

Enhancing
patient engagement
through education

EUPATI ANNUAL REPORT 2022

THE EUROPEAN PATIENTS' ACADEMY ON THERAPEUTIC INNOVATION
(EUPATI)

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ABOUT US

The European Patients' Academy on Therapeutic Innovation (EUPATI) is a **patient-led multi-stakeholder public-private partnership** originally launched as an IMI-EUPATI project (2012-2017) and then hosted by the European Patients' Forum (EPF) from 2017 to 2020.

Today EUPATI is established as a Foundation in the Netherlands (Stichting EUPATI Foundation). It is an independent, non-profit organisation and has the status of a 'Public Benefit Organisation'. The Foundation's governance structure reflects the spirit of a public-private partnership where all the different stakeholder groups (patients, academia and industry) are represented within each decision-making body.

VISION & MISSION

EUPATI's vision is to improve health outcomes through the contribution from patients and patient representatives as valued stakeholders.

EUPATI's mission is to provide accessible, innovative and inclusive **education that empowers patients and patient representatives** with the right knowledge, skills and competencies to effectively engage and partner with all other stakeholders in the medicines R&D process.

At the global level, EUPATI aligns with the UN Sustainable Development Goal 3 - Good Health and Wellbeing. EUPATI's mission contributes to enhancing research and development of and access for medicines, by empowering patients and patient representatives as key actors in this process.

STRATEGIC GOALS 2022

1. Maximise accessibility to educational platforms and resources
2. Define, communicate and deliver leadership in innovative education

EUPATI IN 2022

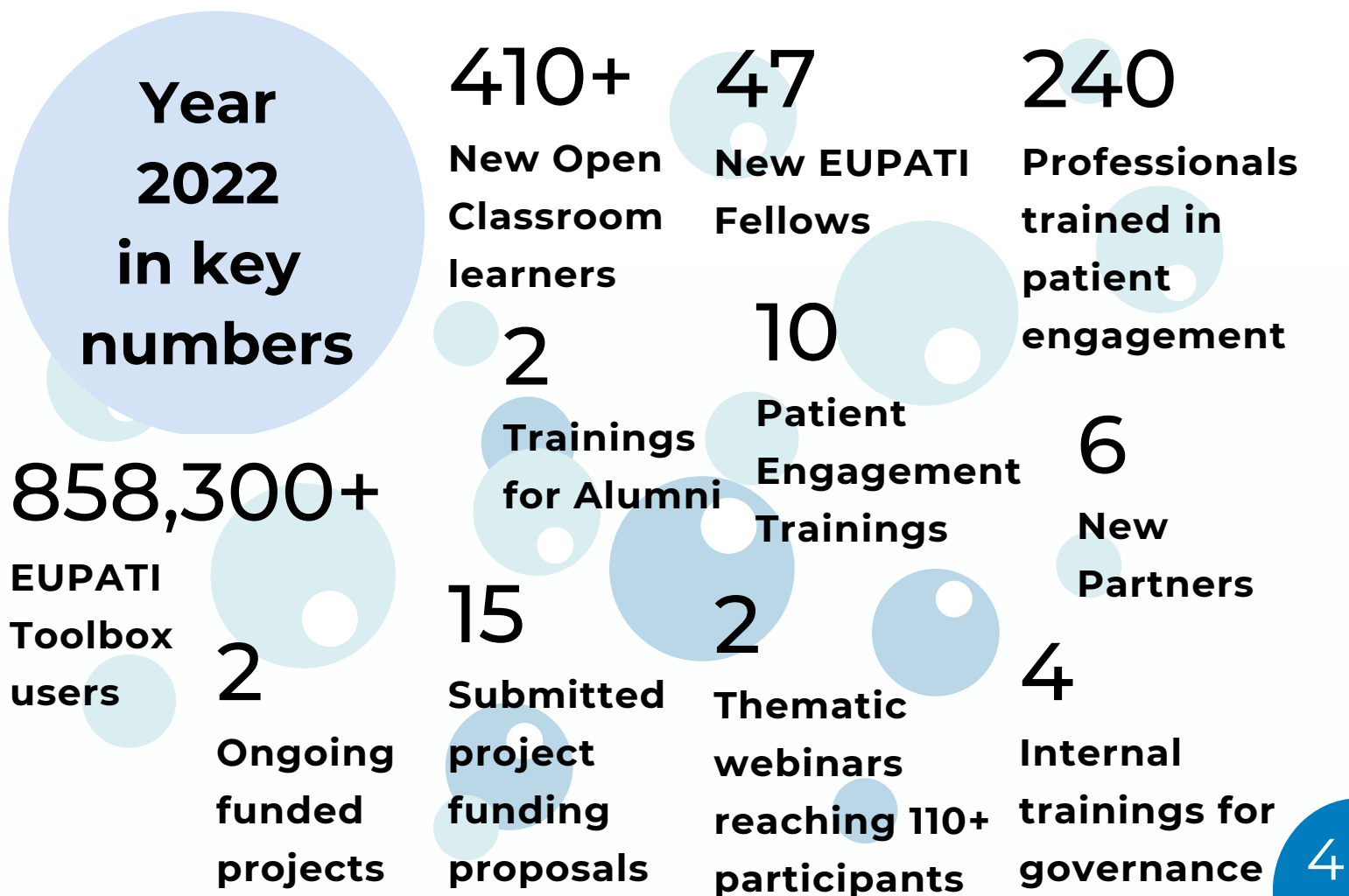
Dear Reader,

This report summarizes the progress that we, as a Partnership, made in 2022 towards our workplan objectives, contributing to our overall vision and mission. Special focus was placed on **accessibility** to patient education and on **strengthening EUPATI's leadership role** in enhancing patient education and patient engagement in medicines R&D.

