

Enhancing  
patient engagement  
through education

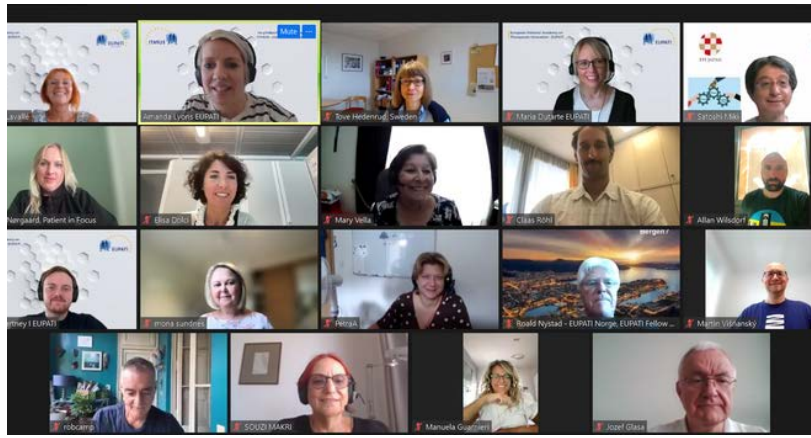


# EUPATI

# ANNUAL REPORT 2023

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# 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.

EUPATI is also committed to enhancing knowledge about meaningful patient engagement across the different stakeholders and strengthening the collaboration between researchers and patients/patient representatives.

## STRATEGIC GOALS 2023

1. Safeguard innovative and high quality education for patients and patient representatives about medicines R&D, while expanding to emerging thematic areas and a wider network of patient communities.
2. Deliver diverse training solutions about patient engagement for researchers and other professionals in academia and industry, co-designed and co-delivered with patients, to facilitate meaningful involvement of patients in the medicines R&D process.
3. Facilitate collaboration between patient experts and researchers to enhance patient engagement in medicines R&D.
4. Maintain a fit-for-purpose multi-stakeholder public-private non-profit structure, based on strong partnerships, a network of National Platforms and collaborations with key actors in medicines R&D and other health technologies.

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.



# EXECUTIVE SUMMARY

Dear Partners,

EUPATI reached a record-wide audience in 2023. The **EUPATI Toolbox** reached 1 million new users (7 million since its launch) and the **Open Classroom** was accessed by over 160,000 new learners. EUPATI's **Patient Expert Training Programme** had the highest number of registrations of all time and 81 new Fellows graduated, which is the largest cohort since the launch of the Programme in 2015 (bringing the total number of Fellows to 330+). These figures demonstrate the important and growing need for patient-friendly information & educational resources on medicines R&D and patients' role in this process - and the **EUPATI Impact Study** shows that training makes a difference in how patients and patient representatives engage with other stakeholders.

EUPATI's reach did not only grow in numbers but also in its geographical reach and the breadth of its content. The Toolbox was made available in **Greek** and the number of Fellows from outside Europe increased. The Open Classroom modules on **Medical Devices and Digital Health** and activities around this content continued to expand EUPATI's horizons - as well as a special emphasis on patient engagement in Health Technology Assessment (HTA) through the kicking off of EUPATI's **HTA4Patients** project.

As for the second pillar of our mission, training of researchers in patient engagement was re-enforced with brand new **EUPATI Learning Lab** portal, demonstrating clearly the offerings of this growing portfolio. 290 individuals were trained through different Learning Lab workshops, enhancing their capacity to meaningfully implement patient engagement.

**EUPATIconnect**, our platform bringing together expert patients and researchers, finalised its piloting phase and expanded its patient pool, with the aim of becoming a central space for collaboration and putting patient involvement into practice. This activity, alongside with other projects and initiatives bringing patients & researchers together, constitutes an important third pillar of our mission.

The EUPATI community increased its activity throughout all social media channels, and several in-person events. The 24 **EUPATI National Platforms** continued their important efforts to bring EUPATI's resources & trainings to the national level, reaching growing audiences in their local language(s). EUPATI's **Partnership** reached 48 organisations from patient organisations, academia and industry.

EUPATI's success today is a living testimony to the lasting and far-reaching impact that education has on patient engagement and we are deeply grateful to all of you for bringing our vision to fruition.

Yours sincerely,

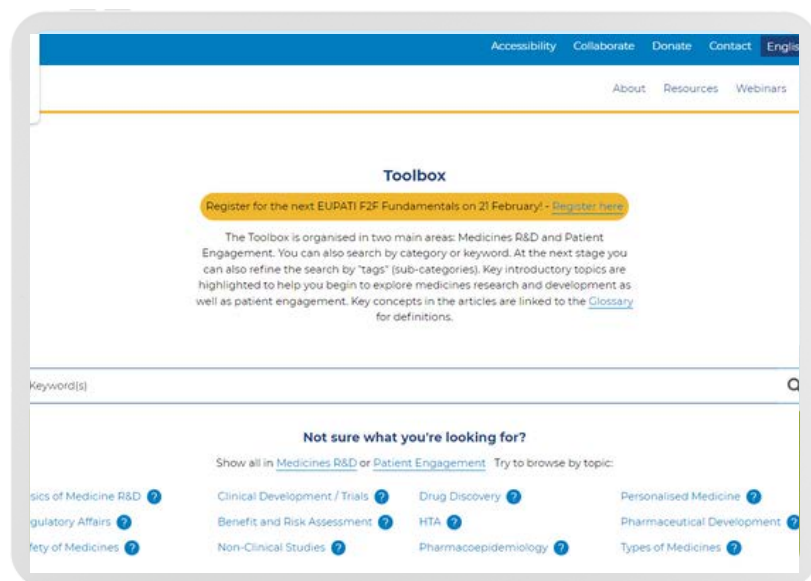


Maria Duterte

EUPATI Executive Director

On behalf of the Secretariat Team

# EUPATI TOOLBOX



1) Easily accessible articles and videos, glossary definitions



2) Materials suitable for creating trainings



3) Available in 14 languages

The EUPATI Toolbox ([www.toolbox.eupati.eu](http://www.toolbox.eupati.eu)) is an online library on the A-Z of medicines research and development (R&D) and patient engagement. It provides access to articles, presentations, videos, webinars, starter kits, factsheets, infographics, and glossary items and is available in 14 languages.

**Objective for 2023:** Expand the number of available translations of the Toolbox, adding 1 new language and develop an instructional online tool presenting different sections of the EUPATI patient engagement roadmap.

## Result:

- The Toolbox content was made available in Greek, increasing the number of languages from 13 to 14.
- Work on an instructional tool on the different sections of the Roadmap was initiated via a video resource and breakout discussion at the AGM in September 2023

**Key activities:** The use of AI-based translation tools was explored for future translations together with EUPATI National Platforms (ENPs). A systematic review of the toolbox content and its allocation into the two main categories of 1) Medicines R&D and 2) Patient Engagement was conducted. Work to improve the user navigation on the main landing page was initiated.

## Highlights:

- An instructional video highlighting the EUPATI Patient Engagement Roadmap was published in September 2023.
- The Toolbox gained 1,000,000 new users reaching 7 million in total since the launch of the platform in 2016.



