



EUPATI

Enhancing patient engagement through education



March 2022



European Patients' Academy on Therapeutic Innovation
www.eupati.eu



EUPATI's journey



Registered as an **independent non-profit Foundation** in the Netherlands as of August 2020



EUPATI Partners



abbvie

AMGEN

AstraZeneca



Boehringer
Ingelheim



Bristol-Myers Squibb

DIA DEVELOP
INNOVATE
ADVANCE

eatris

EA
TG European
AIDS Treatment
Group



ecriin

EF
GCP

ELPA
European Liver
Patients' Association

EORTC
The future of cancer therapy

EPF
European
Patients
Forum

FindMeCure Foundation



GILEAD



greenphire

gsk

IPPOSI

ISPOR
Improving healthcare decisions

Janssen



MSD

MEDICAL UNIVERSITY
OF VIENNA

NOVARTIS

NOVO
NORDISK

Pfizer

Roche

Sant
Joan
de Déu
Research Foundation

SERVIER

sobi

Takeda

ucb

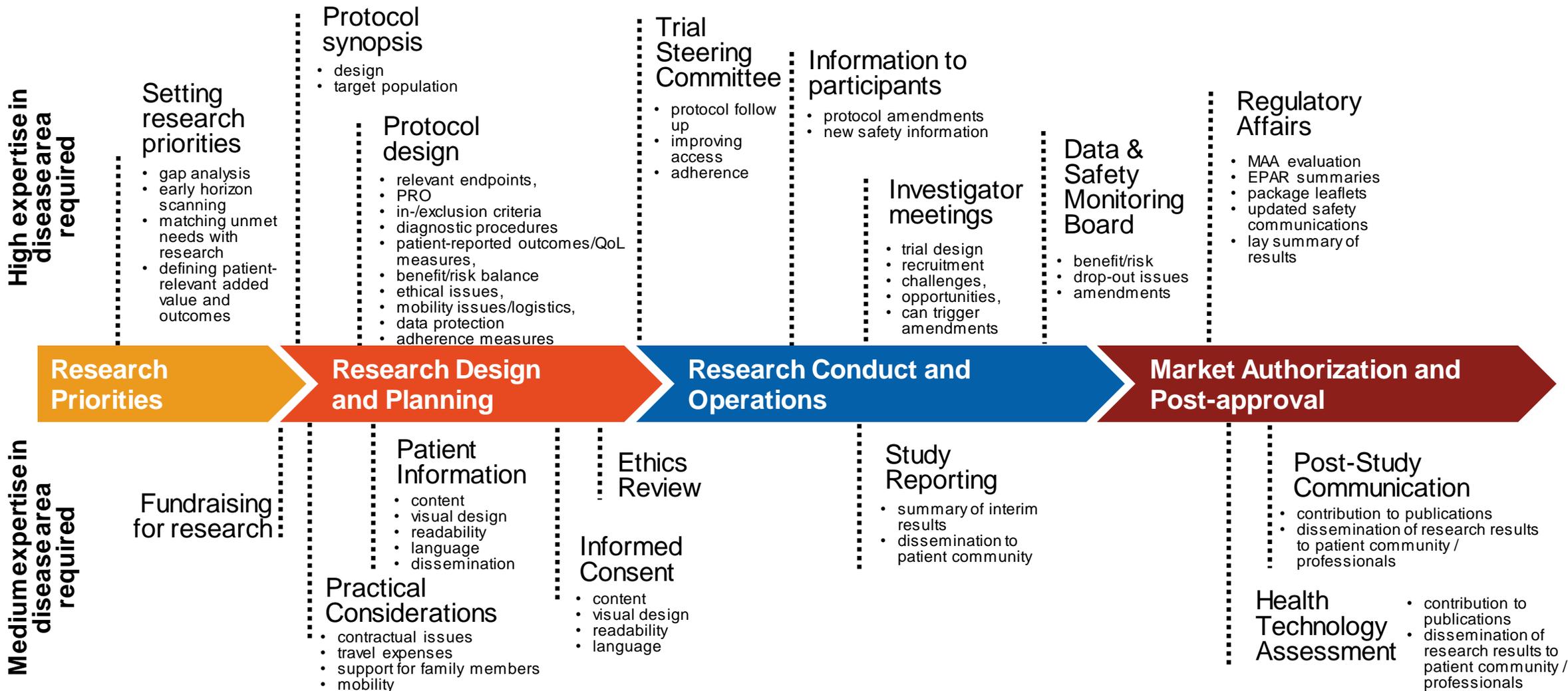


Universidade de Aveiro
três séculos de excelência

Vall
d'Hebron
Barcelona Campus Hospital



EUPATI Patient Engagement Roadmap

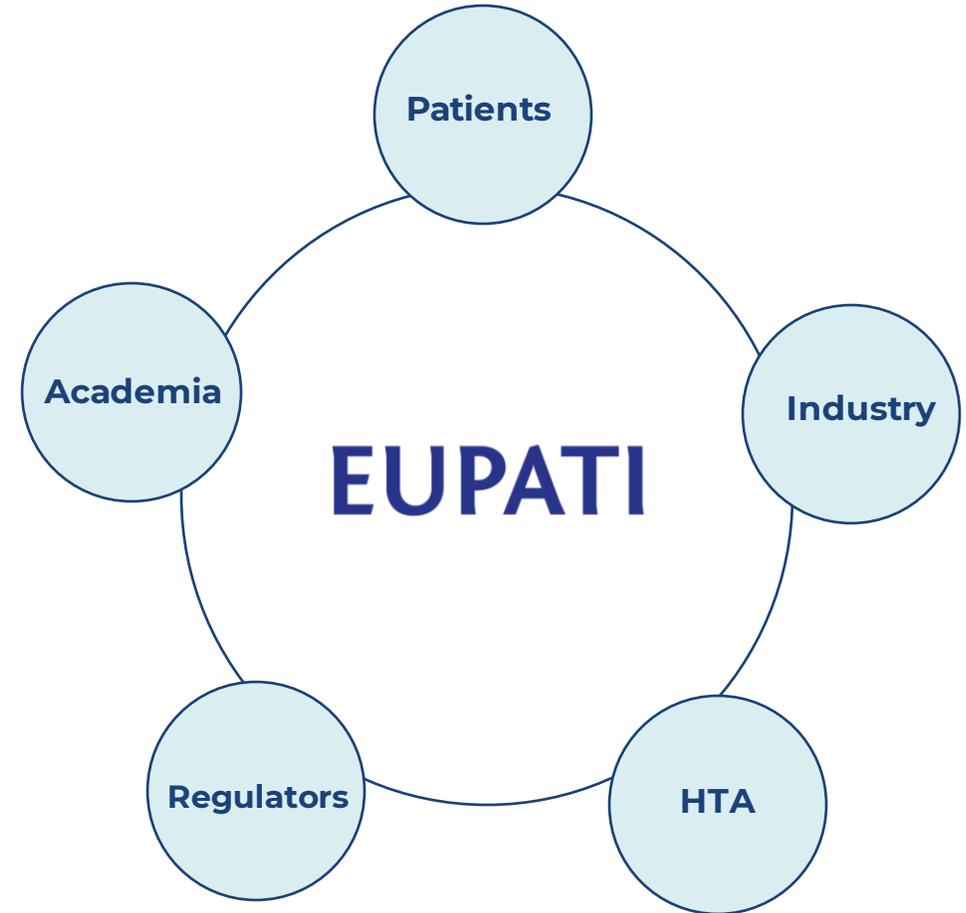




EUPATI's Mission



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's Main Activities



1

Patient Education



2

Stakeholder
Training



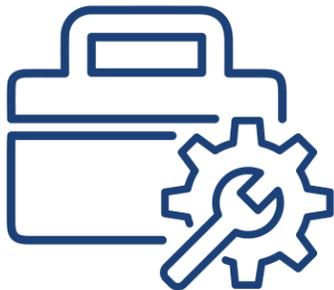
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Enhancing
collaboration
between patients
& researchers