The key **highlights in 2022** include the rollout of the EUPATIconnect matchmaking tool, celebration of EUPATI's 10th anniversary and graduation of a new cohort of EUPATI Fellows - bringing the total number of Fellows to 254 patient experts (representing over 30 countries and 100 disease areas). In addition, we introduced a new training module on Medical Devices on the Open Classroom, and launched a new type of patient engagement training, EUPATI Essentials. A new EUPATI National Platform (ENP) was established, joining the network of 24 ENPs across Europe and beyond.

2022 marked also a moment for EUPATI to **re-establish close connections with key collaborators** within the patient engagement landscape, especially with regulators and actors within health technology assessment. Thanks to all the efforts by our Partners, ENPs and Fellows, EUPATI's role as a unique provider of education, training and information for patients and patient representatives in medicines R&D is today well established on a global scale.

Maria Dutarte, EUPATI Executive Director
On behalf of the Secretariat Team



ACCESSIBILITY, DIVERSITY & INCLUSION

Maximising accessibility to educational platforms and resources for different patient groups

Diversity and inclusion identified for EUPATI and the National Platforms

- A workshop on diversity & inclusion in health literacy organized for EUPATI Partners in May (40 participants)
- Accessibility guidelines for EUPATI Open Classroom compiled
- EUPATI Open Classroom platform upgraded to improve accessibility

Increasing number of trained EUPATI Fellows with diverse representation of different disease areas, geographical areas, gender and differently abled groups

- 47 new Fellows graduated
- Diverse representation of different disease areas and countries
- Two 4-day-training events delivered, one online and one in-person
- Contributions by 20+ Faculty, Patient Expert Training Committee and Editorial Board



Increased understanding of diversity and inclusion in patient education

23% increase of trained expert patients (EUPATI Fellows)



ACCESSIBILITY, DIVERSITY & INCLUSION

Expanding training materials for all stakeholders

Producing new Training and Toolbox content

- A workshop for EUPATI Partners in May on mapping training needs among patient groups conducted (40 participants)
- New **Medical Devices** Training Module published on Open Classroom (see next page)
- Toolbox content on Translational Medicine revised
- Development of new content on cell & gene therapies initiated
- Internal guidelines developed for content production
- New Training Module on Digital Health finalised for publication

Ensuring further content development for patient engagement trainings for stakeholders

- 10 trainings conducted on patient engagement for industry and academia representatives, reaching 240 participants in total
- Revision of EUPATI Fundamentals Training content initiated
- A new training, **EUPATI Essentials**, launched and piloted for 13 participants (see below)
- A new training on Patient Involvement in HTA developed and piloted for industry and academia in collaboration with HTAi

Exploring new target audiences for EUPATI stakeholder trainings

- Patient engagement training for research project consortia (bringing together academia, health care professionals, and industry) rolled out and systematically integrated in 10 project proposals for Horizon2020 and other funding schemes



Expanded
volume of patient
training content

Expanded
trainings about
patient
engagement for
academia and
industry

New stakeholder
groups reached
by patient
engagement
training



EUPATI Essentials - new 4-hour online workshop for professionals from industry & academia

- Builds on EUPATI Fundamentals and focuses on specific topics in depth
- Module 1 now available: 'Establishing successful relationships with patients' - How to manage expectations, set up the right framework, identify the right patient groups and maintain contact