Ensuring availability of new, up-to-date and high quality content on medicines R&D

# EUPATI TOOLBOX



EUPATI Patient Involvement in Medicines R&D Roadmap Video was launched in September 2023 further increasing awareness around this key resource and basis for EUPATI Patient Expert Training Programme

### TOOLBOX USERS

**7M** USERS REACHED SINCE LAUNCH

DATA FROM 1 JAN to 31 DEC 2023



**1M** NEW USERS  
**1,6M** VIEWS  
**8700** FILE DOWNLOADS

### MOST VISITED PAGE

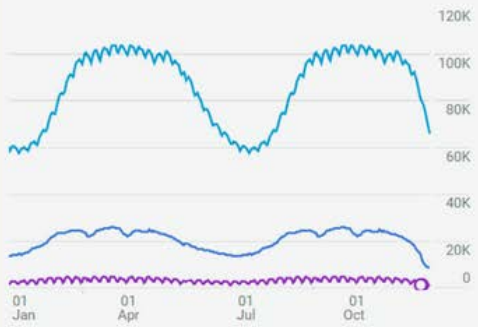
Risk factors in health and disease (Spanish version)

**56%** DESKTOP  
**43%** MOBILE  
**1%** TABLET




### USER ACTIVITY:

MONTHLY WEEKLY DAILY



65.000 USERS 30 DAYS  
8.400 USERS 7 DAYS  
650 USERS 1 DAY

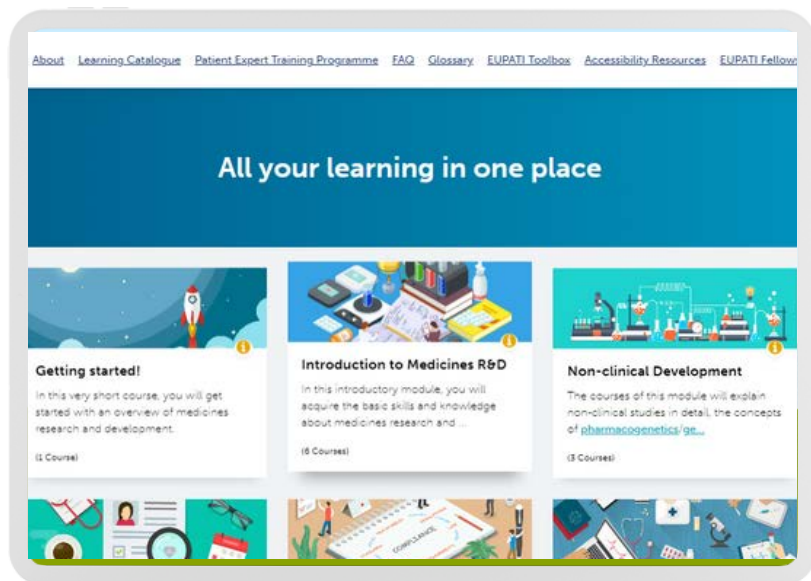
### TOP 10 COUNTRIES



COUNTRY	Nr USERS
MEXICO	94.300
RUSSIA	86.600
ITALY	59.200
JAPAN	53.300
FRANCE	46.700
POLAND	41.600
GERMANY	40.700
US	39.400
ROMANIA	38.500
BRAZIL	35.300

EUPATI Toolbox (www.toolbox.eupati.eu) user statistics 2023

# EUPATI OPEN CLASSROOM



1) Individual courses



2) Individual modules



3) Patient Expert Training Programme

The EUPATI Open Classroom ([www.learning.eupati.eu](http://www.learning.eupati.eu)) is a flexible and on-demand e-learning platform, launched in 2020, providing courses in medicines research and development (R&D), that learners can take at their own pace and preferred order. The content is adapted to the perspective of patients and patient representatives and highlights the importance of patient involvement within the different steps of the medicines lifecycle.

**Objective for 2023:** Increase the number of registered learners by 250 (from 750 to 1,000)

**Result:** 550 new registered users reached (1300+ in total and 160K+ unique visitors - see next page for details )

**Key activities:** Learners were engaged in evaluating and further developing the Open Classroom through direct feedback sought by the Secretariat. Updates were initiated to improve user experience and communication about different learning pathways was enhanced.

## Highlights:

- The Open Classroom presented as a flagship project at the Joint IHI - EIT Health workshop 'Bridging the gap' on 21 November 2023.



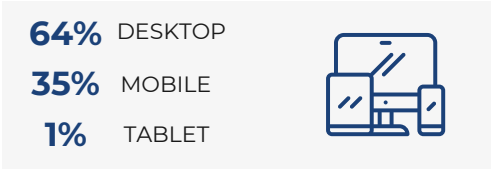
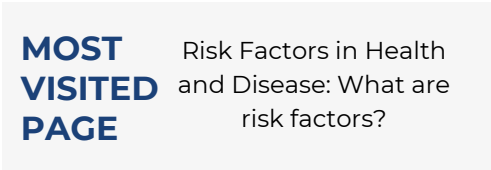
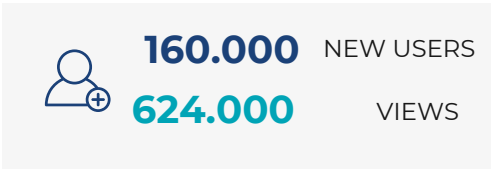
Increased number of persons accessing training on medicines R&D



# EUPATI OPEN CLASSROOM

## OPEN CLASSROOM USERS

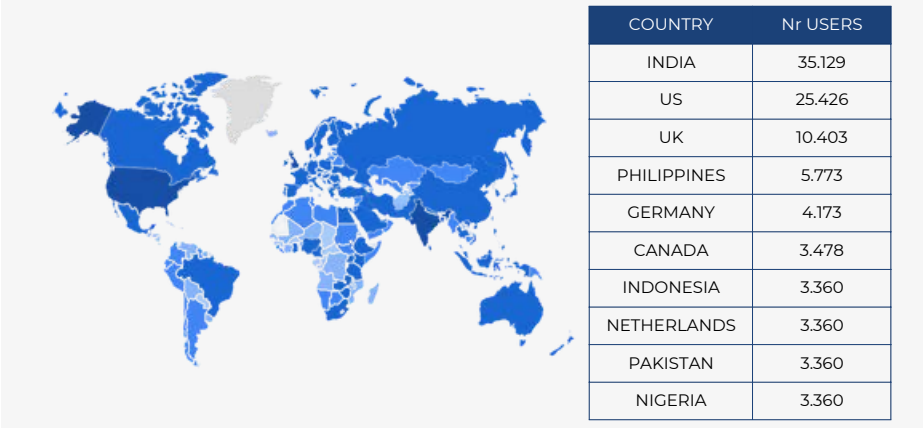
DATA FROM 12TH JANUARY TO 31ST DECEMBER 2023