4

Online Toolbox



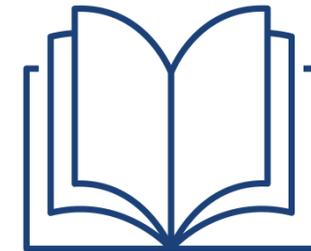
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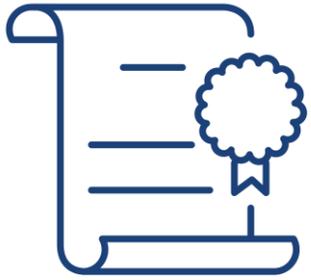
National Platforms



6

Other education &
patient engagement
projects





EUPATI OPEN CLASSROOM

Patient Expert Training Programme



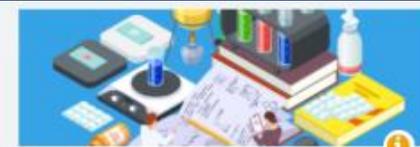
- Expert-level training on medicines R&D
- Non-disease specific
- Online + In-person/live streaming
- 12-14 months
- Continuous enrollment
- 200+ graduates = EUPATI Fellows



Getting started!

In this very short course, you will get started with an overview of medicines research and development.

(1 Course)



Introduction to Medicines R&D

In this introductory module, you will acquire the basic skills and knowledge about medicines research and ...

(6 Courses)



Non-clinical Development

The courses of this module will explain non-clinical studies in detail, the concepts of pharmacogenetics/ge...

(3 Courses)



Clinical Development

This module contains courses on clinical development and trials, including statistics, ethics, the role of ...

(7 Courses)



Regulatory Affairs

The courses in this module will give you an overview on medicines regulation including the different market...

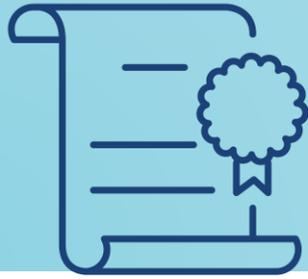
(5 Courses)



Health Technology Assessment (HTA)

The purpose of this module is to introduce you to health technology assessment (HTA). In these courses you ...

(5 Courses)



EUPATI Open Classroom

Three pathways for learning



Individual Courses

- Pick and choose from 27 courses, go through assessment and receive a certificate
- Benefits: Flexibility & freedom

Individual Modules

- Choose from 6 modules containing 3-7 courses each, receive a certificate for all the courses and a badge for the module
- Benefits: Expertise in a particular area within medicines R&D

EUPATI Fellow Programme

- Complete all the courses on the Open Classroom and two training events (online/in-person)
- Benefits: EUPATI Fellow title provides the opportunity to be recognised as expert patient