MEDICAL DEVICES MODULE

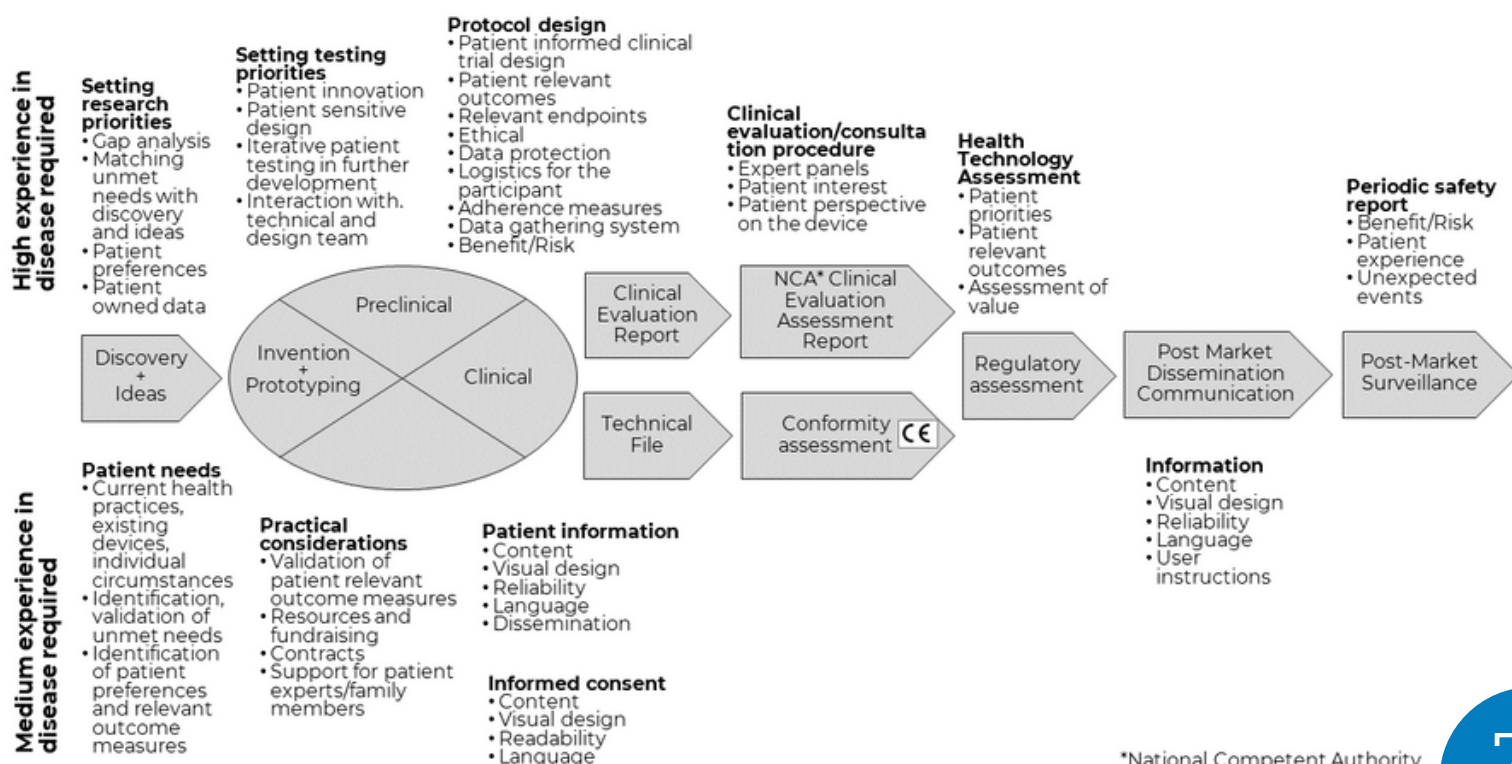


A new **online training module on medical devices** was published in May 2022 on the EUPATI Open Classroom. The content was developed within the framework for EIT Health funded project EUPATI Reload together with University of Oxford, Bayer, Medtronic and University of Copenhagen.

A **dissemination webinar** was held in September, launching a **campaign** around patient involvement in the development of medical devices.

The module consists of four courses and give you an overview on medical devices and their regulatory framework. The learners are introduced to the history of medical devices, their different classifications, the role of Notified Bodies and Conformity Assessment, CE marking and re-certification. The development of medical devices and the lifecycle management, as well as principles for market access and the different aspects of value-based innovation are described in detail. In addition, key definitions about Health Technology Assessment (HTA) in medical devices and HTA principles in medical devices and in vitro diagnostics (IVDs) are provided.

The module also includes a **Roadmap for Patient Engagement in Medical Devices**, as displayed below:



ACCESSIBILITY, DIVERSITY & INCLUSION

Strengthening the preparedness of EUPATI Governance, Secretariat, National Platforms and the Alumni

Further developing the capacity of Governance, Secretariat, National Platforms and the Alumni

- 4 internal 'EUPATI Activity in Focus' workshops organised for Governance and the Secretariat on various topics (Projects and Proposals, Toolbox, EUPATIconnect and Diversity & Inclusion)
- 2 webinars organised for EUPATI Alumni based on needs assessment: Patient involvement in scientific publications (60 participants), and participation of patients in ENPs (30 participants)
- 2 thematic webinars organised on Health Technology Assessment - HTA360 project (with 35 participants) and on Medical Devices Module launch on Open Classroom (76 participants)
- 2 online workshops co-facilitated on Good Lay Summary Practice (GLSP), with many participants from EUPATI Alumni and ENPs



Internal
structures
strengthened by
training



Defining EUPATI's leadership role in patient education and patient engagement

Leading a think tank with all relevant stakeholders addressing trends in global health and patient engagement

- Partners, National Platforms, Alumni, EUPATI Friends and collaborators from a wide range of stakeholders gathered for 10th anniversary event in May (over 140 participants)
- Regular meetings organised with representatives of EMA and national regulators via the EUPATI Advisory Committee
- Contacts established with several national HTA bodies through the ongoing research project with HTAi and EPF
- Close contacts with innovative leaders from other fields established through several European projects and funding proposals

Consolidating EUPATI's innovative role in the global arena of patient engagement and patient education

- Patient Engagement Open Forum (PEOF) 2022 co-organised with PFMD and EPF, including online sessions and an in-person event in October with extensive reach across different stakeholder groups

Initiating a review and update of EUPATI guidances on patient involvement in R&D

- A reflection on the use and development of the EUPATI Guidances initiated, to be continued in 2023