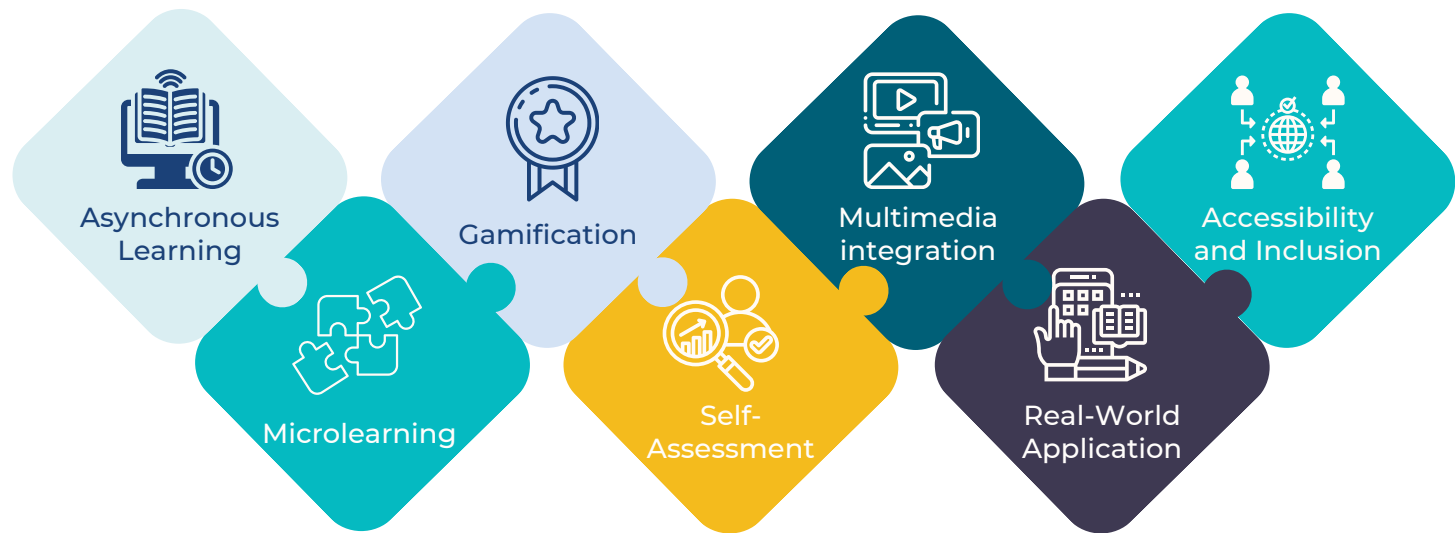
## USER ACTIVITY:MONTHLY, WEEKLY, DAILY



## USERS PER COUNTRY (JANUARY-DECEMBER)



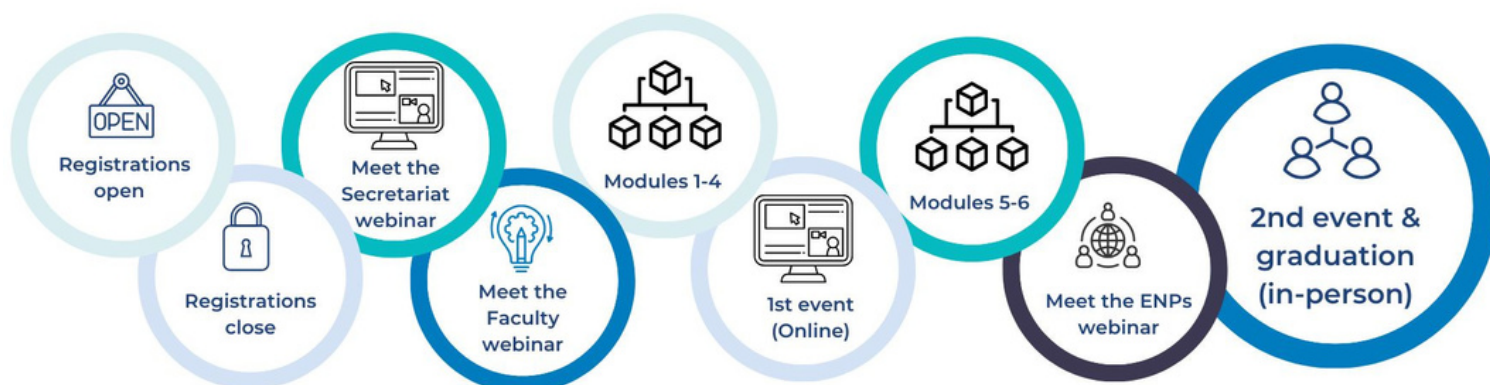
EUPATI Open Classroom ([www.learning.eupati.eu](http://www.learning.eupati.eu)) statistics 2023 for non-registered users



Key elements of the EUPATI Open Classroom online learning approach



# EUPATI PATIENT EXPERT TRAINING PROGRAMME



The EUPATI Patient Expert Training Programme, launched in 2015, is a blended training and consists of 6 compulsory Open Classroom modules (containing 27 courses in total) and 2 training events (1 virtual and 1 in-person). Completing the full programme usually takes 12-14 months. Graduates of the programme are also known as EUPATI Fellows or Alumni. The EUPATI Fellow title certifies the knowledge gained and gives graduates the opportunity to be recognised as expert patients. The two training events are planned and executed by a multistakeholder EUPATI Expert Training Programme Committee and a Faculty of experts and EUPATI Fellows.

**Objectives for 2023:** Increase the number of trained expert patients by 80 new EUPATI Fellows in 2023 (from 250 to 330) and place special focus on collaborating with Patient Organisations and facilitating training of their members and communities

**Result:** 81 new EUPATI Fellows graduated in October 2023

**Key activities:** The number of available seats on the Programme was increased to 130 and this number was rapidly reached. To improve completion rate among trainees, the opportunity to complete the Programme within 2 years after registration was initiated. In addition to Secretariat support, close collaboration was established with partnering Patient Organisations and National Platforms mentoring their affiliated trainees. A EUPATI Scholarship Programme was redefined to cover cost for in-person training travel & accommodation for trainees in need of financial support.

## Highlights:

- Graduation ceremony for new Fellows of Cohort 6 on 26 October, representing 22 different countries, including Canada, US, Cuba, India, Singapore and Australia. This group of Fellows indicated experience and/or interest for over 80 different disease areas.



Increased number  
of trained patient  
experts

# EUPATI PATIENT EXPERT TRAINING PROGRAMME



## Training that facilitates cross-stakeholder understanding

*"I speak the language used by professionals, and by researchers. I know what is the perspective of the industry partners. So, I know how to translate it all to the needs of the patient."*



## Training that enhances leadership

*"I was a patient myself and now I'm founder and president of my own organization."*



## Training that empowers

*"This training was a basis of knowing something about this area of patient involvement as I am not from medical background. Thus, you can be on the same level."*



## Training that creates connections

*"EUPATI provided me with an extensive network of fellow patient advocates who continue to be a source of support, advice and collaboration."*

The EUPATI Patient Expert Training Programme is today established as the global reference of patient education. After completing the training, EUPATI Fellows are widely recognised as patient experts. The programme has been running since 2015 and more than 330 individuals have graduated within 6 cohorts. Since the first cohort, long-term impact surveys have been collected among the Fellows and in 2023, results of these and semi-structured interviews were compiled into a published impact study.

**Objectives for 2023:** Expand evaluation and impact assessment of EUPATI patient education and explore formal accreditation of the EUPATI Patient Expert Training Programme.

### Results:

- A long-term impact assessment was published and disseminated, summarizing survey results from 140 Fellows and over 20 interviews.
- The individual modules of the Open Classroom received ECTS accreditation by the European Agency for Higher Education & Accreditation (EAHEA).

**Key activities:** Efforts to create close links with Fellows and EUPATI National Platforms (ENPs) were continued and a specific webinar for trainees and ENPs was organised in May 2023. Within the framework for the Continued Education Programme for the Fellows, a webinar introducing the new Digital Health module was organised for 75 participants in May 2023.

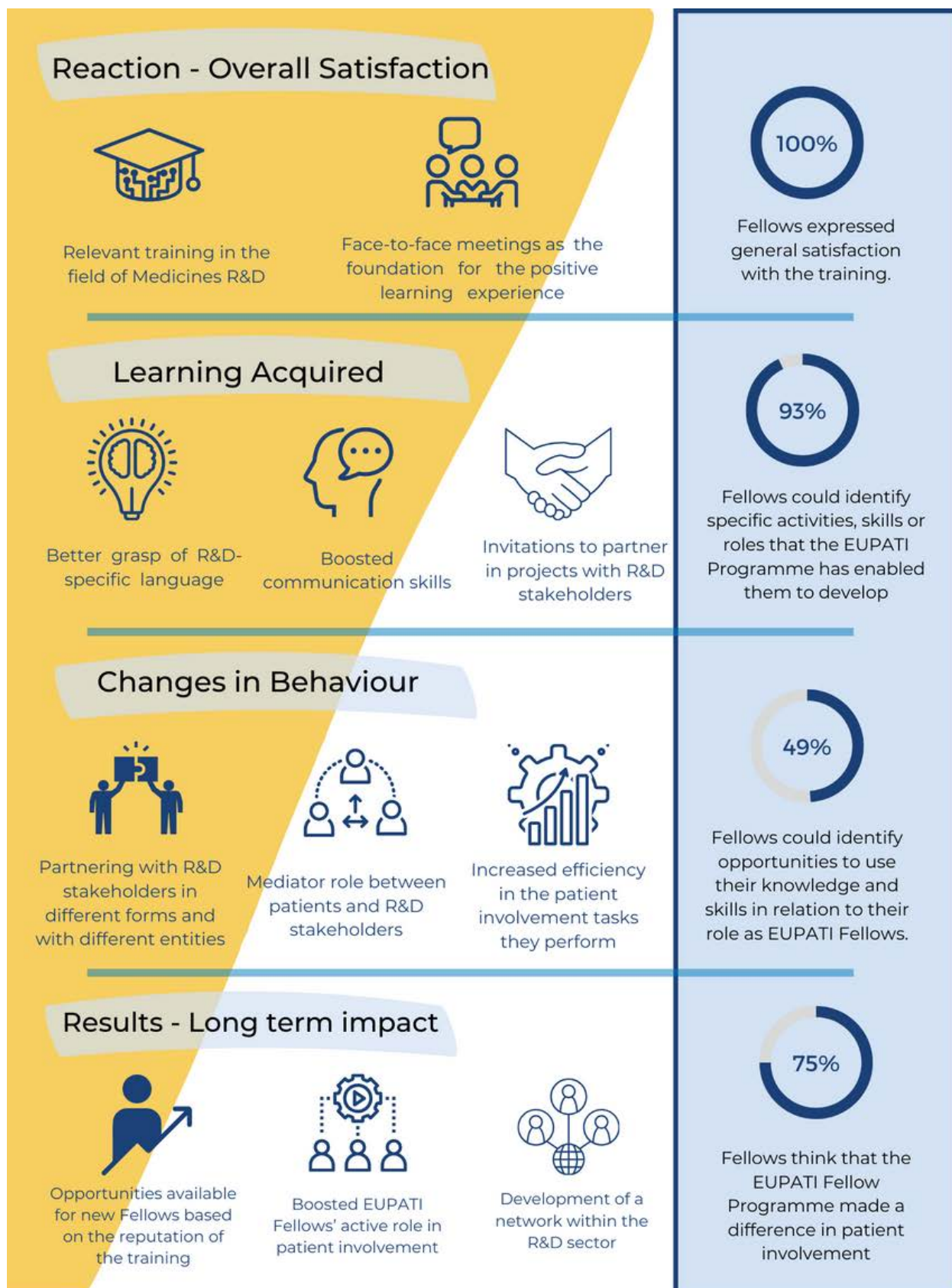
### Highlights:

