchell (The Synergist), Maddalena Benivento (PFMD) PE Enthusiasts (HCPs, Academia, Regulators, ..)

17:15 - 18:15 WINTER GARDEN

### **Networking Coffee Break**

18:15 - 19:15 CARLO 1

**Made with Patients Awards Ceremony** 

The Made With Patients Awards spotlight the people and initiatives redefining what patient engagement can be. More than recognition, it's a moment to reflect on the progress we've made and to celebrate those leading with integrity, creativity, and impact. Join us as we elevate stories that inspire and ripple across healthcare systems.

19:15 - 21:30 ROYAL **PAVILION** 

#### **Cocktail Celebration & Dinner**

**SESSION MAIN THEMES:** 

REIMAGINING INNOVATION THROUGH PATIENT INSIGHT







**EXPANDING PARTICIPATION TO REFLECT REAL-WORLD DEMANDS** 





## **DAY 3** 12 JUNE 09:00-14:30 including lunch



07:00 - 09:00 HOTEL RESTAURANT

#### **Breakfast**

09:00 - 09:30 CARLO 1

### Day 3 Plenary - Re-Connect, Re-Focus and Re-Energise

After two intensive days of co-creation, and before moving ahead with the last sessions of co-creation, we will gather again in plenary to re-connect, re-focus and re-energise. Building on the work from the past two days, we will launch the last day's work with a forward-looking spirit.

**Speakers and moderators:** Valentina Strammiello, EPF

09:45 -11:30 **CO-CREATION** SESSIONS **PLANETARIO 1** 

### **Money Meets Mission: Connecting Patients & Investors**

Patient engagement is a driver of smarter, more meaningful innovation, but how does it align with investment? This session brings patients and investors together to explore how patient-centric investments can drive real impact. Participants will learn from expert insights, enter bold discussions and craft actionable strategies to reshape the future of patient-powered healthcare investment.

**Speakers and moderators:** Robby Spring (Independent Expert), Pommeline Korstanje (Gilde Healthcare), Marc Boutin (Healthcare Investment Advisor), Nicola Bedlington (Millwater Partners), Hayley Chapman (PFMD, The Synergist)

09:45 -11:30 **CO-CREATION** SESSIONS **PLANETARIO 3** 

### From Innovation to Reality: Co-Creating Guidelines & Care Pathways That Work

Medical guidelines can fall short in practice, especially when patient voices are missing. This session explores how co-creating guidelines & care pathways with patients can close that gap. Participants will identify key moments for engagement and co-design strategies for building diagnostics and treatments, that are not just evidence-based, but experience-informed.

**Speakers and moderators:** Cristiana Sessa (Oncology Institute of Southern Switzerland, Former Co-Chair ESMO Guidelines Committee), Bianca Cucoş (Ino.Med), Eva Bretschneider (Bayer), Josef De Guzman (PsorPhil, International Federation of Psoriasis Associations -IFPA), and Lidewij Vat (The Synergist).

09:45 -11:30 **CO-CREATION** SESSIONS **PLANETARIO 2** LEFT

### **Patients, Pandemics, and What Comes Next**

From vaccine access to clinical trial participation, the COVID-19 pandemic exposed deep variations across different communities and prompted innovation. This session unpacks what we've learned about engaging patients during, before, and after health crises and how to apply those lessons to build more resilient, patient-centered healthcare systems in the future.

**Speakers and moderators:** Melanie Hoste (University of Antwerp), Nadine Boesten (EPF), Estefania Callejas De Luca (EPF)



09:45 -11:30 **CO-CREATION** SESSIONS CARLO 1

## **Future-Proofing Healthcare: Trust and Innovation in the Digital Era**

Digital health is reshaping the future of healthcare, but its true potential can only be realized through one critical factor: trust. As AI, wearables, and patient data drive innovation, trust and transparency are essential to unlocking their full impact. This session will explore how we can lead the way in building data solidarity and embedding patient engagement at every stage, ensuring technology empowers patients and shapes the future of care.

**Speakers and moderators:** Derick Mitchell (PFMD, The Synergist), Barbara Prainsack (University of Vienna), Charles Alessi (Nightingale Health), Doreen Tembo (Health Research Data UK), and Birgit Bauer (DSL DE).

09:45 -11:30 **CO-CREATION** 

PLANETARIO 2 RIGHT

SESSIONS

### Global Vision to Local Mission: Social Participation from Paper to Practice (Part 3/3)

Building on Wednesday's session of the same name, this co-creation break-out focuses on region-specific tangible and concrete strategies to translate the WHA Resolution on social participation into hands-on pathways that patients can embed at national and local levels to further elevate and accelerate their existing work. Participants will map opportunities, strategies and support each other by sharing ideas across regions, thereby bringing this global potential to life from the ground up.

**Speakers and moderators:** Nobutaka Yagi (YORIAILab), Dani Motchi (IAPO), Lara Bloom (Ehlers-Danlos Society), Mark Barone (Intersectoral Forum to Fight NCDs), Jennifer Austin (GlobalSkin) and Abigail Simon-Hart (The Bricon Foundation)

WINTER GARDEN

### **Coffee Break**

## 12:00 - 13:00

CARLO 1

We've looked at where we are and what we're doing, but what will it take to push further? What will it take to strengthen and scale patient engagement across systems, sectors, and geographies? This plenary will explore practical strategies for turning local success into global momentum, even in times of uncertainty. We'll hear what's working and what's needed to build staying power for the future of patient engagement.

Closing Plenary - The Future of Patient Engagement: What Will it Take?

**Speakers and moderators:** Jamie White (Independent Advocate), Joe Ryan (Health Service Executive, Ireland), Doreen Tembo (Health Data Research UK)

13:00 - 14:30 HOTEL **RESTAURANT** 

## **Goodbye Lunch & Departure**

**SESSION MAIN THEMES:** 

ENHANCING MULTI-STAKEHOLDER COLLABORATION IN PE



EXPANDING PARTICIPATION TO REFLECT REAL-WORLD DEMANDS





#### **CHANGE MAKERS ENABLING PEOF 2025**

Back to the event page













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Innovative Medicine





