Effective multi-stakeholder collaboration around patient engagement

Recognition as an innovative leader in patient education

Enhanced guidance on patient engagement



LEADERSHIP, INNOVATIVENESS, VISIBILITY & COLLABORATION

Communicating EUPATI's vision, mission, real world value and outcomes

Increasing visibility

- New Instagram channel launched (160+ followers) - Regular story highlights & interactive content in an effort to build a community
- Special focus on LinkedIn: 1,720 new followers (reaching now 4,000+ in total), 6,200 page views, 2,524 unique visitors, 240,845 total impressions with 7,188 reactions, 180 comments and 697 reposts
- Twitter: 354 new followers (reaching now 7,750+ in total), 159,413 impressions and 42,854 profile visits
- Facebook: Reaching 3,900 followers in total, 60,098 impressions and 56,151 reach
- Further updates on EUPATI website rolled out, home page reaching 35,200 users in 2022

Celebrating the success and accomplishments

- 10-years-anniversary campaign run accross multiple channels throughout the year
- EUPATI 10-year-anniversary hybrid event organised in Brussels in May with 110 attendees on site and more than 30 online
- An internship research project conducted on the impact of EUPATI Patient Expert Training Programme
- An online campaign run marking 2 years since establishment of EUPATI Foundation

Consolidating EUPATI's legacy as a success story of a multi-stakeholder public-private partnership model

- A video on EUPATI's 10 main achievements since 2012 published and disseminated widely



Enhanced cross-media visibility

Acknowledged and documented achievements

Increased recognition as a successful Public-Private Partnership



LEADERSHIP, INNOVATIVENESS, VISIBILITY & COLLABORATION

Delivering leadership and impact in patient education and patient engagement

Strengthening the EUPATI Partnership and involvement with key actors from the Regulatory and HTA fields

- Bilateral meetings with all Partners conducted
- Regular cluster-specific meetings organised with patient organisations, academia/non-profits and industry - supporting decision-making by the EUPATI Board
- Strong collaboration with regulators established via the EUPATI Advisory Committee

Strengthening leadership and multi-stakeholder collaboration at national level through the EUPATI National Platforms

- Quarterly meetings held for ENP representatives
- Bi-monthly newsletters compiled and circulated
- A new ENP established in Czech Republic
- Plans to launch a platform in Romania pursued



Reaching out and enhancing collaboration with other organisations involved in patient engagement and education

- EUPATI patient education featured in the DIA Europe 2022 programme
- Close collaboration continued with PFMD through Patient Engagement Open Forum
- Cooperation with EMA continued both via Advisory Committee and bilateral meetings

Strengthening the EUPATI Alumni's role and affirm patient-initiated and patient-led approaches throughout EUPATI activities

- An internal survey conducted among EUPATI Fellows about their role in EUPATI and its governance, results underlining the importance of continuing Secretariat's close collaboration with the Alumni

Maintaining a well-resourced and fit-for-purpose Secretariat to support the Partnership

- An internal training programme established for EUPATI Secretariat providing access to the Open Classroom and other resources
- Volunteer and internship programmes established to support the different workstreams
- 4 Internal 'EUPATI activity in focus' sessions conducted for Governance and Secretariat



Strong and committed Partnership

Active National Platforms

Mutually beneficial collaborations

Re-enforced patient-led approach

Well-resourced Secretariat

Seeking to attain stable revenue generation and drive partnership towards growth

Balancing Partner contributions to ensure 50-50 public-private funding base in the long-term

- Mid-term goals for Partnership expansion and orientation defined
- Pricing structures for stakeholder trainings revisited
- New European funding schemes explored (15 proposals submitted) and criteria for EUPATI's involvement defined
- EUPATIconnect launched (30 projects received from industry, academia, agencies and patient organisations)

Engaging the Partnership in ensuring the implementation of EUPATI's long-term sustainability plan

- New in-kind contribution model implemented
- Many Partners actively engaged in further developing EUPATIconnect and Stakeholder Trainings (updating EUPATI Fundamentals and finalising EUPATI Essentials)

Strengthening the funding base of the National Platforms

- Quarterly meetings for ENP representatives
- Active engagement with EUPATI Governance and Partners
- Training resources on fundraising made available for ENPs



Fully implemented funding model with diversified income streams

Secured Sustainability

Striving towards well-resourced National Platforms

EUPATIconnect

Bringing EUPATI Patient Experts and researchers together



Researcher



EUPATI Patient Expert

EUPATI 10 YEAR ANNIVERSARY

“It’s important to recognise all the people who have been involved in helping EUPATI reach this incredible 10-year milestone; a strong partnership and belief has been central to success. When I reflect on the early ambitions and where EUPATI is now, I feel proud of the numerous achievements and EUPATI’s ability to enhance patient engagement in medicines research and development through education.”

