

PRESENTATION OF EUROPEAN PATIENTS' FORUM AND WAYS OF COLLABORATION

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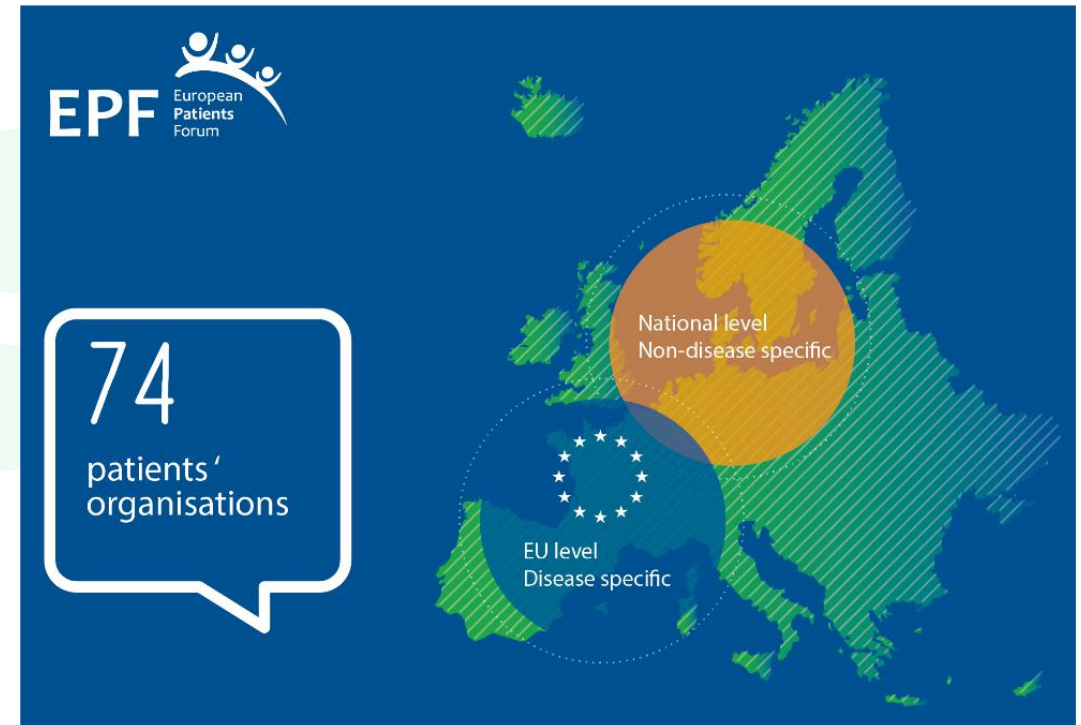


@eupatientsforum

“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”



- European Patients' Forum
 - Independent & non-governmental
 - Umbrella organisation
 - Active since 2003
 - EU patients' voice
- Our members
 - 74 patient Umbrella groups
 - EU disease specific organisations &
 - National patient coalitions



Our Vision:

All patients in the EU have **equitable** access to **high quality, patient-centred** health and social care.



Our Mission:

To ensure that the patient community drives health policies and programmes that affect them.

Our Strategic Goals



Health Literacy



Healthcare Access
and Quality



Patient involvement



Patient
Empowerment



Sustainable Patients'
Organisations



Non-discrimination

Evolution of EPF activities 2003-2017

Strengthening Patients' voice in the EU

2003-2007

Influencing **policy developments** at EU-level



From 2008

EPF partnering in EU projects to gather evidence-based knowledge



2012 – present

Capacity Building and targeted activities for patient leaders, like EUPATI and Summer Youth Training



Evolution from 1 to 3 “pillars”

EUPATI: An unprecedented collaboration

Collaboration between: Patient organisations, academia, health NGOs, pharmaceutical industry

- ▶ IMI-EUPATI: Funded by IMI (PPP between EC and EFPIA), ran for 5 years from Feb 2012 – Jan 2017, Consortium of 30+ members led by EPF
- ▶ EUPATI as current EPF programme: continuation of Patient Expert Course, along with support for ENPs and expansion of IT and capacity building tools for patients