- EUPATI Impact Study shows that 75% Fellows see that the EUPATI Patient Expert Training Programme made a difference in patient involvement (more details on the following page).



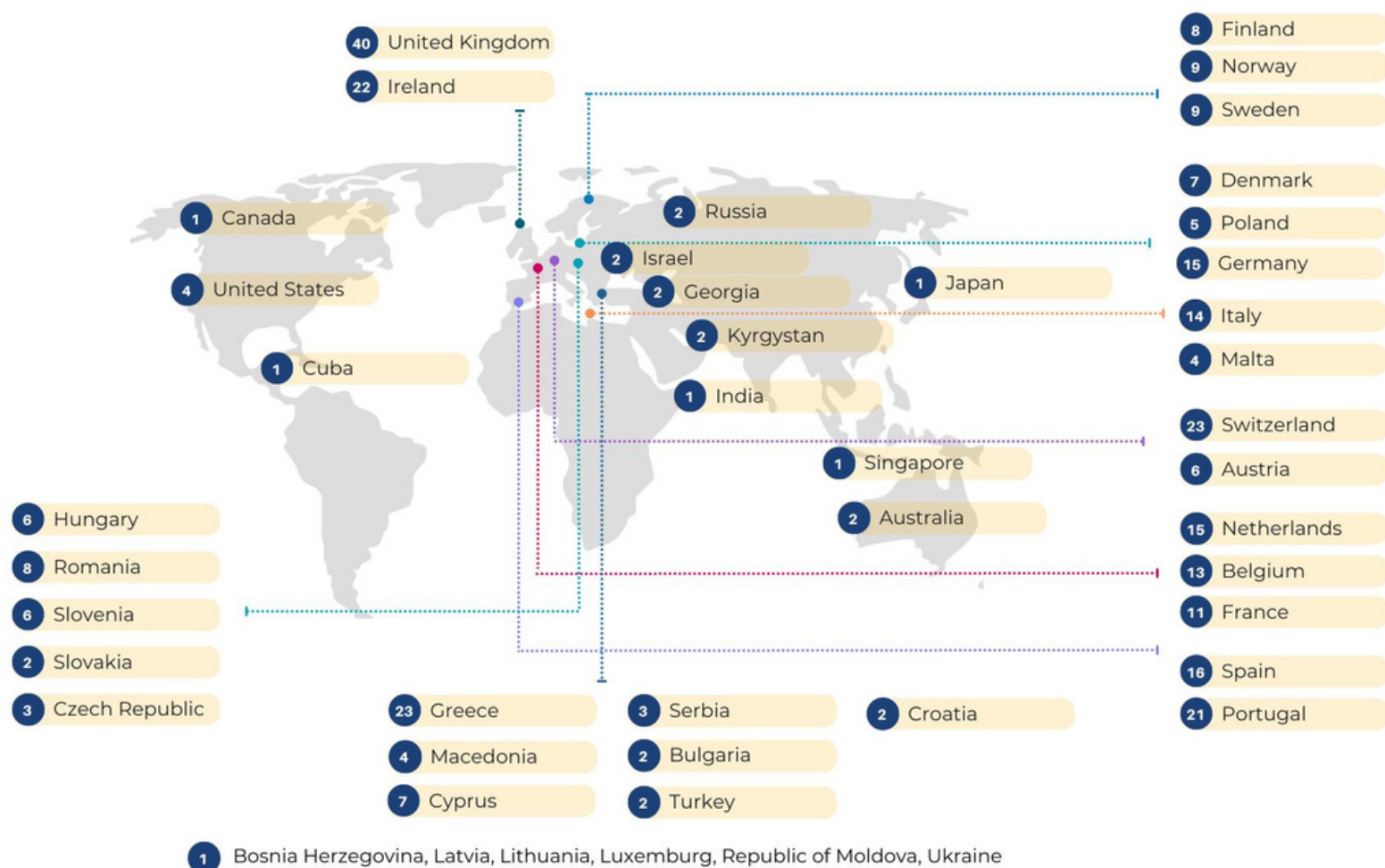
**Widely established, evaluated and acknowledged training programme**

# EUPATI PATIENT EXPERT TRAINING PROGRAMME



Summary of Impact Study Results (surveys collected 18 months after the completion of each cohort 1-3 and interviews conducted in 2022 among representatives from cohorts 1-4).

# EUPATI FELLOWS - ALUMNI



*Geographical representation of 331 EUPATI Fellows, cohorts 1-6.*

There are today 331 EUPATI Fellows who have graduated from the EUPATI Patient Expert Training Programme since 2016. The group is geographically very diverse (see above) and 303 of them identify primarily as patients or patient representatives. These individuals represent a variety of therapeutic areas (see next page), some more than one area.

**Objective 2023:** Continue close collaboration with EUPATI Fellows as ambassadors, trainers, reviewers, content authors, project partners and ENP collaborators - and enhance their contacts with other Fellows and EUPATI National Platforms