Kay Warner (GSK, EUPATI co-chair)

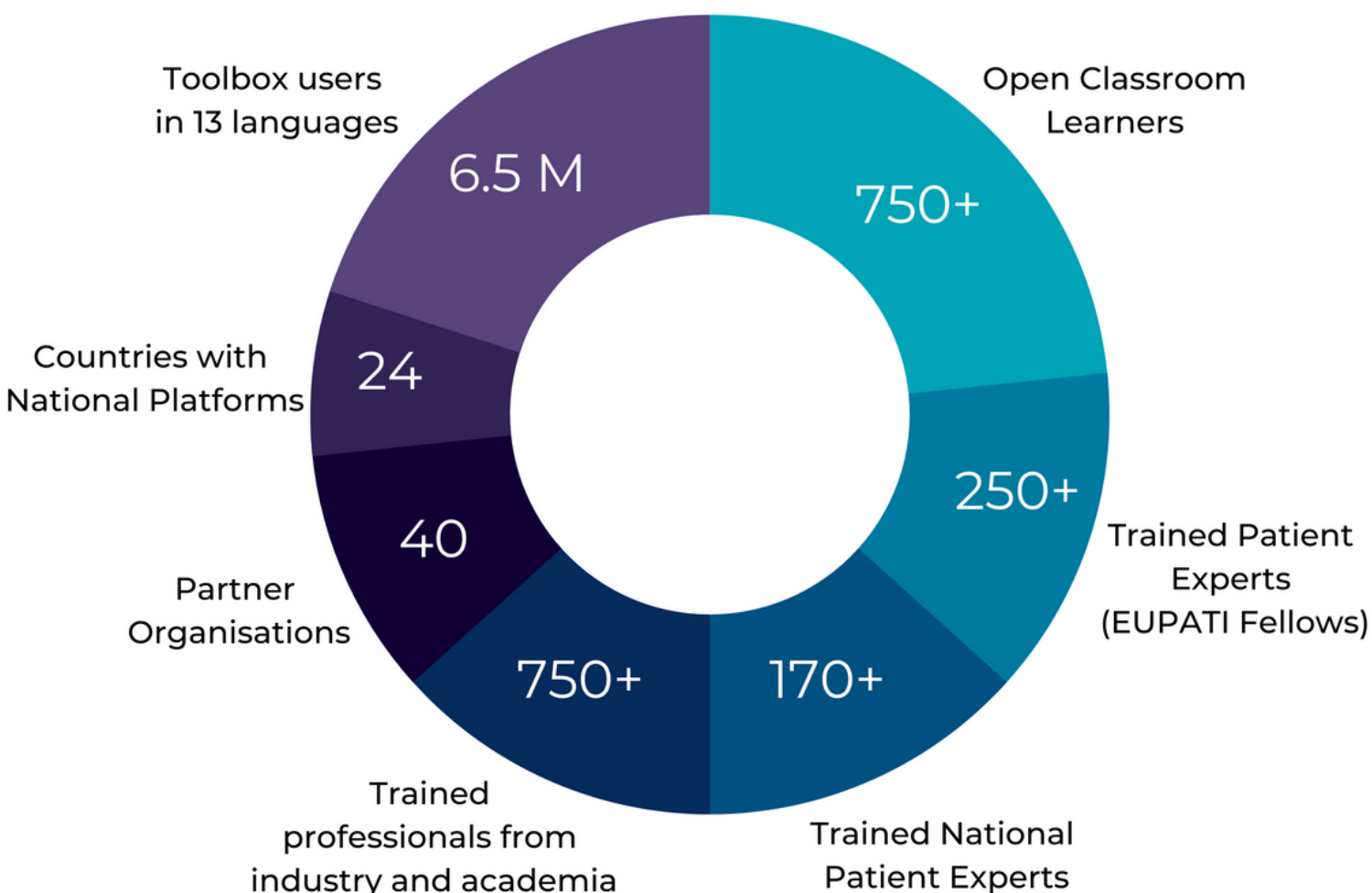
Over 140 participants were present on 19 – 20 May (both in person in Brussels and online) to reflect on EUPATI’s key achievements since its establishment in 2012, to discuss the challenging and evolving landscape of patient education, how to strengthen partnerships and the National Platforms, to achieve sustainability, and agree on a vision for the future.

On the second day of the event, the participants were invited to take part to two different workshops: “Diversity & inclusion in health literacy” and “Changing role of patient experts and needs for further training & education”.

