PRESENTATION OF EUROPEAN PATIENTS' FORUM
AND WAYS OF COLLABORATION

Valentina Strammiello
Programme Manager

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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
Mission and vision

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 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.

“A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE”
EUPATI: Three audiences

- **EUPATI Patient Expert Training Course**
  - for expert patients
  - 100 participant experts

- **EUPATI Educational Toolbox**
  - for patient advocates
  - 12,000 patient advocates to date

- **EUPATI Internet Library**
  - for the health-interested public
  - 100,000 individual users

*Different approach*

*60 participants in English*
## EUPATI Fellows are 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>2%</td>
<td></td>
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<tr>
<td>Active role in a patient organisation</td>
<td>62%</td>
<td></td>
<td>71%</td>
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<tr>
<td>Leadership role in a patient organisation</td>
<td>62%</td>
<td></td>
<td>71%</td>
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<tr>
<td>Employee of a patient organisation</td>
<td>25%</td>
<td></td>
<td>23%</td>
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<tr>
<td>Volunteer role in a patient organisation</td>
<td>60%</td>
<td></td>
<td>67%</td>
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<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>
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<tr>
<td>Advising a reimbursement agency</td>
<td>4%</td>
<td></td>
<td>8%</td>
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A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE
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.
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.
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

- Legitimacy
- Representativeness
- Accountability
- Transparency
Patient Engagement

Mainstreaming Patient Engagement

PE

Unmet needs

R&D

EDs

Clinical development

Regulatory

HTA and health economic assessment

Post marketing monitoring

RWE

Pharmacovigilance
Recommendations for Patient Engagement in Research

- 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

More information
www.eu-patient.eu
info@eu-patient.eu

A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE