

# ACCESS AND EQUITY EU PERSPECTIVES

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Warsaw, Poland

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

1. Background on EPF
2. EPF's role in striving for access and equity
3. Examples of our policy impact and priorities linked to access and equity
4. Creating the right 'political' environment- the EPF Campaign
5. The Access Partnership – where do we go from here ??

# Who is EPF?



## Overview

- Set up in 2003, based in Brussels since 2006
- Federation of Polish Patients joined in 2008
- Independent, non-governmental advocacy organisation – works with EU institutions to represent the collective patients' voice at EU level
- Currently 61 member organisations
  - EU-level disease-specific umbrella organisations
  - National patients' platforms
- Collectively represent 150+ million patients in EU
- Cross-cutting issues of relevance to all patients with chronic diseases

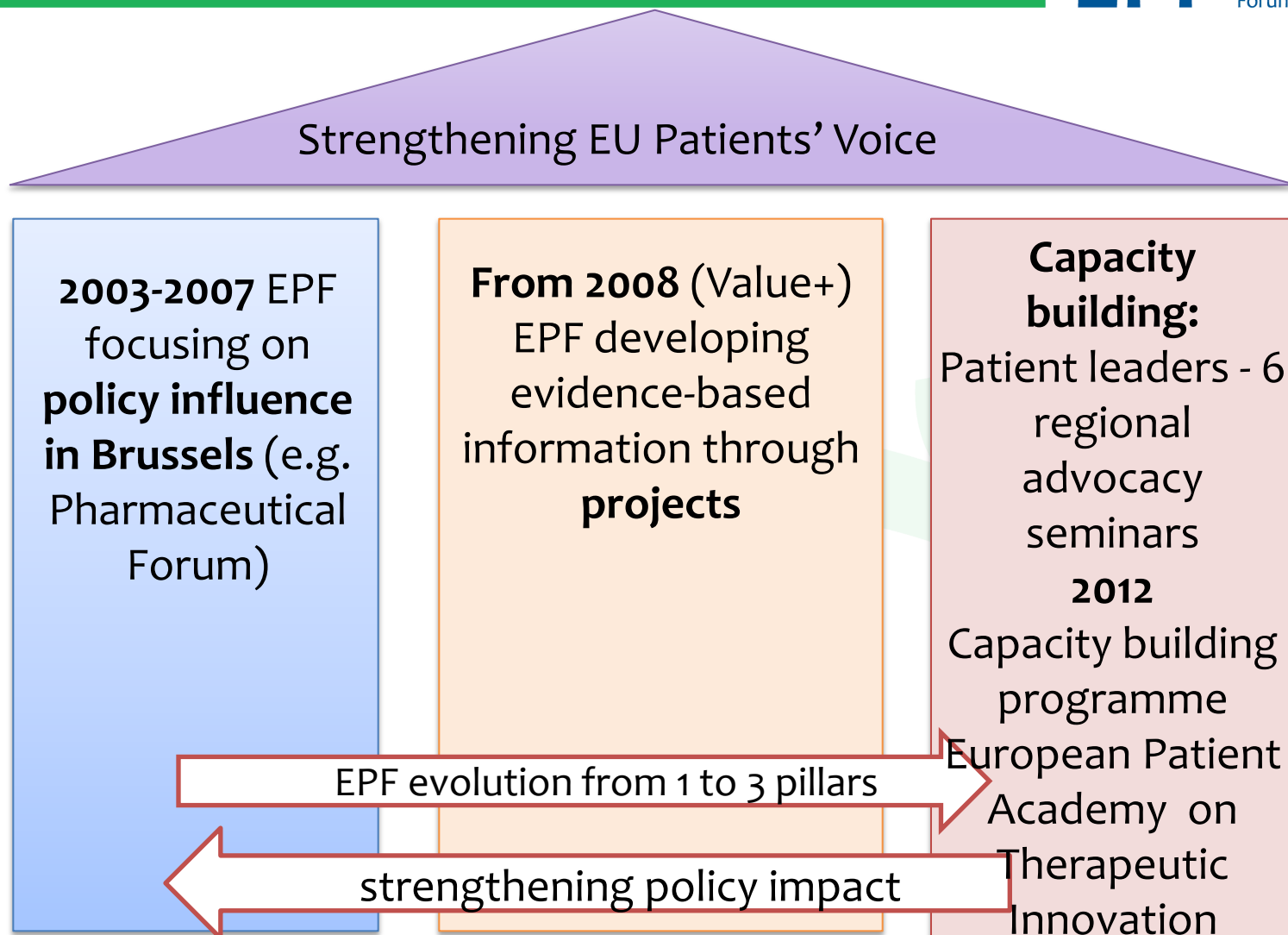
# Why EPF was set up

- Patients move from passive recipients.... to informed and engaged actors
- Patients = real partners in healthcare, together with health professionals and other stakeholders
- Growing expectations: access , equity , and also sustainability-

The need for a rights- based approach

- Growing involvement: patient-centred care, self-management...
- The patient perspective is unique – experiential knowledge is an under-used resource for improving healthcare systems

**Need for a united patients' voice on the wide range of issues affecting all patients to work effectively with EU Institutions**



# EPF works with all EU Institutions



- **Commission:** participation in working groups; **pro-active** discussion on key patients' concerns, response to consultations, upcoming legislative proposals, etc.  
Patient safety working group (DG SANCO), Access to medicines initiative (DG Enterprise), personalised medicine (DG Research)...
- **Parliament:** input into legislative process – working closely with Rapporteurs, involving **MEP champions** in supporting EPF's work
- **Council:** also through **successive EU Presidencies** on key priority areas  
Belgium: Cross-border healthcare; **Poland: Older Patients** ;  
Denmark: Empowerment: Lithuania : Sustainable HC Systems

# Cross-Border Healthcare

- Draft Directive launched by EC in June 2008 , first reading by the European Parliament in April 2009
- Controversial dossier – much inter-institutional negotiation
