

COULD MULTI-STAKEHOLDER PARTNERSHIP IMPROVE PATIENT ACCESS TO BETTER HEALTHCARE IN LATIN AMERICA?

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 @eupatientsforum

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



About EPF



- **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 with chronic conditions in Europe have **equal** access to **high quality, patient-centred** health and related care



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EUPATI: an innovative training model



An unprecedented collaboration: 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



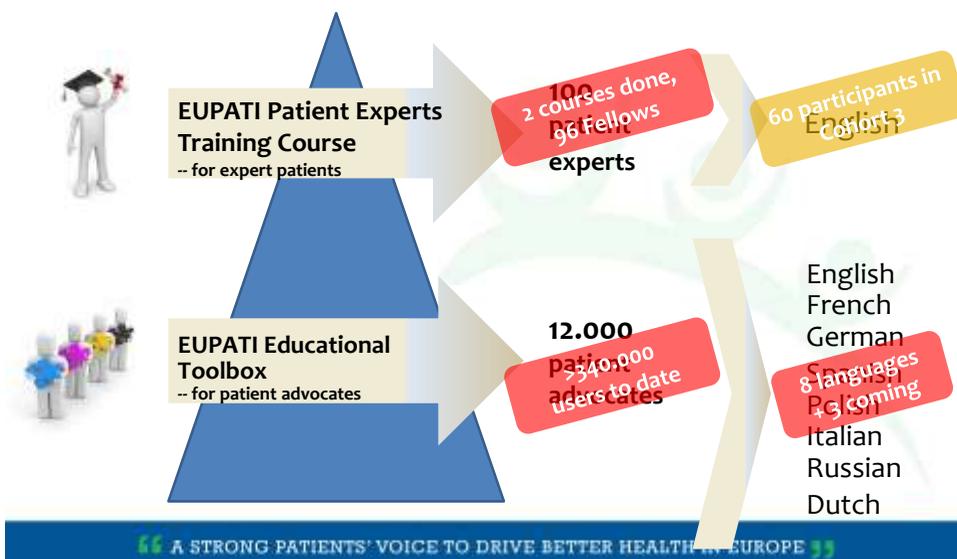
EUPATI develops and disseminates **objective, credible, correct and up-to-date information** on medicines R&D in 8 European languages (3 more on the way!)

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.

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EUPATI addresses two audiences:



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EUPATI Fellows has created influencers and leaders



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

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%



18+ EUPATI National Platforms



EUPATI National Platforms

- bring all stakeholders together in respective countries
- address educational needs in R&D
- disseminate EUPATI's training material to patient organisations



National platforms set up in AT, FR, DE, IE, IT, LU, MT, PL, ES, CH, UK, DK, SK, PT



Additional platform initiatives ongoing in BE, NO, GR, RO, SRB



EUPATI Guidances supports patient interaction in R&D and regulatory affairs



Following an extensive consultation of the community, EUPATI has developed guidance for the interaction of patient organisations:

- in industry-led R&D
- with HTA bodies
- in regulatory processes
- in ethics committees

See [EUPATI.eu](http://eupati.eu) > Resources > Guidances or <http://eupati.eu/guidances>

Webinar series – recordings available <https://www.eupati.eu/category/webinar/>

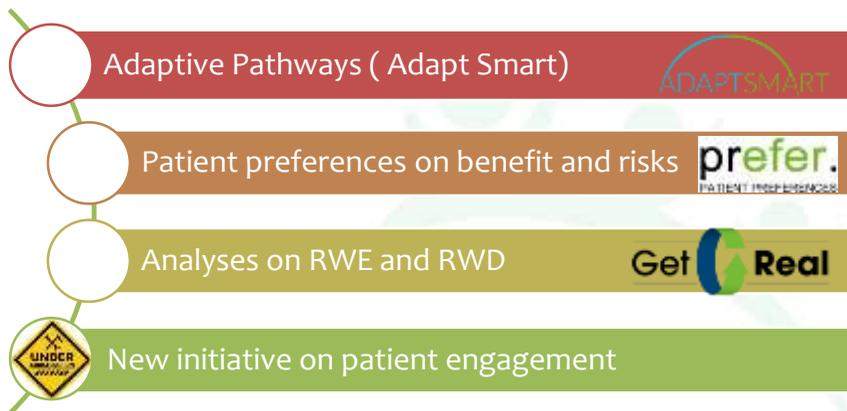


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Current and future initiatives...



...looking at patients’ perspectives



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Patient Access Partnership - PACT



- Patient Access Partnership (PACT) is a **patient-led multi-stakeholder network** of which EPF was a founding member
- Other members: policy-makers, academia, industry, public health organisations, health care professionals



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Guide. Exchange. Inspire!



PACT enables different health stakeholders to join forces to develop, drive and propose sustainable solutions to ensure equitable patients’ access to quality healthcare in the EU



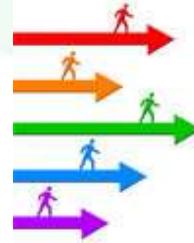
5 A's of Access: Availability, Adequacy, Accessibility, Affordability, Appropriateness

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Conclusions



- New climate of **cooperation** and **trust** between industry/patients, and among the health stakeholder community
- Essential to address **access and wider societal challenges**
- These relationships - not '*comfortable*' but dynamic, challenging, ambitious, solution-oriented
- Precious, new and potentially fragile – must be underpinned by **highest level of integrity and ethics**
- External perceptions key- vigilance and rigor

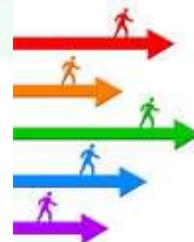


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Conclusions 2



- We need to **maximise value** of dialogue and collaboration
- **Patient Engagement in the entire innovation chain** or life cycle – a must
- This requires **patient education and training** on therapeutic innovation
- It also requires a '**full circle**' approach and **capacity building** at national level
- And an **enabling policy** environment



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THANK YOU



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