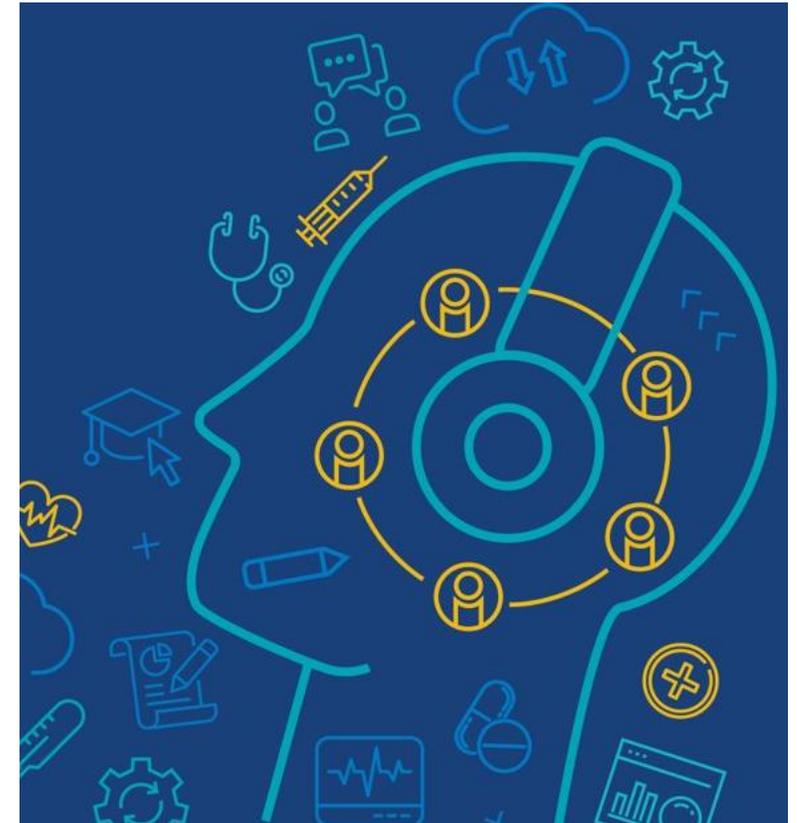


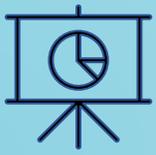
EUPATI FELLOWS

Graduates of Patient Expert Training Programme



- The title certifies the expert-level knowledge and understanding of the medicines R&D process
- Recognition as expert patients
- Well-known label within the patient engagement landscape
- Highly sought-after partners by different stakeholders
- Active in e.g. patient organisations and providing advice to industry, regulator and HTA partners





	EUPATI Fellows before training...	EUPATI Fellows after training...
1. Leadership roles in patient organisations	58%	72%
2. Advising pharmaceutical companies	22%	59%
3. Advising a regulatory agency	14%	51%
4. Advising a reimbursement / HTA body	5%	14%

Source: Internal EUPATI Cohort 1-3 Surveys

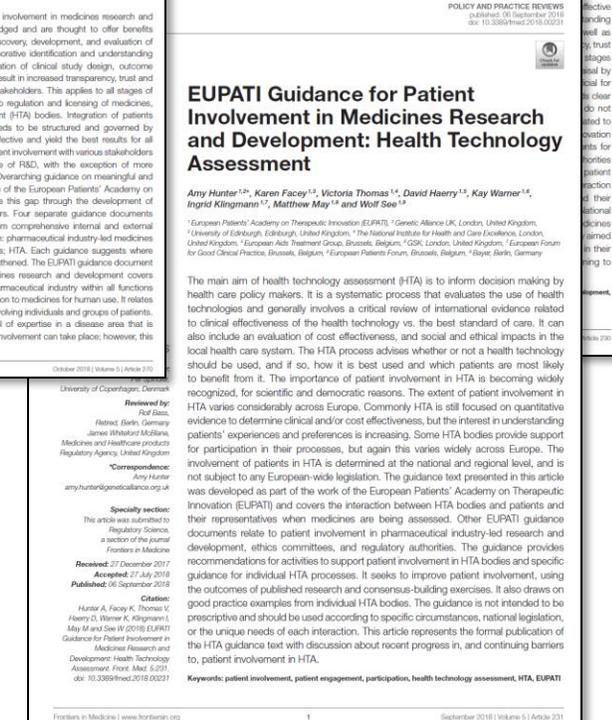
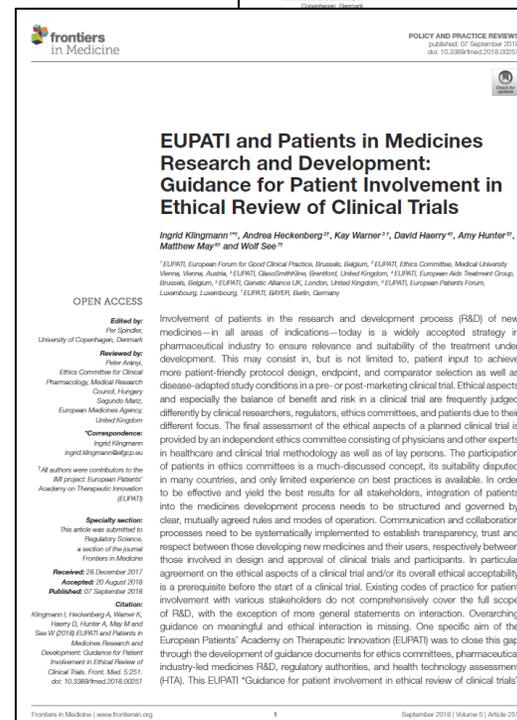


