

PATIENTS HAVE THE LAST WORD?

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EPF Secretary General

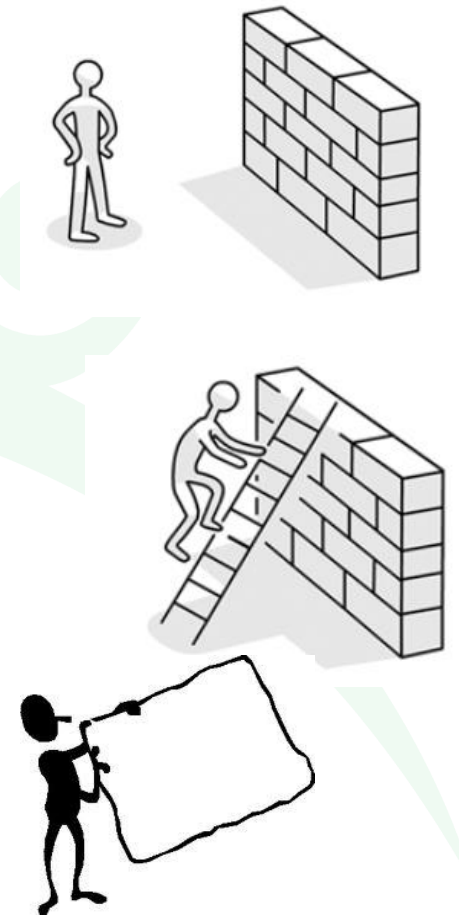
13 October 2015

PPRI conference

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

Presentation Outline

- Background on EPF and who we stand for
- The bigger picture - access - where does this really leave **patients and society** ?
- Where can we go from here ?
 - Political will and existing instruments
 - Thinking and doing things differently
 - **The intrinsic role of patients – not just the last word- but part of the conversation**
- Conclusions – **Preparedness**