- EPF High Level Round Table on the eve of the Council Decision – December 2010 under Belgian EU Presidency – *deal-breakers for the patients community*

Final outcome – EPF's Verdict : **A compromise rather than a panacea** ..some concerns on equity, lack of clarity etc

However.....

# Cross-Border Healthcare

- EPF welcomes CBD – codification of **patients' rights** to access healthcare and be reimbursed
- Aspects of the Directive will help to achieve **better quality care for all patients** – cooperation on quality and safety, eHealth, HTA and rare diseases...
- Impact will only become clear in coming years– EPF will monitor and report on the experiences of patient organisations in this process.
- Crucially, we continue to work with EC and stakeholders on implementation AND very closely with our national members. Transposition deadline 25 Oct
- 4 Regional Conferences 2014– informal network of patient leaders - support and constructive critique



- Pharmacovigilance – preventing side effects of medicines and harm to patients
  - EPF advocated for *direct patient reporting* of adverse events
  - Just before EP vote, **Joint EP meeting** with European Community Pharmacists and the European Doctors' orgs
  - Highly **effective work with EP rapporteur-evidence based**
  - Draft Directive endorsed by European Parliament in September 2010 and adopted in early 2011
  - EPF working closely with our members regarding a **patient-centred transposition of the Directive**, and also with the European Medicines Agency – Member of Pharmacovigilance Regulation Advisory Committee ( PRAC)

## Key EU legislation

- **Clinical trials:** Revision of EU Clinical Trials framework in progress
- **Medical devices** : revision of legislation in progress
- In vitro diagnostic medical devices: revision of legislation in progress
- **Data Protection** Legislation – striking the right balance – privacy, confidentiality and research
- **Pharmacovigilance:** Implementation phase, EPF cooperation with EMA re: information to patients on direct reporting, patient leaflets...
- **Falsified medicines** : implementation phase (EPF toolkit forthcoming)

## EU programmes for the period 2014-2020

- Health programme (“**Health for Growth**”)
  - Health literacy, chronic diseases, patient empowerment
- Research framework programme (**Horizon 2020**)
  - Biomedical and public health research, unmet patient needs, personalised medicine...
- **Structural and Investment Funds - cohesion policy**
  - Health inequalities, investment in health at MS level, possibilities for PO to benefit...
  - EPF Toolkit