EUPATI Patient Engagement Guidance



Guidance documents for the interaction of patient organisations with other stakeholders:

- ✓ academic researchers
- ✓ in industry-led R&D
- ✓ in HTA bodies
- ✓ in regulatory processes





EUPATI FUNDAMENTALS

Patient Engagement Training



- Training about Patient Engagement
- For industry & academia
- Co-designed & Co-delivered by patients
- 2-day workshops
- Live streaming, small groups
- 500+ trained individuals

Principles of patient engagement

Patient engagement roadmap

Setting up a patient engagement activity

Quality criteria in patient engagement

eupati.eu/training/patient-engagement



EUPATICONNECT

Enhancing collaboration between patients & researchers



- Matchmaking platform
- Bringing together EUPATI Patient Experts with researchers
- Enhancing patient involvement e.g. protocol review, focus groups, speaking opportunities, patient advisory boards, ethical committees, regulatory processes



connect.eupati.eu



EUPATI TOOLBOX

Free online resources on medicines' R&D



- 5 million users worldwide
- 13 languages
- Information about medicines R&D and patient engagement
- Comprehensive, scientifically reliable, and user-friendly
- Non-disease specific
- Articles, presentations, webinars, glossary & acronyms, videos, infographics, factsheets

Toolbox

The Toolbox is organised in two main areas: Medicines R&D and Patient Engagement. You can also search by category or keyword. At the next stage you can also refine the search by "tags" (sub-categories). Key introductory topics are highlighted to help you begin to explore medicines research and development as well as patient engagement. Key concepts in the articles are linked to the [Glossary](#) for definitions.

Keyword(s)

Not sure what you're looking for?

Show all in [Medicines R&D](#) or [Patient Engagement](#) Try to browse by topic:

Basics of Medicine R&D ?	Clinical Development / Trials ?	Drug Discovery ?	Personalised Medicine ?
Regulatory Affairs ?	Benefit and Risk Assessment ?	HTA ?	Pharmaceutical Development ?
Safety of Medicines ?	Non-Clinical Studies ?	Pharmacoeconomics ?	Types of Medicines ?



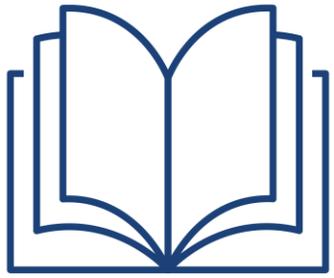
EUPATI NATIONAL PLATFORMS (ENPs) Patient Education at the local level



- 23 platforms established in Europe + Japan
- Independent multi-stakeholder structures
- Patient education activities in national languages