About the European Patients' Forum

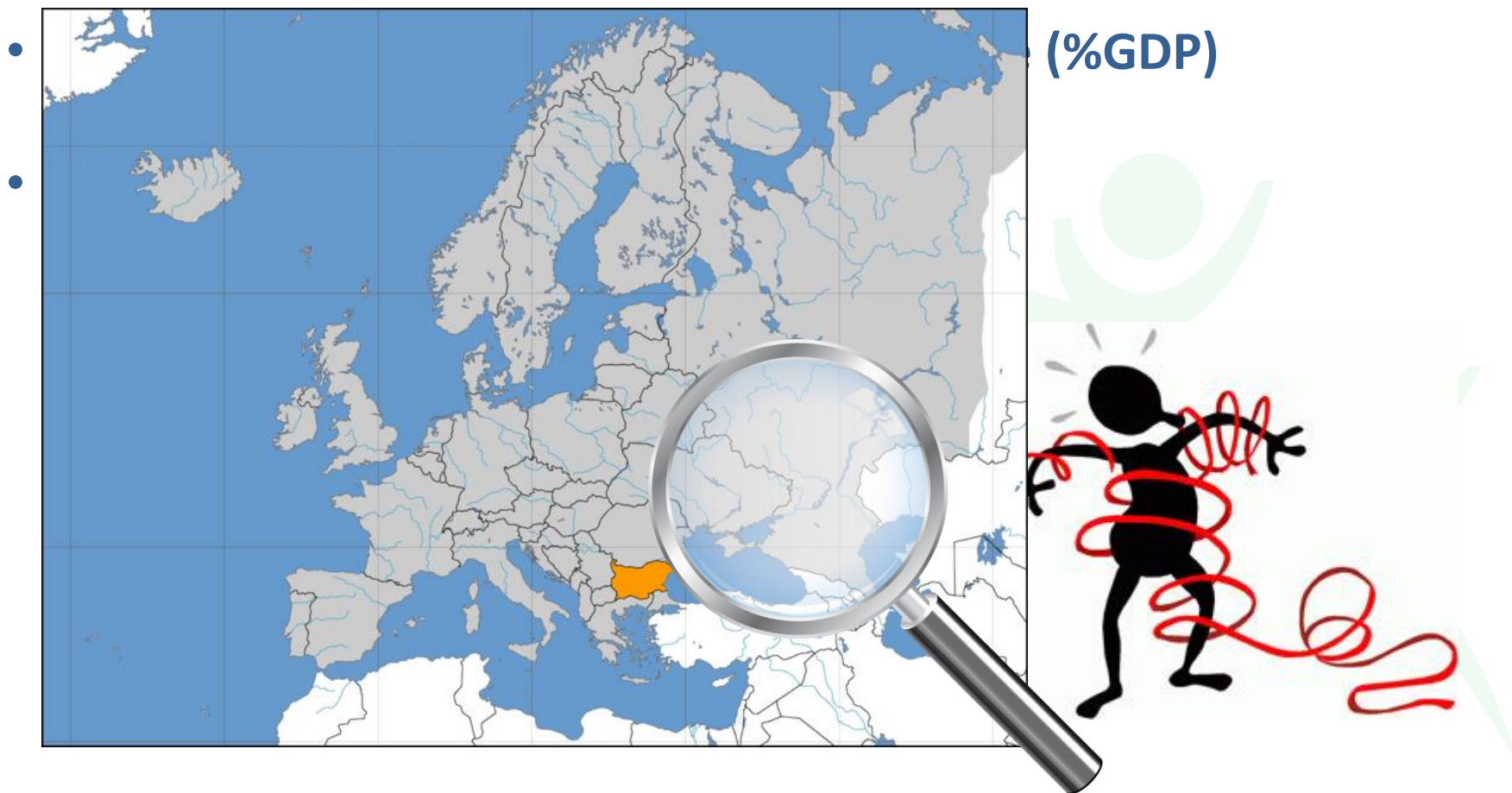


- Independent, non-governmental umbrella organisation set up in 2003
- **OUR VISION:** All patients in the EU have **equitable access** to high quality, patient-centred health and social care
- **OUR ROLE:** United patients' voice in EU health and social policy
- **OUR MEMBERS:** disease-specific EU & national coalitions – 64 member organisations



Obstacles and Bottlenecks

Bulgarian Patients' Movement speaks out on Access



Impact of crisis on equity of access

Wide disparities are not new:
pre-existing the crisis -effect of austerity measures ever visible

Demand for social support and healthcare higher

Measures impacting Access

Cuts in health budgets, in insurance coverage, increased fees and co-payments, cuts in social protection measures, freezing/decrease of HCPs salaries

Significant impact on patients on the ground!

- Feedback from our members on the realities facing their patient communities in many places in Europe

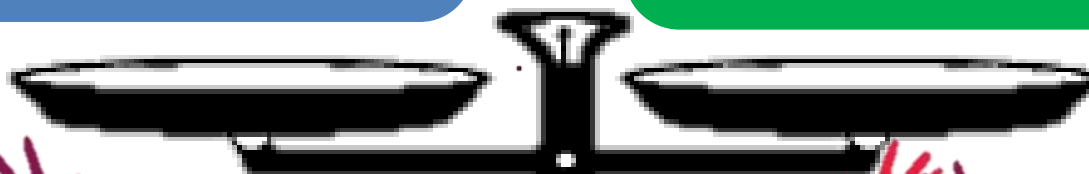
Access and equity – a major concern

Innovative treatments that add real value should be **accessible to all** patients, not only those who can pay

A **holistic approach** is needed that embraces not only therapeutic innovation, but also **systems and societal innovation**

Healthcare provision must be based on the fundamental values of **equity and solidarity**

Huge disparities across the EU and within countries in access to even basic healthcare, let alone innovative treatments



WHERE DO WE GO FROM HERE ?

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Political will and leadership



other instruments at EU level

- Access to Medicines Platform (Tajani Initiative)
- 2020 Strategy – Health Indicators
- **WHO** Health 2020, Updated **Priority Medicines** Report
- **Access to New Medicines** report
- Cross Border Healthcare Directive
- Health Systems Performance Assessment
- The Semester Process
- Structural and Investment Funds,
- HORIZON 2020 and IMI
- Health in All Policies



Can we use these better, more coherently ??