EUPATI

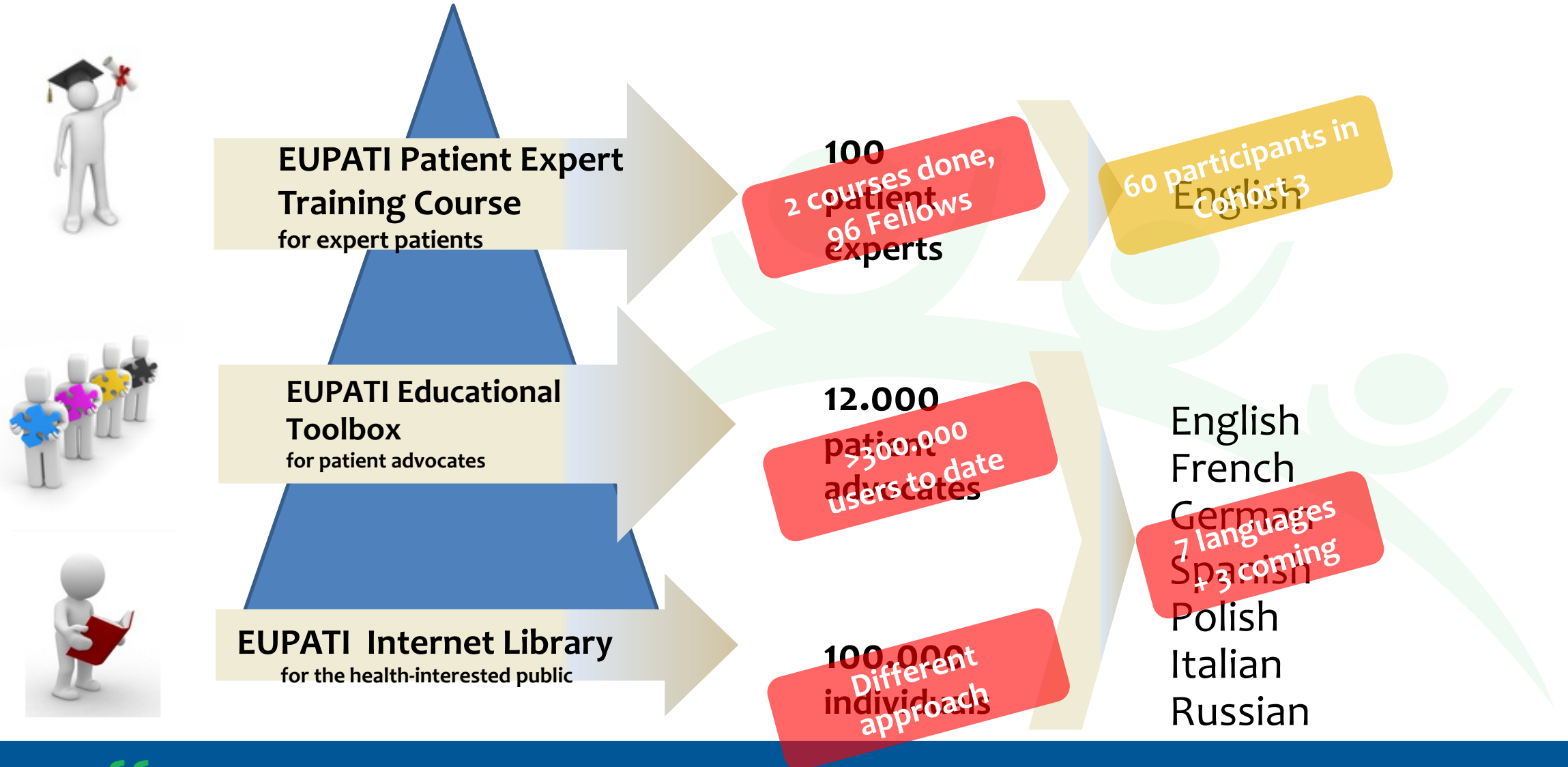
European Patients' Academy
on Therapeutic Innovation

EUPATI develops and disseminates **objective, credible, correct and up-to-date information** on medicines R&D in 7 European languages (3 more on the way!).

EUPATI helps build **competencies and capacity** among patients and public to get involved.

EUPATI facilitates patient **involvement** in R&D to support academia, industry, authorities and ethics committees.

EUPATI: Three audiences



EUPATI Fellows are influencers and leaders

Role	Before Course	EUPATI	Post Course
Member of patient organisation, not actively involved	17%	➔	2%
Active role in a patient organisation	62%	➔	71%
Leadership role in a patient organisation	62%	➔	71%
Employee of a patient organisation	25%	➔	23%
Volunteer role in a patient organisation	60%	➔	67%
Presenting at conferences, workshops etc.	63%	➔	83%
Advising a pharmaceutical company	13%	➔	44%
Advising a regulatory agency	21%	➔	42%
Advising a reimbursement agency	4%	➔	8%

Source: The EUPATI Fellow Experience Poll, December 2016, 52 respondents (83 Fellows)

ADAPT-SMART and Medicines Adaptive Pathways to Patients (MAPPs)

The current drug development paradigm is challenged by numerous factors:

- ✓ Growing patient demand for quicker access to new/ innovative drug
- ✓ Increased fragmentation of treatment populations
- ✓ Reduced healthcare budget and rising payer influence
- ✓ Pressure on pharma/investors to ensure sustainable drug provision and an R&D model

ADAPT-SMART is an Innovative Medicines Initiative (IMI) funded project that seeks to address the above by establishing a neutral platform for enabling MAPPs related activities within the consortium and with all relevant stakeholders.

Patient engagement in the life cycle of medicines- 2



Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER)

PREFER is a five year project that has received funding from the Innovative Medicines Initiative and receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.