More information about 10 years of EUPATI can be found on www.eupati.eu



EUPATI - 10 YEARS OF SUCCESS



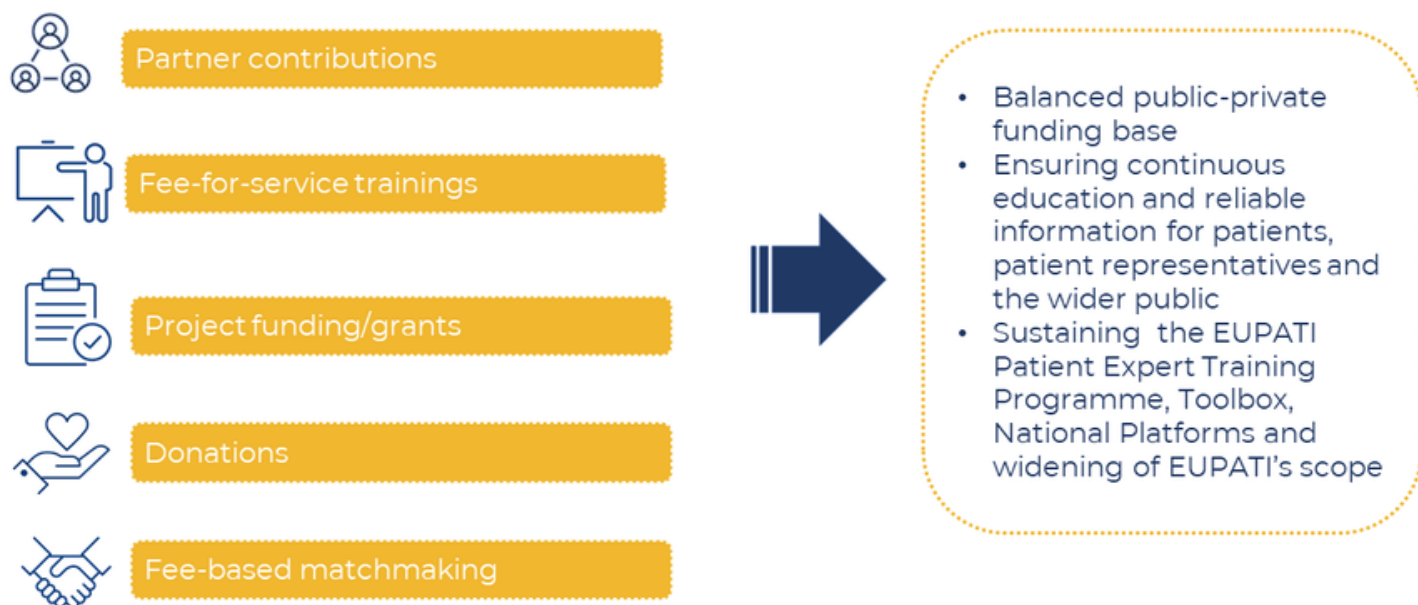
EUPATI is today the global leading platform for patient education in medicines R&D. It has trained more than 250 **Patient Experts (EUPATI Fellows)** since 2015, and there are currently more than 750 learners enrolled on the **Open Classroom** online learning platform launched in 2020. In addition, 170 Fellows have graduated from the national EUPATI trainings in Ireland, Italy and the Netherlands.

EUPATI is active in 24 countries through its **National Platforms**, and also provides an open-access multilingual Toolbox that has served more than 6.5 million users in 13 languages around the world since its launch in 2016.

In order to enhance patient engagement, EUPATI also provides **trainings about patient involvement in medicines R&D for professionals** working in academia and the pharmaceutical industry. To date, more than 750 individuals have participated in these trainings, launched in 2019.

The **EUPATIConnect platform**, piloted in 2022, facilitates collaboration between trained patients and other stakeholders, by providing a 'matchmaking' service for patient involvement in e.g. protocol reviews, focus groups, speaking opportunities, patient advisory boards, ethical committees, regulatory processes and more. Over 30 projects have been processed via this platform during the first implementation phase.

SUSTAINABILITY



EUPATI is established as a Foundation in the Netherlands (Stichting EUPATI Foundation). It is an **independent, non-profit organisation** and has the status of a 'Public Benefit Organisation'. The Foundation's governance structure reflects the spirit of a public-private partnership where all the different stakeholder groups (patients, academia and industry) are represented within each decision-making body.

EUPATI is committed to offering educational materials and information for patients, patient representatives and the wider public **free of charge**.

This is made possible by financing in form of **cash contributions** from industry partners and **in-kind contributions** from public partners. In addition, EUPATI provides **fee-based trainings** (EUPATI Fundamentals, EUPATI Essentials and customised in-house trainings) and a **matchmaking service** (EUPATIconnect) for academia and industry. EUPATI also receives grants in form of **project funding** (e.g. IMI, EIT Health, Horizon 2020, EU4Health, EFPIA) and **donations** from individuals and organisations.

According to its non-profit nature, all generated income of the Foundation is re-invested in patient education.

An annual **financial report** is provided annually by the end of June of the following year and published, together with the official report for Dutch public benefit institutions (ANBI) and the independent auditor's report on the EUPATI website <https://eupati.eu/about-us/finances-transparency/>.

PARTNERSHIP

In 2022, EUPATI welcomed **6 new partners** to the Sustaining Partners Assembly, namely the European Federation of Allergy and Airways Diseases Patients' Association (EFA), Galapagos, Incyte Biosciences, Menarini, Servier and University of Aveiro Portugal bringing the total number of partners within the partnership to 40.

Overall, the Partnership is balanced in terms of representation from patient organisations, academia/non-profits and industry. It is especially important to note that the Patient Organisations involved in EUPATI are large networks of different patient organisations, representing tens of thousands of patients all around Europe and globally.

A revised **in-kind contribution model** for public partners was introduced. The model was amended to create a more flexible approach based on mutually defined activities, removing the previously set numeric value for in-kind contributions in terms of invested staff time. This requirement had been an obstacle for engagement for some partners, particularly in the academic and patient organisation clusters where resources are limited.