### EPF Strategic Plan 2014-2020

- Defines our strategic goals and broad policy priorities
- On-going work to contribute to above programmes – shaping annual work programmes, calls for proposals, feeding into policy

## “Soft-law” areas and non-legislative cooperation

- **Health Literacy / Information for Patients**
  - Cross-cutting priority, EPF & in cooperation with other stakeholders
- **Health Inequalities (COM) , Equity and Access**
  - Cross-cutting priority, focus on regional events & EPF campaign → EU platform
- **Patient safety & quality of care (COM, CR)**
  - EPF in JA PaSQ & EC working group
- **European Innovation Partnership on Active and Healthy Ageing**
  - WGs on Adherence, health literacy, **patient empowerment, integrated care** (frailty, nutrition)
- **EU chronic disease strategy, sustainable health systems**
  - EPF input into consultations & reflection process, EPF Campaign, EC tender on PE, CHRODIS-JA
- **eHealth and HTA, eHealth Stakeholder Group, EUnetHTA**

# Partnership – EPF ‘s ‘leitmotif’

## collaboration & partnerships

- EU Health Policy Forum
- EC working group on patient safety & quality of care
- EC initiative on corporate responsibility in the field of pharmaceuticals – ethics & transparency, access to medicines
- e-Health Users Stakeholders Group
- High-level group for health research (DG Research)
- EU-funded projects, joint actions, tenders – e.g. ChroDIS (chronic disease), tender on patient empowerment
- Etc .....

Platforms and partnerships with **all relevant stakeholders** – industry , public health NGOs, health professionals at EU level

Based on **ethics, transparency and respect for independence of policy positions**

# Lithuanian Declaration

- Conference on Sustainability of health systems
- Collaboration between Lithuanian Health Minister, EFPIA , EPF and the European Public Health Alliance
- Unprecedented Declaration **to ensure European health systems are people-centred, sustainable and inclusive – and that they deliver good health for all.**
  - Increase investment in health promotion and disease prevention
  - Ensure **universal access to high-quality, people-centred health services**
  - Ensure that health system reforms — are evidence-based and focus on cost-effectiveness, sustainability and good governance.

# Access Partnership

- A **bold** new approach
- **Close collaboration** with NPO ,FPP and other in identifying the **need** for **an Initiative**
- **Strong support** from EP, Commission, health professionals, insurers, some national authorities, WHO

*‘ We have tried, and tried, we cannot do this alone – we need something new, based on **solidarity, compassion and competence** of ALL the actors ‘*

- **KEY MEETING IN BRUSSELS LAST WEEK**

# Next Steps

- Define ‘ Access’ for the Partnership
- Legal entity – transparency- funding to organise the work
- Lean structure – where all stakeholders have a place, and a patient-led approach
- Action not just Talk - Priorities
  - Evidence base on access in Europe
  - Real solutions and models shared and supported
  - “Noise”



## Patients + Participation = Our Vote for a Healthier Europe

Patients' View  
matters

Engage patients  
collectively and  
pro-actively  
through Patient  
Organisations

Empowered  
patients are an  
asset to society

Adopt an EU  
strategy on  
empowerment

**Breaking down  
access barriers**

Support an EU  
initiative on  
equitable access to  
healthcare for all  
European citizens

Patient involvement  
= Healthier Europe

Develop a clear  
framework for  
patient involvement  
across the spectrum  
of health research

Ensure that patients' rights is part of the next health Commissioner's portfolio

# Moving forward on Access and Equity

## Possible role of the Polish Health Community

- Already organised and active at national level
- Ensuring the Polish perspective
  - Evidence and information from Poland
  - Proposed solutions and models that work in a Polish context
  - Applying proven ideas in a Polish context
  - Advocacy and dialogue work – strong conduit of political messages to and from Brussels
  - Mobilising political actors and allies

# OVER TO YOU

Thoughts , Reflections

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