The Access Partnership

Working towards a European Partnership for equity of access to quality healthcare



New momentum: EPF Election Campaign

A multi-stakeholder partnership with patients, healthcare professionals, healthcare industries, and health experts, and key decision makers

Wide Definition of Access – a holistic approach

Objectives

- Join forces to **explore solutions to overcome inequities**, based on individual and collective expertise
- **EU political agenda- MEP Interest Group**
- **Commission's Expert Panel Report on Access**

THINKING AND DOING THINGS DIFFERENTLY



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Promoting Innovation – Key dimensions

WHO Priority Medicines Report



Public Health Based R&D



Public Private Partnerships learning from IMI

Models for Stakeholder Involvement including patients and citizens

Redesigning of the Regulatory System



Real life data and learning from practice

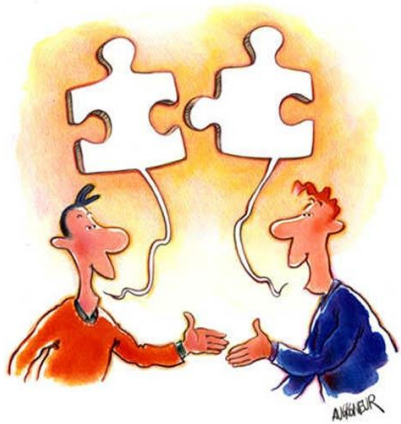


New pricing and reimbursement mechanisms for innovation



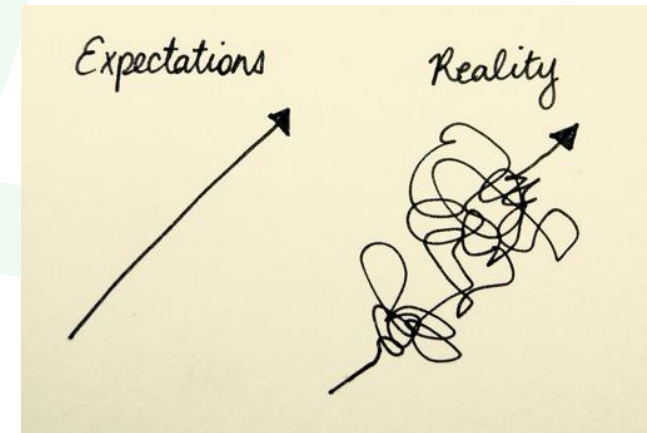
The Regulatory System

Evidence
v. Access
Trade -Off



- Early access to innovative medicines – exploring the potential of **adaptive pathways**
ADAPT SMART.. Including ‘exit strategies’
- Critical importance of **very early dialogue with all stakeholders concerned** – one of the lessons from the Pharmaceutical Forum – predictability – clarity – establishing a **price ceiling ?**
- **Benefit Risk Analysis** – understanding the perspective of the patient
 - Weighing the psychosocial factors
 - Permissiveness for patients with very serious illness
 - QoL – other options

- Medicine use in clinical practice **frequently differs** widely from the (pre-approval) clinical trial settings:
 - Patient population;
 - Adherence and concordance
 - Effects of policy and the healthcare environment
- Need to bridge bench and clinical research with **real-world practice**
- **eHealth and mHealth** – trust and acceptance
- **Electronic Health Records** – ownership and input by patients
- **IMI Big Data for Better Health Outcomes**



More efficiency in drug development

Dire need for “breakthrough” therapies – no room for inertia

A changing industry

- New socio-economic realities – post crisis
- New environments, new settings
- Traditional approaches no longer fit for purpose
- Need to ‘*innovate the innovation process*’
 - More flexibility, simplification
 - New models and pilots, using new technologies
 - Targeted populations – stratified, precision medicines