eupati.eu/national-platforms

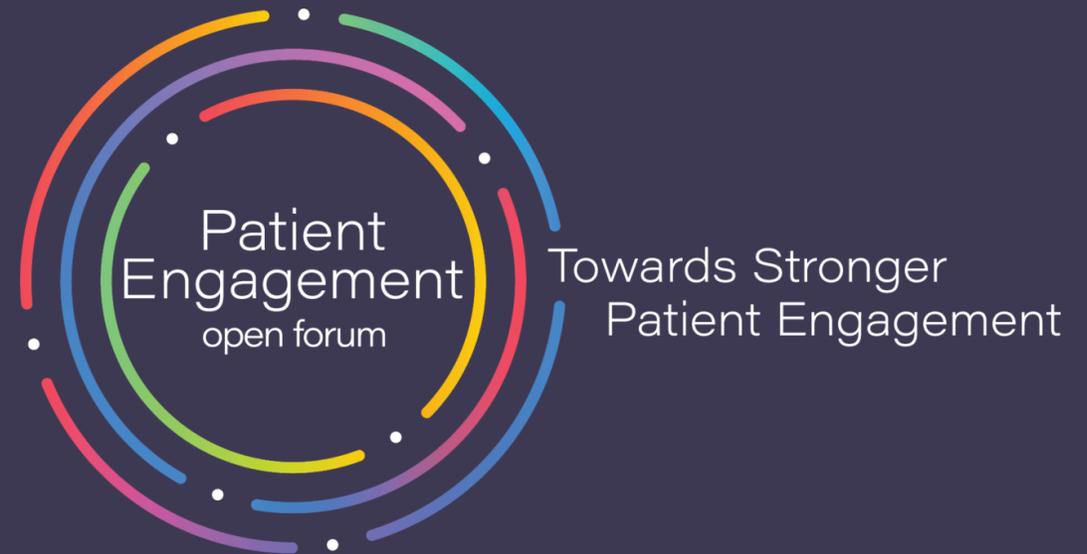


OTHER INITIATIVES

Enhancing patient engagement through education

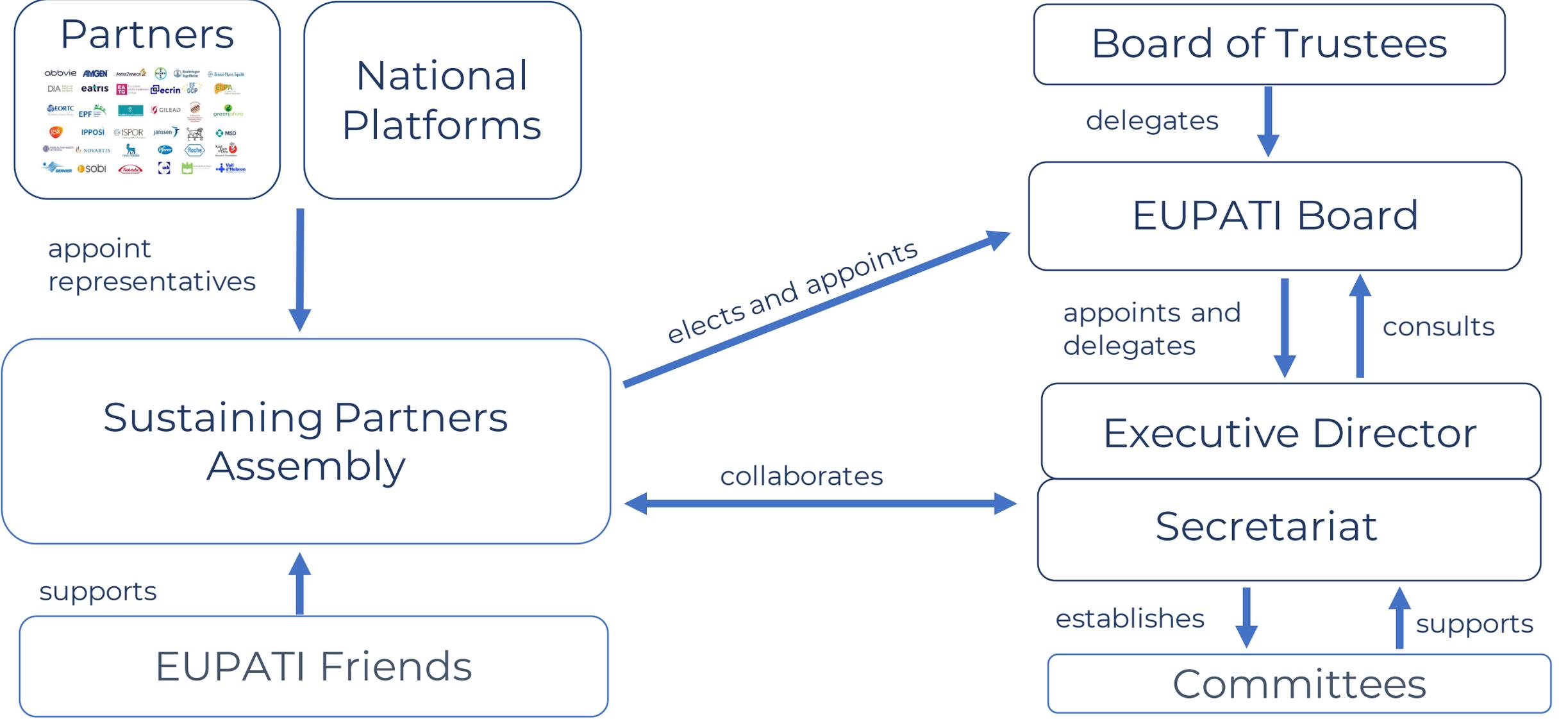


- Active in worldwide patient education and engagement initiatives
- Collaboration with EMA, IMI/IHI, PFMD, EFPIA Patient Think Tank
- Co-organizer of Patient Engagement Open Forum
- Partner in several European research projects





