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

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Secretary General
European Patients’ Forum

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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
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.

EUPATI addresses two audiences:

- **EUPATI Patient Experts Training Course** – for expert patients
  - 100 patient experts
  - 2 courses done, 50 fellows

- **EUPATI Educational Toolbox** – for patient advocates
  - 12,000 patient advocates
  - 8 languages
  - 5 languages coming

A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE

EUPATI Patient Experts Training Course

EUPATI Educational Toolbox

A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE
EUPATI Fellows has created influencers and leaders

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

<table>
<thead>
<tr>
<th>Role</th>
<th>Before Course</th>
<th>EUPATI</th>
<th>Post Course</th>
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<tbody>
<tr>
<td>Member of patient organisation, not actively involved</td>
<td>17%</td>
<td></td>
<td>2%</td>
</tr>
<tr>
<td>Active role in a patient organisation</td>
<td>62%</td>
<td></td>
<td>71%</td>
</tr>
<tr>
<td>Leadership role in a patient organisation</td>
<td>62%</td>
<td></td>
<td>71%</td>
</tr>
<tr>
<td>Employee of a patient organisation</td>
<td>25%</td>
<td></td>
<td>23%</td>
</tr>
<tr>
<td>Active role in a patient organisation</td>
<td>62%</td>
<td></td>
<td>71%</td>
</tr>
<tr>
<td>Leadership role in a patient organisation</td>
<td>62%</td>
<td></td>
<td>71%</td>
</tr>
<tr>
<td>Volunteer role in a patient organisation</td>
<td>25%</td>
<td></td>
<td>23%</td>
</tr>
<tr>
<td>Presenting at conferences, workshops etc.</td>
<td>63%</td>
<td></td>
<td>83%</td>
</tr>
<tr>
<td>Advising a pharmaceutical company</td>
<td>13%</td>
<td></td>
<td>44%</td>
</tr>
<tr>
<td>Advising a regulatory agency</td>
<td>21%</td>
<td></td>
<td>42%</td>
</tr>
<tr>
<td>Advising a reimbursement agency</td>
<td>4%</td>
<td></td>
<td>8%</td>
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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
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 > Resources > Guidances or http://eupati.eu/guidances

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

Current and future initiatives…

...looking at patients’ perspectives

- Adaptive Pathways (Adapt Smart)
- Patient preferences on benefit and risks
- Analyses on RWE and RWD
- New initiative on patient engagement
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

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

**Guide**
- MEP Interest Group
- Position statements
- EU Presidencies input
- Engage with EU Commission

**Exchange**
- Showcase excellence (offer a collection of best practices and projects on access)

**Inspire**
- Country level stakeholder meetings – national partnerships

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

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
THANK YOU

www.eu-patient.eu

"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"