EUPATI NATIONAL PLATFORMS

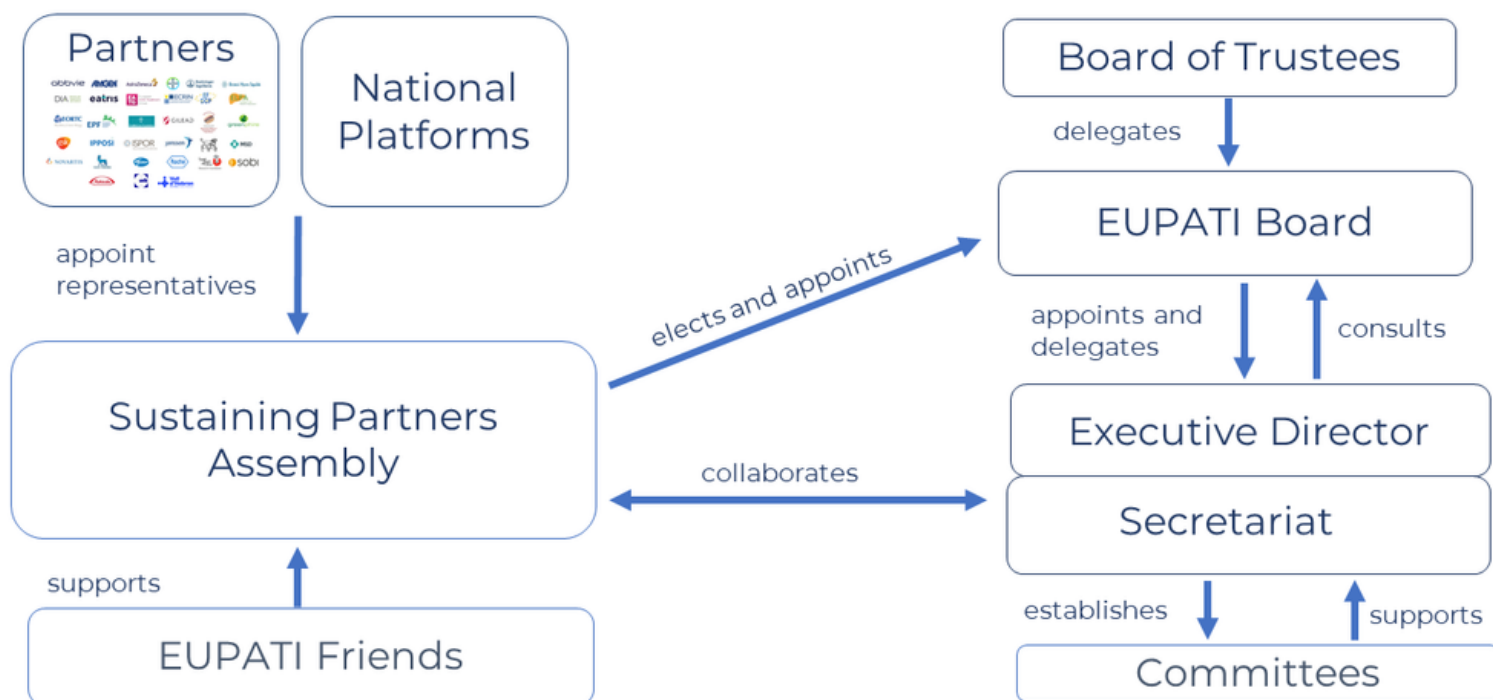
EUPATI has 24 EUPATI National Platforms (ENPs) which also join the Sustaining Partners Assembly and have representation at the EUPATI Board. While the ENPs are independent entities, they reflect the EUPATI multistakeholder structure with representation from patients, academia and industry. Their role is crucial in bringing the EUPATI vision and mission to the national level.

In 2022, a new National Platform was launched in **Czech Republic**, joining the network of ENPs as listed below:

Austria
Belgium
Czech Republic
Cyprus
Denmark
Finland
France
Germany
Greece
Ireland
Italy
Japan
Luxembourg
Malta
Netherlands
Norway
Poland
Portugal
Slovakia
Spain
Switzerland
Sweden
Turkey
Scotland (UK)



GOVERNANCE



The Board of Trustees

Jytte Lyngvig, Denmark (Chair)
 Ivett Jakab, Hungary (Vice-Chair)
 Clayton Heijman, Netherlands (Treasurer)
 Matthias Gottwald, Germany
 Richard Bergstrom, Sweden

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Anders Olauson, EPF (Chair)
 Kay Warner, GSK (Co-Chair)
 Paul Clift, EATG
 Derick Mitchell, IPPOSI
 Daniel de Schryver, Janssen
 Donatella Decise, Novartis
 Christine Kubiak, ECRIN
 Begonya Nafria Escalera, San Joan de Deu Hospital
 Jozef Glasa, ENP Slovakia
 Sandrine Laval, ENP Luxembourg

EUPATI Advisory Committee

Co-Chairs: David Haerry, Patvocates/EATG
 and Wolf See, Ruhr University Bochum

HTA arm:

Neil Bertelsen, independent - Lead
 Karen Facey, independent

Ethics arm:

Ingrid Klingmann, EFGCP - Lead
 Hugh Davies, independent
 Uta Wernke, DLR

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 Birka Lehmann, University of Bonn/form. BfArM
 Wolf See, Ruhr University of Bochum
 Léa-Isabelle Proulx, Roche

