

Advance Patient Engagement Capacity Building

A shared purpose of EUPATI and PFMD



The [European Patients' Academy \(EUPATI\)](#) and [Patient Focused Medicines Development \(PFMD\)](#), which EUPATI contributed to establish, have been collaborating closely since 2015 to achieve a shared purpose of:



Empowering patients to be more and meaningfully involved in the medicines research and development (R&D) continuum.



Making patient engagement a systematic norm, the new *status quo*.

EUPATI, through its partnership set-up, focuses on empowering patients through the Patients' Academy with content that is co-created in a multi-stakeholder environment. EUPATI has trained over 150 patients and patient representatives who can confidently partner with researchers, pharmaceutical companies and other stakeholders in engaging and designing solutions in medicines R&D. Additionally, EUPATI has informed more than 4 million users worldwide via its Toolbox, accessible in more than 9 languages. The focus of EUPATI on training goes hand in hand with increasing awareness and transforming patient engagement through education across stakeholders.

Patient Focused Medicines Development (PFMD) aims to transform the way in which we understand, engage, and partner with patients globally in the design and development of research and medicines by focusing on unmet patient needs. PFMD was established in October 2015 as an open, independent global coalition of health stakeholders.

Joint effort

The specific focus of the two organisations **complement each other to allow reaching the shared purpose of making patient engagement the new normal**. PFMD and EUPATI have joined efforts in **providing training and increasing awareness about patient engagement to all stakeholders**. This collaboration enables breaking down existing silos, identifying and disseminating best practices across the board, avoiding redundancy and fragmentation, and building coherent and complementary capacity to deliver patient engagement.

The goal is to **collaborate in developing a capacity building portfolio available in different formats: online (self-paced) and in-person (classroom training)**, long and short versions to meet the needs of the various stakeholder groups and audiences.

For all stakeholder groups, the patient engagement curriculum has been divided into three levels.

1

The first level is an **introduction to patient engagement** focusing on its value, definition and scope. This is the first step to shift the culture and behaviour.

2

The second level is about **starting your capacity building journey**, HOW to start and integrate patient engagement across the lifecycle of medicine coupled with concrete examples.

3

The third level is dedicated to **specific topic areas** such as specific activities (e.g. designing a clinical trial protocol WITH patients), specific contexts (e.g. paediatrics, rare diseases or other conditions), or specific functions and skills.



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Multi-stakeholder patient engagement training

GOAL

FORMAT

Level 1

Addressing the 'Why? What? When?' of Patient Engagement

- Raise awareness about patient engagement
- Drive culture change and adoption of good practices.
- Align the shared purpose of doing patient engagement.



- **PFMD:** Online - Short version (multilingual)
- **PFMD:** Online - Full version (English)
- **EUPATI:** In-person - Fundamentals

Level 2

Addressing the 'How?' of Patient Engagement

- Provide tools and practices on how to start a patient engagement journey
- Introduce the basics and transversal components of patient engagement



- **PFMD:** Online (English)
- **EUPATI:** In-person - Fundamentals

Level 3

Providing advanced level training for professionals

- Implement the day-to-day patient engagement activities
- Address specific tools and skills to well-defined needs
- Activity, skill or function specific training



- **EUPATI:** In-person - Essentials (coming soon!)
- **PFMD:** Collection of advanced trainings. More information coming soon

Patient education in medicines research and development

The EUPATI Expert Training Course is a unique opportunity offering patients and patient representatives expert-level training in medicines research and development. The Course is a mixture of independent e-learning coursework and face-to-face training events.

The training provides EUPATI Fellows in-depth knowledge about the medicines research and development, and allows them to get meaningfully involved in patient engagement activities.

- [EUPATI Training Course](#)
- [Roadmap of Patient Involvement](#)



PATIENT FOCUSED
MEDICINES DEVELOPMENT

- Since 2015
- Open, independent global coalition of health stakeholders
- Patient engagement through bringing together and synergizing disparate but complementary efforts that integrate the voice of the patient across the lifecycle of medicine.
- More information about **PFMD** [here](#).



- Since 2012
- Patient-led public-private multi-stakeholder partnership
- Patient engagement through education and training to patients and other stakeholders to ensure meaningful, systematic and mutual collaboration across the research and development of therapeutic innovations.
- More information about **EUPATI** [here](#).