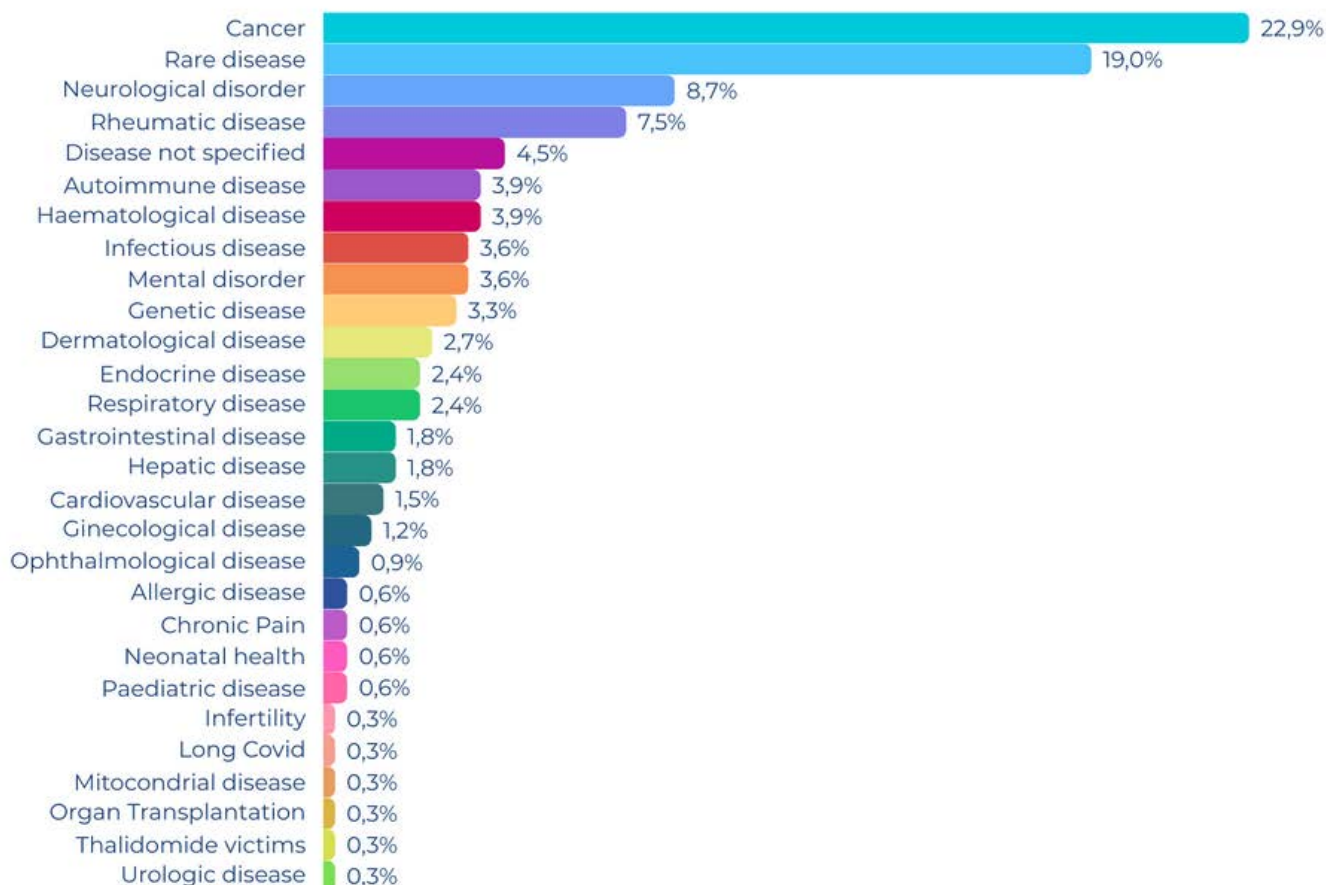
## Results:

- A webinar introducing National Platforms to the future Fellows (trainees in cohort 6) was organised in May
- EUPATI Fellows were assigned speaker roles in a variety of international conferences and events (e.g. DIA2023, SCOPE Summit 2023, ISPOR2023) and memberships in several committees (e.g. ERA4Health)

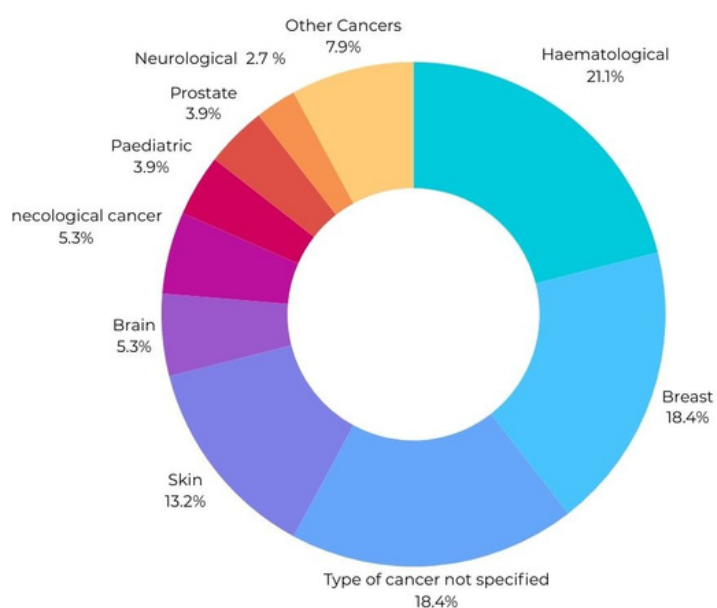
**Key activities:** An initiative to build a 'community' website, discussion forum and regular meetings to create connections among the EUPATI Fellows and feature their activity and accomplishments was put forward.



# EUPATI FELLOWS - ALUMNI



## TYPES OF CANCER



## RARE DISEASES

Addison's disease	Hereditary hemorrhagic telangiectasia (HHT)
Autoinflammatory disease	Muscular dystrophy
COAT's	Osteonecrosis of the jaw
Congenital Disorder of Glycosylation	Pitt Hopkins Syndrome
Cystic Fibrosis	Propriospinal myoclonus
Duchenne Muscular Dystrophy	Rare genetic disease
Ehlers-Danlos syndrome	Rare liver disease
Epidermolysis bullosa	Rare neuromuscular disease
Fibrodysplasia ossificans progressiva	Rare optic diseases
Friedreich's ataxia	Rare Paediatric disease
Gaucher disease	Sanfilippo Syndrome
GNE Myopathy	Spinal Muscular Atrophy
	Trisomy 8
	Usher Syndrome

Duchenne and Cystic Fibrosis are the most common rare diseases with 8 and 7 trainees respectively.

Representation by therapeutic area of 303 EUPATI Fellows, cohorts 1-6, and detailed breakdown by types of cancer and rare diseases.

# EUPATI HTA4PATIENTS PROJECT

- Co-Funded by EU4HEALTH for 3 years (2023-2026)
- Designing an Open Classroom course on European Union Health Technology Assessment Regulation (EU HTAR)
- Developing interactive online training sessions preparing participants to take part in joint clinical assessments and joint scientific consultations with national HTA bodies at the European level

**Objectives for 2023:** Launch the project, form a strong project team with Partners, EUPATI Fellows, National Platforms, HTA bodies and members of the EUPATI Network and start the implementation of the project according to its workplan.

## Results:

- Project Kick-Off Meeting organised in Brussels in March 2023 with 18 participants.
- Project Management and Project Expert Panel established bringing together Partner representatives, EUPATI Fellows, National Platforms, HTA bodies and members of the EUPATI Network with HTA expertise.
- A 6-month progress meeting with good outcome attended with the European Commission.
- Open Classroom course content finalised for Editorial Board review by the end of December.
- Close collaboration initiated with 'sister'-project EUCAPA.

**Key Activities:** An Authoring Group for a new Open Classroom course established and an intensive content co-creation process initiated in September. An in-person meeting organised for 12 participants of the Authoring Group in Copenhagen in November 2023 resulting in the finalisation of the content. A webinar held for 19 members of the Workgroup of European Cancer Patient Advocacy Networks (WeCan) in November together with EUCAPA.

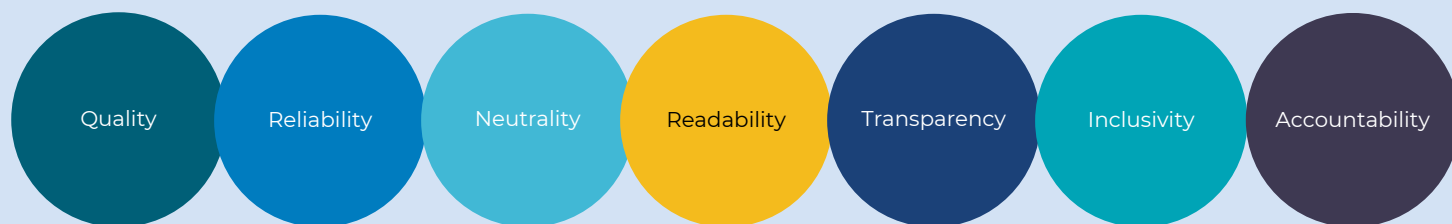
**Highlights:** An abstract successfully submitted to the ISPOR2023 conference resulting in a session: 'Training Patients in Europe for Effective Contribution to Health Technology Assessment'



Increased number  
of expert patients  
with up-to-date  
knowledge in HTA



# EUPATI CONTENT & MATERIALS



EUPATI content development is a multistakeholder process, bringing together Partners, EUPATI Fellows, ENPs and external experts, and aiming to produce well-structured, comprehensive, scientifically reliable, and user-friendly educational materials for patients and patient representatives. EUPATI maintains today thousands of high-quality content items published on the EUPATI Toolbox and Open Classroom in multiple languages.