PREFER aims to establish recommendations to support development of guidelines for industry, regulatory authorities, HTA bodies, and payers on how and when to include patient preferences on benefits and risks of medical products.

The logo for the PREFER project consists of the word 'prefer.' in a lowercase, sans-serif font. The 'pre' is in black, 'fer' is in green, and there is a period at the end. Below this, the words 'PATIENT PREFERENCES' are written in a smaller, all-caps, black, sans-serif font.

prefer.
PATIENT PREFERENCES

Upcoming work on Patient Engagement -3

EPF works with key stakeholders aiming to enable and enhance meaningful and sustainable patient engagement in the medicines lifecycle, with focus on three key decision points:

1. R&D prioritisation,
2. Design of clinical trials,
3. Early dialogue between regulators and HTA bodies.

Key actions:

- Respond to the evolution of medicine development and new opportunities and expectations for more effective engagement,
- Address ethics and added value of engagement,
- Contribute to increasing the understanding and appreciation of the added value of patient engagement by providing consensus-based recommendations and solutions on how to join up and 'mainstream' current disjointed engagement practices.

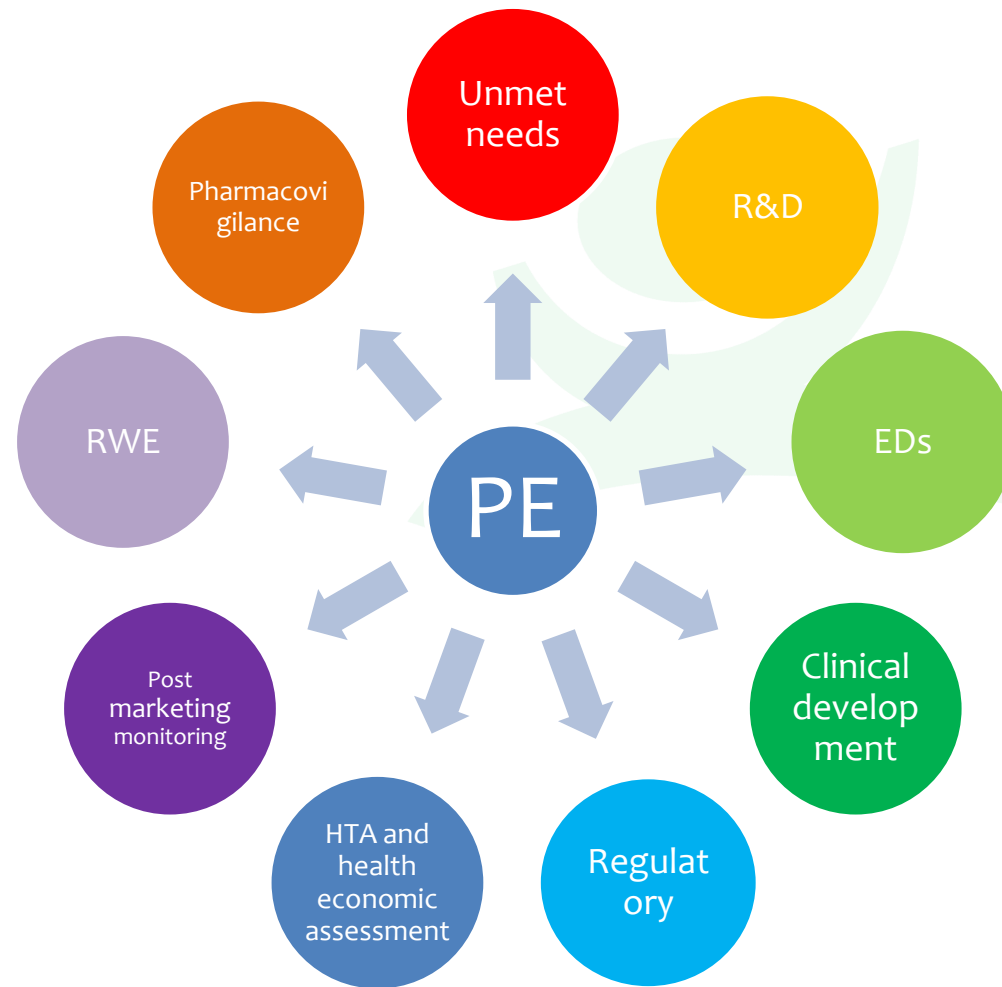


Patient Engagement in the body politic of IMI

Four key principles of Patient Engagement



Mainstreaming Patient Engagement



- Information
- Education
- Systematic approach to PE to build
 - Tools
 - Infrastructure
 - TRUST



Conclusions

Take home messages for you

- ✓ Patient engagement no longer an optional but a **strategic imperative** to enhance health research and lead to better outcomes for patients
- ✓ EPF is ready and able to collaborate with the BIOMEDICAL Alliance to help to achieve this



THANK YOU FOR YOUR ATTENTION!

Follow the campaign on Social Media!

#ACCESS2030



/europeanpatientsforum



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/eupatient



eu-patient.eu/blog

More information

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