Better outcomes for less cost....patient engagement key



Innovation in pricing

- More **transparency** on pricing mechanisms and what elements go into the **final price tag**
- Exploration of **meaningful alternatives** to external reference pricing *The value of ERP as a policy tool for regulating prices warrants further **examination**..... LSE Report 2012*
- Study – enhanced cross country cooperation in the area of pharmaceutical product pricing – led by Austria
 - External Price Referencing
 - Differential Pricing (sensitivity to purchasing power of countries)
 - Parallel Trade
 - Generic Medicine Substitution
 - Joint Procurement
- Complex, political nature of most policy options – but recognition that the current models do not work



Innovation in pricing

- EPF+ EURORDIS appeal to national competent authorities- **‘table for price negotiations’** – scale up of **early dialogue pilots** involving **payers**
- STAMP Council Working Party (**Safe and Timely Access to Medicines for Patients**)
- Recent bilateral and trilateral discussions between
- countries – moving towards a **‘Coalition of the Willing’**
- Major focus on the upcoming **NL EU Presidency**
- **Collaboration, collaboration, collaboration**

Alone we can do so little, together we can do so much

Helen Keller



THE INTRINSIC ROLE OF PATIENTS



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Patients as part of the solution

Smart
spending
where
needed!

Patients as experts: to identify unmet service and therapeutic needs and point out inefficiencies and waste in systems and processes

Strong evidence base
Patient-centred care models:
cost-effective, better health
outcomes, and patient satisfaction

Patient involvement
in co-designing healthcare

Patient empowerment,
self management and self care

➔ **Health literacy**, the right skills and competencies for all players and an enabling environment

Patient-centred innovation



Innovation that is important for patients



- Priority-setting for research
- Better alignment of innovation with real needs
- Valuable innovation



Need to involve patient throughout the innovation chain

Co-design research/patient-centred clinical trials, pricing and reimbursement decisions...

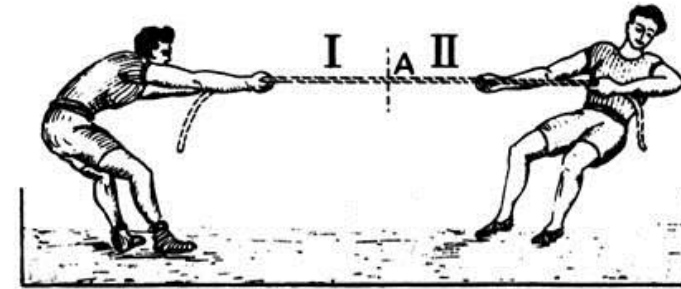


- Better quality research results
- Strengthened trust and acceptance

Challenges in HTA

Main challenges in **involving patients in HTA** are:

- Lack of an agreed methodology
- Lack of resources/capacity
- Not knowing the best stages to involve patients in HTA
- Patient evidence not being credible enough



Need for

- a **framework and methodology** for patient involvement in HTA
- education/training for patient representatives *and* the HTA community
- Key role of **EUnetHTA, HTAi Patients and Citizens Group, ISPOR, EUPATI**



EUPATI: an innovative training model



An unprecedented collaboration: Patient organisations, health professionals, regulators, health tech experts, health NGOs, pharmaceutical industry

Ethical framework and ethics panel

- ▶ Funded by IMI (PPP between EC and EFPIA)
- ▶ Launched Feb 2012
- ▶ Runs for 5 years
- ▶ Consortium of 29 members – led by EPF



Will develop and disseminate **objective, credible, correct and up-to-date information** on medicines R&D in 7 European languages

Will **build competencies & capacity** among patients & public to get involved

Will **facilitate patient involvement** in R&D to support academia, industry, authorities, HTA and ethics committees

- New IMI project to be coordinated by EURORDIS , MSD (leads) and EPF, UCB.
- Sustainable Multi-stakeholder Approach from Research to Treatment (SMART): A structured Patient Engagement Knowledge Platform (PEKP) for Improved Outcomes

Understanding how, and at which juncture, patients can be engaged and facilitating this in a coherent, ethical and effective way.

Conclusions

Patients are **engaged** and committed to be part of the change process that is needed: **preparedness** and clarity

Fair, transparent, participatory systems = **societal acceptance** of difficult choices

We need to strive for the balance between **innovation** and **solidarity**

and together, create a **trusted, enabling** environment to **move forward**



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