**Objective for 2023:** Define and document the quality assurance process for all content.

## Results:

- A process description of EUPATI content development and detailed guidelines for authoring groups were published on the EUPATI website.
- Guiding principles for content development were defined by the EUPATI Editorial Board (listed above).
- Terms of Reference of the Editorial Board were revised and published.

**Key activities:** Work on two authoring groups were facilitated: Cell & Gene Therapies and HTA4Patients. A working group to work on a publication on the Patient Engagement Roadmap in Medical Devices was established.

## Highlights:

- The EUPATI Editorial Board had an in-person meeting in conjunction to the DIA2023 conference in Basel, in March 2023.



Ensuring  
availability of new,  
up-to-date and  
high quality  
content on  
medicines R&D

# EUPATI CONTENT & MATERIALS

Creating new content

Updating existing content

Ensuring accessibility

EUPATI's key objectives for content developed are a three-folder: creating new content, updating existing content and ensuring accessibility. This was also applied in EUPATI 2023 workplan.

**NEW CONTENT - Objectives for 2023:** Develop new content on Cell & Gene Therapies for the Open Classroom and explore adding new content to the Digital Health module of the Open Classroom

**Results:** A new module on Digital Health was published on the Open Classroom in May 2023.

## Key Activities:

- A multi-stakeholder authoring group continued their work on Cell & Gene Therapies. A review of the Open Classroom was conducted and the placement and format of new content was defined. Allocation of sections for different authors was initiated.
- Real World Data (RWD) and Real World Evidence (RWE) were identified as topics to be added to the module. Establishing contacts with experts & potential authors for these was started.

## Highlights:

- An open webinar was organised on 10 May 2023 with 75 participants on the launch of the Open Classroom Digital Health module with speakers representing different stakeholders.



Ensuring availability of new, up-to-date and high quality content on medicines R&D



- Digital Health Introduction - Classification & Impact
- Digital Health Applications - Infostructure & Infrastructure
- Digital Health Development Process
- Legal, Regulatory, and HTA Concepts of Digital Health
- Digital Health Transformations and Challenges



# EUPATI CONTENT & MATERIALS

Creating new content

Updating existing content

Ensuring accessibility

**UPDATING CONTENT - Objectives for 2023:** Develop a process for systematic updates for all training and Toolbox content.

**Results:** A process for systematic updates for all training and toolbox content was drafted.

**Key activities:** As part of the framework for systematic updates, a process of identifying experts for content updates was initiated.

**Highlights:** As part of the Cell & Gene Therapy authoring group work, a systematic review of the Open Classroom core modules was conducted and areas requiring updates were highlighted.



Ensuring availability of new, up-to-date and high quality content on medicines R&D

**ACCESSIBILITY - Objectives for 2023:** Share information and resources about accessibility to patient education on EUPATI Open Classroom

**Results:** A new 'Accessibility Page' on Open Classroom was made available for learners, with focus on patients with visual impairment.

**Key activities:** Accessibility needs were highlighted as a key factor to be taken into account in the next upgrade of the Open Classroom platform (planned for 2024).

**Highlights:** The Secretariat's knowledge around accessibility to educational resources was enhanced through direct feedback and collaboration with EUPATI Trainees and Fellows.



Increased awareness about accessibility to online learning and easy navigation around EUPATI materials



Key principles for Accessibility and Inclusion: The content meets the accessibility features to ensure that students with disabilities can fully participate in the learning process.

# EUPATI LEARNING LAB



## PRINCIPLES OF PE

Understanding the benefits of PE in medicines R&D



## PE ROADMAP

Learning where engagement should occur



## PE ACTIVITIES

Including patient engagement at different stages



## QUALITY IN PE

Identifying the challenges when making it happen

Aligned with its vision and mission, EUPATI seeks to increase the knowledge of academic researchers and industry professionals on meaningful patient engagement in medicines R&D. These trainings are based on the experience of EUPATI Fellows working with different stakeholders, as well as EUPATI Guidances and other resources (e.g. FDA and EMA publications and the IMI-Paradigm Toolbox). Under the so-called 'Learning Lab', EUPATI offers today three different types of trainings: EUPATI Fundamentals, EUPATI Essentials and customised trainings for specific teams or project consortia.

**GENERAL PORTFOLIO DEVELOPMENT - Objectives 2023:** Update the existing needs assessment for patient engagement training, explore commonly agreed learning objectives with other external partners, and refine the EUPATI training offerings on patient engagement (exploring joint training opportunities with partners and expanding to new target audiences).

### Results:

- EUPATI's approach and objectives for patient engagement trainings redefined at a series of internal workshops Spring 2023
- Learning Lab and a dedicated website launched in June 2023
- A new offering labeled 'EUPATI Spotlights' introduced in November 2023, focusing on specific endpoints along the Patient Engagement Roadmap

**Key activities:** A needs assessment & defining learning agreements for training continued at quarterly industry-cluster Partner meetings, through EFPIA Patient Think Tank blog co-authorship and a dedicated Patient Engagement Open Forum (PEOF) session in June 2023

### Highlights:

- EUPATI together with several partners contributing to the publication of EFPIA View blog article: 'How companies are moving patient voices centre stage'



Enhanced reach and delivery of the patient engagement training portfolio

# EUPATI LEARNING LAB

Patient engagement training for academia and industry

**LEARNING LAB Objectives 2023:** Organise at least 12 trainings reaching 250 participants in 2023, strengthen the trainer pool and enhance promotion and communications around the training offerings.

## Results:

- 290 individuals trained at 14 different trainings
- 6 new trainers introduced, bringing the number of Learning Lab Faculty to 17 individuals
- A handbook for Learning Lab Faculty created
- Dedicated newsletters and social media posts disseminated for EUPATI Fundamentals and Essentials

**Key activities:** With the first module of EUPATI Essentials running, the development of the second module continued (to be completed in 2024)

## Highlights:

- 21 participants joined an in-person EUPATI Fundamentals training in Brussels in April 2023.
- EUPATI organised a patient engagement training for the EU project consortia SIMPATHIC in Amsterdam in July 2023 with 45 participants.

POSTPONED OBJECTIVE 2023: Develop and implement systematic impact assessment of patient engagement trainings - *to be launched in 2024*



Enhanced reach and delivery of the patient engagement training portfolio



# EUPATICONNECT



## Providing opportunities to practice learnings from EUPATI

*"There's a certain responsibility that comes with being a EUPATI fellow. We need to use what we have learned to make a real difference! EUPATIconnect means that I am working with trusted partners on topics that matter to patients. We learn from each other and make meaningful solutions together."*



## Creating collaborations with practical implications

*"We had a fantastic response following our request for patient review of our informed consent template. EUPATI fellows had some hugely valuable feedback which will be used to inform our future template to make it clearer and more user friendly."*



## Creating connections to share insights

*"We received some great insights in interviews with EUPATI fellows. Within 24 hours of placing a request, we were connected to three patients. All interviews were completed in 2 days and gave us a great understanding of the patient perspective.."*



## Facilitating change through collaborative projects

*I had the opportunity to be involved as Patient Advisor in several clinical research projects, especially working on the study protocols and the development of patient relevant material. The involvement of a EUPATI Patient Expert means that any clinical research becomes more focused on the patients' real needs as well as having the voice of the patient included in all steps.*

Enhancing collaboration between trained Patient Experts and researchers is a strategic objective for EUPATI. EUPATIconnect ([www.connect.eupati.eu](http://www.connect.eupati.eu)), our matchmaking platform, launched in 2022, is the central element of this activity. A roadmap for further development of the platform continues to be refined together with EUPATI Fellows, Partners and EUPATI National Platforms.

**Objectives 2023:** Increase the pool of individuals on the EUPATIconnect platform, facilitate an increasing number of collaborative projects via the platform, evaluate the user experience of the platform and enhance promotion and communications around EUPATIconnect.