EUPATI Governance





Partner contributions



Fee-for-service trainings



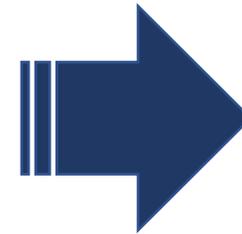
Project funding/grants



Donations



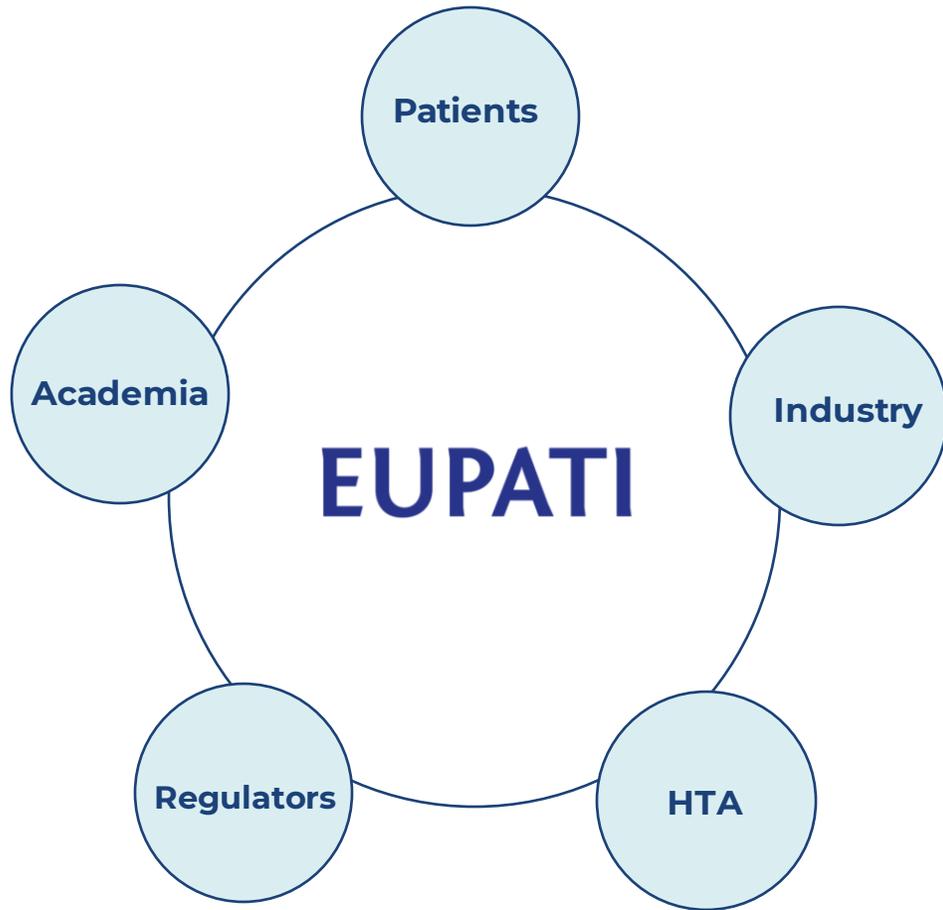
Fee-based matchmaking



- Balanced public-private funding base
- Ensuring continuous education and reliable information for patients, patient representatives and the wider public
- Sustaining the EUPATI Patient Expert Training Programme, Toolbox, National Platforms and widening of EUPATI's scope