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 Bruno Gago, University of Aveiro
 Ilaria Galetti, FESCA, GILS
 Ingrid Klingmann, EFGCP
 Birka Lehmann, University of Bonn
 Jeanette Ryan, GSK
 Victoria Siegriest, Roche
 Wolf R. See, Ruhr University of Bochum
 Thomas Smith, EUPATI Fellow
 Carla Torre, University of Lisbon
 Natacha Vaz Liti, EUPATI Fellow
 Fiona Waters, Retina International

Regulatory arm:

Birka Lehmann, ex BfArM - Lead
 Gabriela Zenhäusern, Swissmedic
 Heather Rogers, MHRA
 Daniel O'Connor, MHRA
 Fokaline Vroom, MEB
 Leon Bongers, MEB
 Juan Estévez Álamo, AEMPS
 Christa Wirthumer-Hoche, AGES
 Katharina Prenner, AGES

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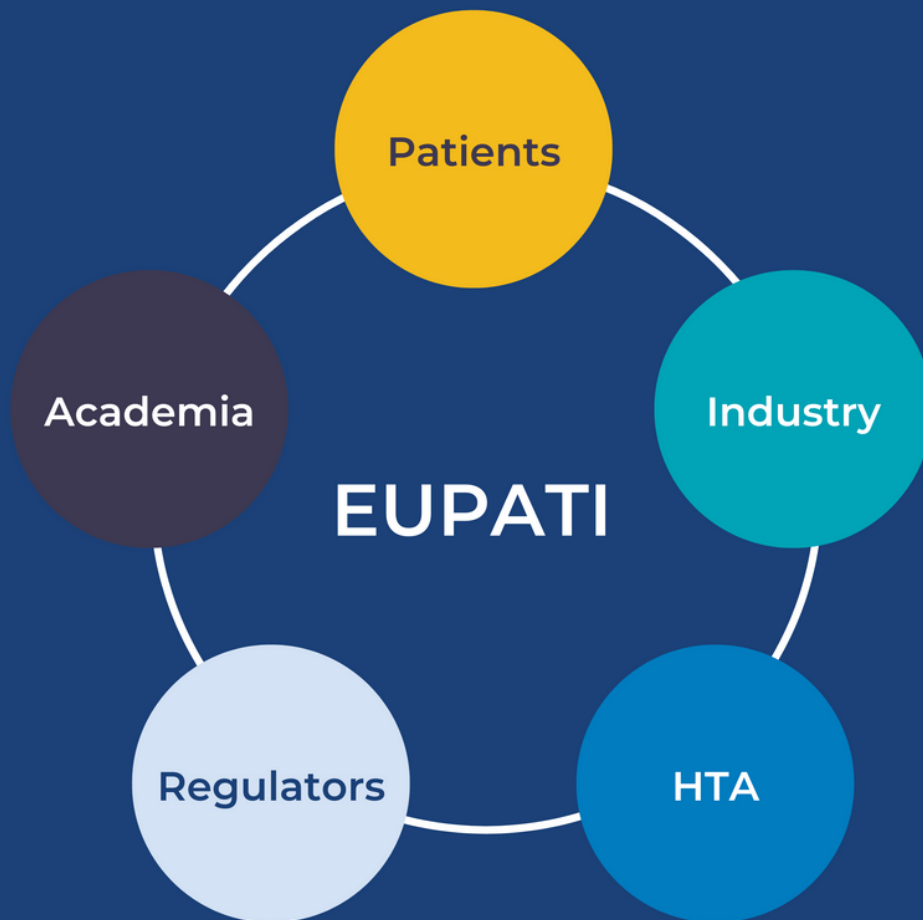
In addition to its Sustaining Partners, EUPATI collaborates with a wide range of stakeholders within the patient education and patient engagement landscape. The different collaborations strengthen EUPATI's multi-stakeholder public private partnership. We would like to thank the following organisations for their collaboration during this calendar year (in alphabetical order):

Dublin City University
European Connected Health Alliance (ECHAlliance)
European Federation of Pharmaceutical Industries and Associations (EFPIA)
European Institute of Innovation and Technology (EIT Health)
European Organisation for Rare Diseases (EURORDIS)
European Medicines Agency (EMA)
Health Technology Assessment International (HTAi)
Innovative Health Initiative (IHI)
MedTech Europe
Medtronic
National Institute for Health and Care Research (NIHR)
Orchard Therapeutics
Patient Focused Medicines Development (PFMD)
Patvocates
PGOSupport
Politecnico di Milano
PTC Therapeutics
Trinity College Dublin
University of Oxford
VMLY&Rx (previously known as WPP Health)
and the many more institutions who contributed to enhancing patient education!

THE SECRETARIAT

- Laia Bisbal, Open Classroom Coordinator (role occupied by Ieva Lukase until end of November)
- Bojan Cigan, Partnerships & Operations Coordinator
- Maria Dutarte, Executive Director
- Ingrid Heyne, Training Organisation & Alumni Coordinator
- Gemma Killeen, Business Development Coordinator
- Vitalii Luchinskii, IT Coordinator
- Amanda Lyons, Networks & Communications Coordinator (temporarily replaced by Coline Guiol, January-August)
- Francisca Pinheiro, Intern and Temporary Training Assistant
- Jana Popova, Patient Engagement Training Coordinator
- Silvia Scalabrini, Project Coordinator





Education
empowering patients
to engage and partner
with all stakeholders
in medicines R&D