### Results:

- Cohorts 5 and 6, as well as National Fellows from EUPATI Netherlands and Ireland were introduced to the portal, bringing the number of Expert Patients in EUPATIconnect to 258 in total, representing a vast number of disease areas
- 14 collaborative projects were facilitated through the platform (initially set annual goal 35)
- User experiences of both Fellows and researchers were collected via surveys and interviews as part of an internship project
- Promotion increased on social media and EUPATI newsletters.



Increased number of established and documented collaborations between expert patients and researchers

See next page for Key activities & Highlights



**Key activities:** The technical requirements for the platform were reviewed and updated

**Highlights:**

- A well-attended dedicated session about matchmaking was organised at the Patient Engagement Open Forum (PEOF) in June 2023.
- Dedicated staff resources were established for EUPATIconnect coordination

POSTPONED OBJECTIVES 2023: Define criteria for including advanced Open Classroom learners and other patient experts on the platform and document the collaborative projects in form of case studies published on the Toolbox- *to be launched in 2024*



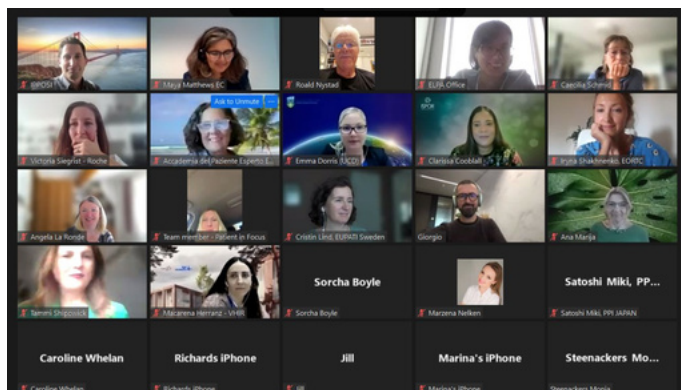
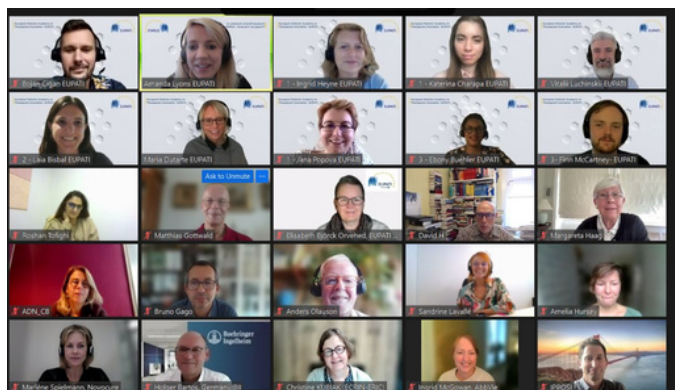
Increased number of established and documented collaborations between expert patients and researchers



An evaluation was conducted to collect feedback on the user experience of EUPATIconnect since its launch in 2022. Both Expert Patients and Researchers were involved in this small-scale study (24 surveys & 8 interviews). The findings will help drive the strategic plan and roadmap for further development of the platform. Some of the key findings are captured below:

- **Quality & Speed:** The quality of the matchmaking and the input of Patient Experts are crucial, but timely follow-up is equally important for researchers.
- **Awareness & Relationship Management:** Both sides wanted an improved updating mechanism that included successful match stories, patient/researcher expectations, etiquette, covered disease areas, and tips for optimizing site usage. EUPATI identified a need for regular follow-up to learn about these success stories. On the patient side, there was a need for active engagement, guidance on expectations, and a supportive network.
- **Technical side:** The platform remains manual for the Secretariat, and there are some technical issues to be addressed. Patient Experts encountered usability issues, and researchers were eager to enhance the algorithm for improved matching rates.
- **Challenges in collaboration:** Researchers primarily relied on relationships with patient/scientific organizations for matchmaking and had not used matchmaking platforms before. Many patient organization leaders, however, reported feeling overwhelmed by matchmaking requests, suggesting an opportunity for EUPATIconnect to help.

# EUPATI FOUNDATION & GOVERNANCE



**Objectives for 2023:** Enhance the different ways Partners can contribute and collaborate with EUPATI, evaluate and enhance functioning of EUPATI governance & internal communication, continue developing onboarding and internal training processes for members of the governance and secretariat

## Results:

- EUPATI Partnership grew to include 50 partners in 2023.
- 2 Sustaining Partner Assembly (SPA) meetings were held online, March and September (AGM) 2023.
- Board elections were held in June-August 2023 through online nominations and voting.
- EUPATI Board initiated an internal evaluation of their functioning and contributed to further developing onboarding processes.
- 7 Board meetings (2 in-person and 2 extraordinary) and 6 Trustees' meetings (1 in-person and 3 extraordinary) were held in 2023.
- Three internal 'EUPATI Exchange' sessions were held for EUPATI Governance and the Secretariat (on Patient Expert Training Programme, Communications and EUPATIconnect)

**Key activities:** Close collaboration was continued via Partners' involvement in EUPATI governance, HTA4Patients project, Patient Expert Training Committee, Editorial Board, several webinars and the different content authoring groups.

## Highlights:

- EUPATI continued bilateral meetings (online and in-person) with Partners and attended several events organised by them.
- Well-attended online AGM meeting featuring Maya Matthews from EU4Health as a key note speaker, September 2023



**Strengthened,  
well-informed and  
fit-for-purpose  
partnership and  
internal structures**

# EUPATI PARTNERSHIP



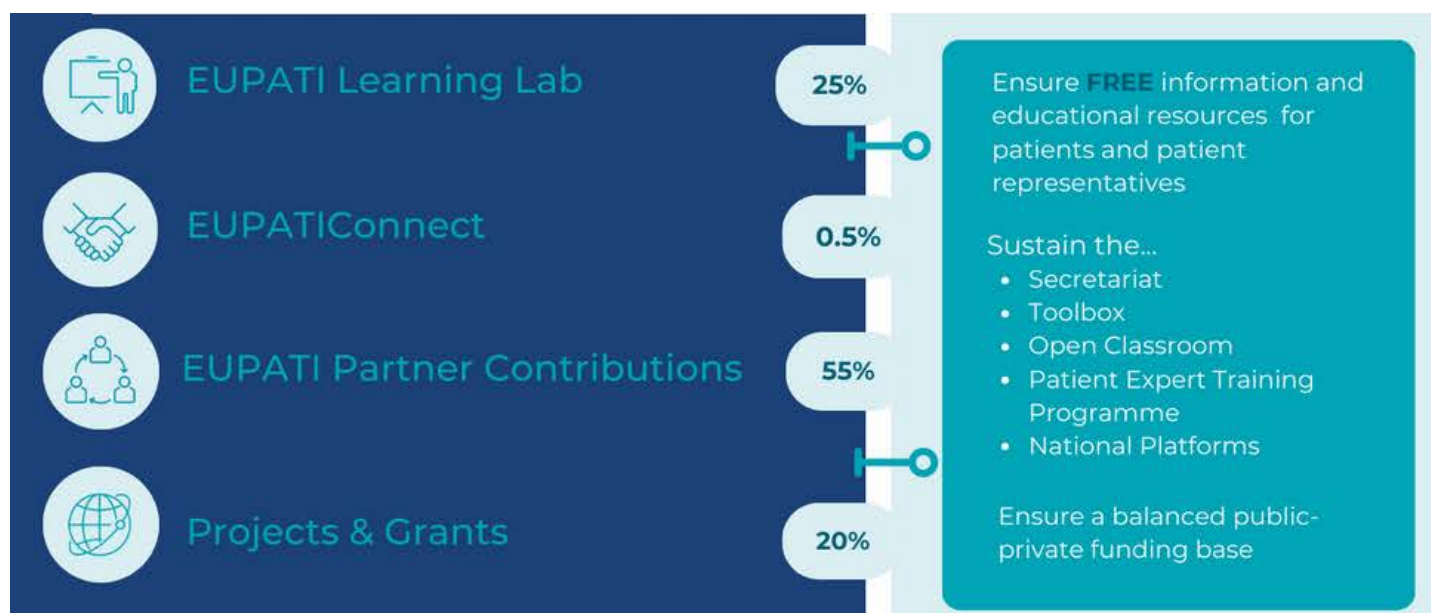
EUPATI Partnership grew to include 46 partners in 2023 (8 patient organisations/networks, 15 academic/non-profit organisations and 23 industry members representing pharmaceutical companies and CROs). The new Partners are the following:

- Global Heart Hub (Patient Organisation)
- KU Leuven (Academic organisation)
- NovoCure (industry)
- Parkinson's Europe (Patient Organisation)
- South East Technological University (Academic Organisation)
- TOPRA - The Organisation for Professionals in Regulatory Affairs (Non-profit Organisation)
- University College Dublin (Academic Organisation)

Moreover, six other organisations have initiated the process to join the partnership in 2024.