EUPATI's Multi-Stakeholder Structure

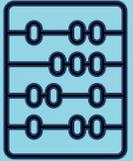


Governance

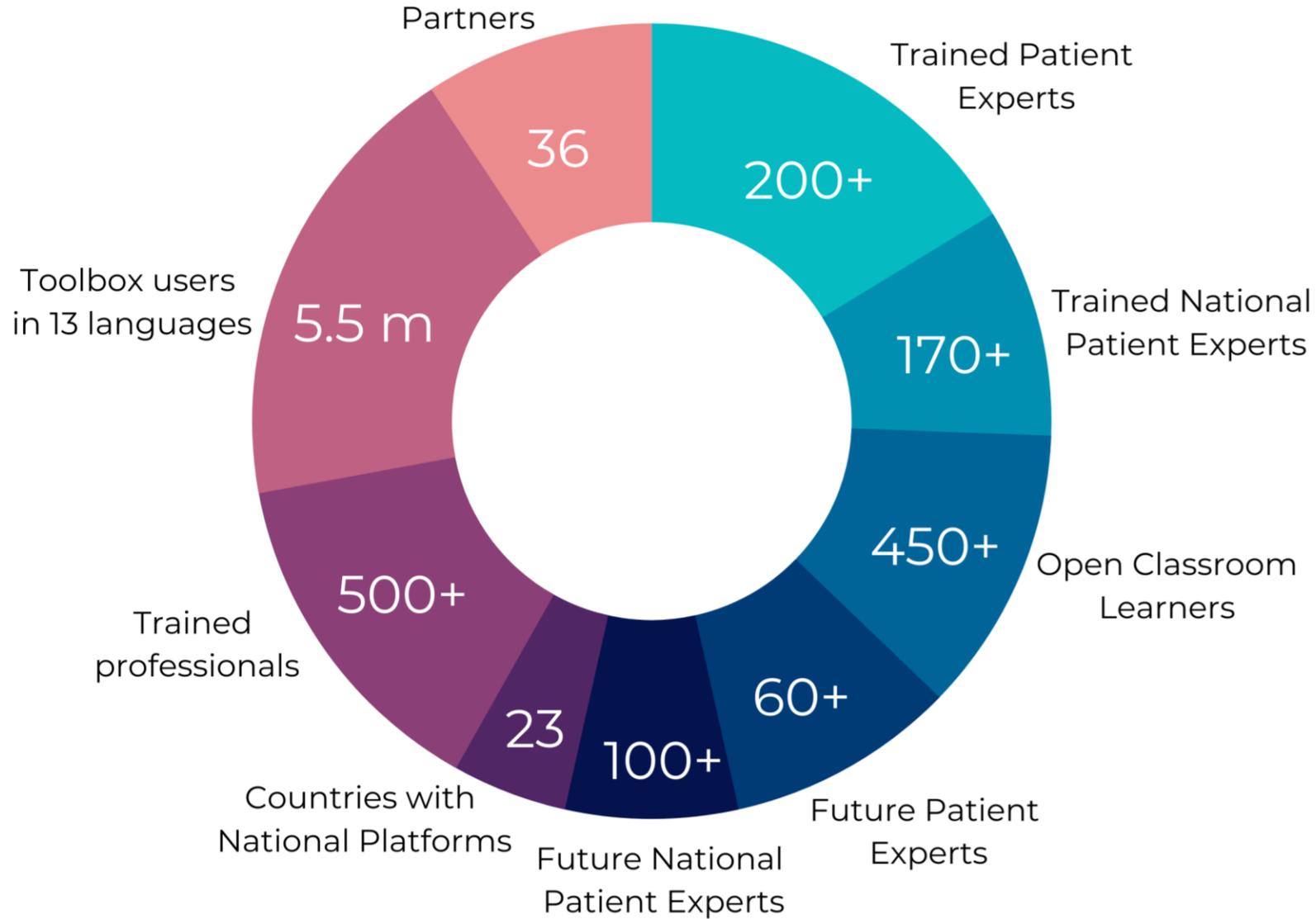
Sustainability

National Platforms

Trainings & Content



EUPATI in numbers



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[/PatientsAcademy](https://youtube.com/PatientsAcademy)



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Thank you!



Contact: info@eupati.eu



European Patients'
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