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.

# EUPATI SUSTAINABILITY



The sustainability of the EUPATI Foundation is based on four main pillars: the Learning Lab, EUPATIconnect, Partner contributions and projects & grants. In addition, EUPATI receives donations from individuals and institutions.

**Objectives for 2023:** Re-evaluate the Foundation's overall sustainability plan and long-term financial outlook/budgeting and continue engaging in European-wide project funding proposals.

## Results:

- Interviews with authors of the original sustainability plan dating back to 2020 were conducted
- An internal 'Our vision for the future' document capturing all aspects of EUPATI's sustainability plan was drafted and feedback collected from Trustees at their in-person workshop in July 2023.
- Internal capacity building initiated for financial management of EU projects

**Key activities:** 'Our vision for the future' document brought to the EUPATI Board and the Secretariat for further input (final version to be drafted in 2024).

## Highlights:

- Long-term project funding secured through HTA4Patients (EU4Health), SIMPATHIC (Horizon), COMBINE-CT (IHI) and GEREMY (Horizon). 4 additional proposals were submitted (outcome pending).

**POSTPONED OBJECTIVES 2023:** Evaluate the Secretariat's capacity and required additional resources for continued growth. Update operating rules as necessary (following the internal Board evaluation) - *to be done in 2024*

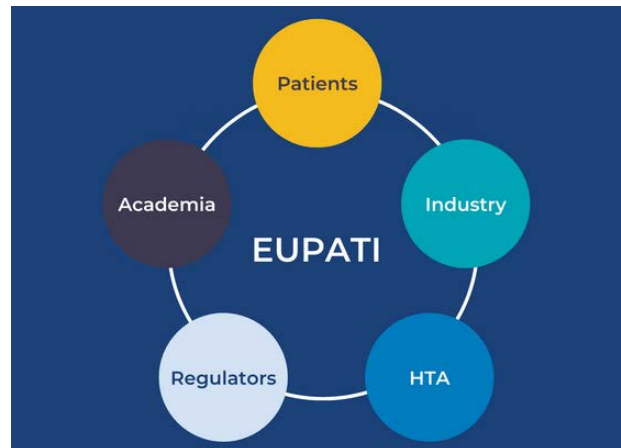


**Guaranteed long-term sustainability**





# EUPATI COLLABORATION WITH HTA & REGULATORY



In addition to the Partner organisations representing patients, academia/non-profits and industry, EUPATI collaborates with regulators and key actors in Health Technology Assessment (HTA).

**Objectives 2023:** Establish EUPATI's role in HTA, working closely with national HTA bodies/HTA actors and function as a platform for regulatory agencies to collaborate around patient involvement.

## Results:

- HTAi, ISPOR, EUNETHA and HTA bodies actively connected to the HTA4Patients project

**Key activities:** Alongside the HTA4Patients project, attendance at DIA HTA Forum and webinars organised by Cancer Patients Europe preparing patients for EU's HTA Information Days. Regular meetings with the Advisory Committee Regulatory Arm bringing together representatives of 5 European National Competent Authorities and the EMA.

## Highlights:

- Joint roundtable session with EMA organised at DIA Europe 2023: Enhancing patient involvement in the regulatory area through training and education
- Attending the Patients Representatives' Roundtable at the ISPOR2023 Europe conference in November 2023



# EUPATI NATIONAL PLATFORMS



Providing patient education and engagement locally



There are 24 EUPATI National Platforms (ENPs) across Europe and worldwide: in Austria, Belgium, Czech Republic, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Japan, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Slovakia, Spain, Switzerland, Sweden, Turkey and Scotland (UK). They all aim to promote patient education and engagement at the national and local level. ENPs reflect the EUPATI multi-stakeholder structure with representations from patients, academia and industry. ENPs are EUPATI partners and have representation at the EUPATI Board.

**Objectives 2023:** Strengthen the EUPATI National Platforms by raising their awareness of existing EUPATI materials and resources

## Results:

- Quarterly catch-up meetings organised, highlighting the available EUPATI materials and resources
- Greek translation of the EUPATI Toolbox made possible with the contribution of ENP Cyprus
- New EUPATI national training programme in the Czech Republic and 2 new (introductory level) EUPATI training programmes launched in Switzerland and Sweden

**Key activities:** Bilateral meetings facilitated by the Secretariat and regular progress updates shared via bi-monthly newsletters to all ENPs and the general public

## Highlights:

- Side-event organised with the Czech ENP at the Patient Expert Training Event in Prague, October 2023, introducing the National Platform, its activities and the different ways to get involved in an ENP to the future Fellows.

# EUPATI COMMUNICATIONS

**Objectives 2023:** Strengthen internal and external understanding of EUPATI's vision and mission and EUPATI's multistakeholder public-private structure, communicate effectively about EUPATI's impact, establish a clear visual identity across different media, increase EUPATI's visibility online (website & social media), at events and conferences and via publications, harness Patient Engagement Open Forum PEOF 2023 as a platform for collaborations around patient education and content development.

## Results:

- A new EUPATI brochure produced outlining EUPATI's vision, mission and key values
- Increased visibility attained via in-person events and consistent social media presence (LinkedIn, x/Twitter, Facebook & Instagram)
- Strong & consistent use of EUPATI branding colours via website redesign, social media posts & presentation templates
- Launch of new design for EUPATI websites: home page, Learning Lab, HTA4Patients and National Platforms page
- Active participation in PEOF2023.

**Key activities:** Regular social media posts, bi-monthly newsletters and active website updates, targeted use of printed promotion materials.

## Highlights:

- Launch of new design for EUPATI websites: home page, Learning Lab, National Platforms and HTA4Patients project pages.
- Increased visibility through our social media platforms.
- On X/Twitter, EUPATI has 7,819 followers, LinkedIn; 5,934 followers, Facebook; 3,900 followers and on Instagram; 326 followers.
- The main social media highlight was the final event of the Patient Expert Training Programme (PETP). The total number of impressions across all channels was 42,847 K.



Increased visibility and clear visual identity linked to EUPATI's vision & mission

**POSTPONED OBJECTIVE 2023:** Enhance the role of ENPs, Fellows & Partners as EUPATI ambassadors by providing information packages adapted to different languages - *will continue in 2024*





## Vision

Improve health outcomes  
by including patients  
as valued stakeholders  
in medicines R&D



## Mission

Provide education that  
empowers patients to engage  
& partner with all stakeholders  
in medicines R&D

## How we are creating change...

Information

Education

Network

Connection

Collaboration

1

Online Toolbox



EUPATI TOOLBOX

2

Patient Education



EUPATI OPEN  
CLASSROOM

3

Patient Engagement  
Training



FUNDAMENTALS  
& ESSENTIALS

4

National Platforms



ENPs

5

Connecting Patients  
& Researchers



EUPATICONNECT

6

Other Education &  
Patient Engagement  
Projects



PROJECTS

## Our values...



[www.eupati.eu](http://www.eupati.eu)







**The European Patients' Academy on  
Therapeutic Innovation (EUPATI)  
Stichting EUPATI Foundation  
Daltonlaan 600, 3584BK Utrecht, The  
Netherlands**

**VAT: NL861533197B01 - Registration: KVK  
80029019**

**[www.eupati.eu](http://www.eupati.eu) - [info@eupati.eu](mailto:info@eupati.eu)**