

**4th European Healthcare Policy Deciders
Forum, LSE
London, 17 February 2011**



europeanpatients'forum

**Effectiveness of current medicines
policies– the Patients' Perspective**

European Patients' Forum

- NGO set up in 2003, based in Brussels
- United Patients' Voice in EU health policy
- Umbrella of 47 'umbrellas' National Patients' Coalitions EU-level disease-specific POs
- Over 150 million patients with chronic conditions across EU

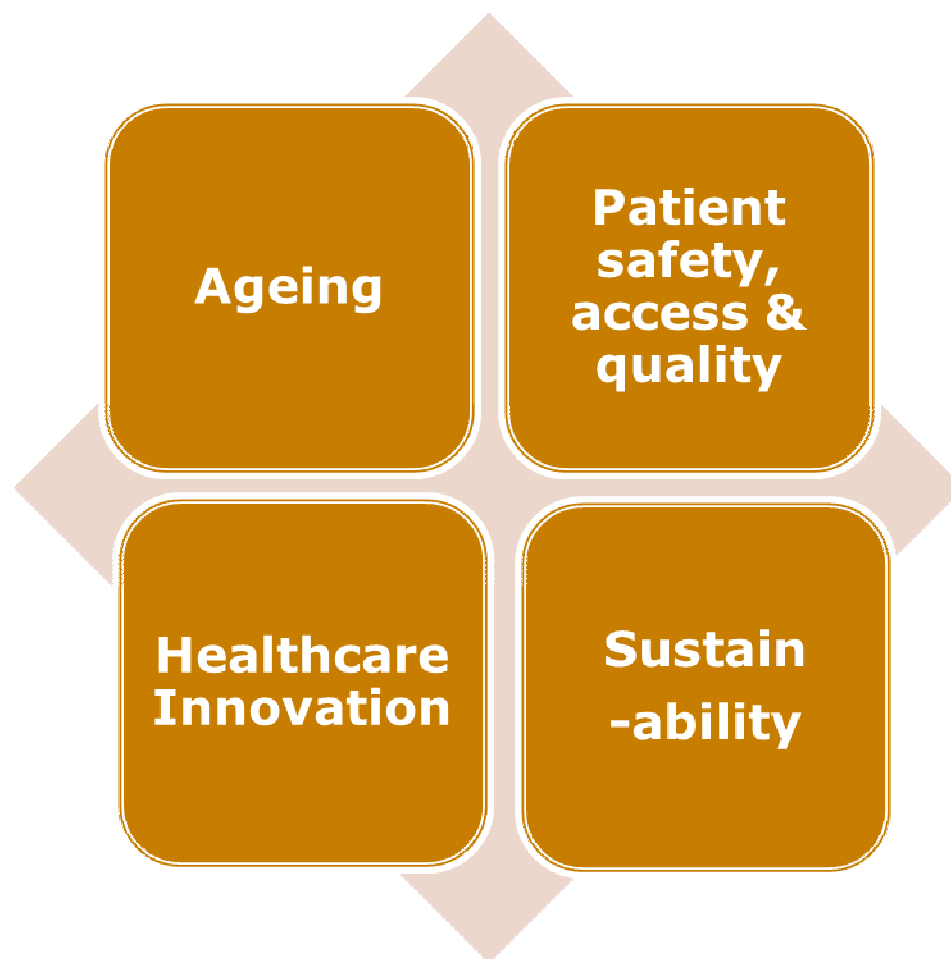


Aim of Medicine policies : Accessible, Safe and Affordable Medicines

A multifaceted approach :

- ▶ Identifying/addressing the **unmet needs** - **specific groups** of patients
- ▶ Reducing bottlenecks in effective **Pharmaceutical Innovation**
- ▶ Reducing bottlenecks in **Generics Access**
- ▶ Addressing **medicines safety** – e.g. clinical trials pharmacovigilance, anti-counterfeiting, polypharmacy, concordance
- ▶ **Evidence based, transparent appraisal** of medicines
- ▶ **Transparent pricing and reimbursement** decisions
- ▶ **Patient involvement** in Health Technology Assessment

4 major challenges EU Health systems



Patient involvement - specific role



Policy and Practice Interface in Health Care

- ▶ **Translational research**
- ▶ **Connectivity** : primary care , hospitals, home setting, regional health authorities, non-governmental organisations (patients, HP, public health), insurers, industry and ministries.
- ▶ Enhancing **the policy and practice interface** improves the delivery of health care.
- ▶ **Researching and understanding** this interface and developing enhanced mechanisms to facilitate practice- and policy-relevant research - **crucial**.

Policy & Practice – often not a blissful marriage!

- ▶ Difficulties in interpretation (language)
- ▶ Lack of clear legal framework
- ▶ Rigidity of the system and policies
- ▶ Identifying good practice and its transferability
- ▶ Conflicting interests, lack of resources
- ▶ **Lack of knowledge, awareness, capacity building and trust**
- ▶ Transferability of evidence has to fit within the individual context. “No one size fits all”
- ▶ Setting up routine monitoring and evaluation to ensure implementation and refinement

Shortcomings in current medicine policies –patients' perspective

- ▶ **Lack** of opportunities and **structures** for patients to give their direct input –their unique experience, expertise, **socio-economic , quality of life impacts**
- ▶ **Patients knowledge** is not always perceived as **appropriate evidence for healthcare decisions**
- ▶ Lack of **access to clear and accurate information, and health literacy - key for patients'** informed choices and decision-making, concordance
- ▶ Lack of **cooperation between Member States** (e.g. Pharmacovigilance; **uneven** access to medicines between and within Member States)

An example of discrepancy between policy and practice: Generics

- ▶ **Patients choice** between/ across different types of treatment (branded drugs, generics, telemedicine, psychosocial supports.....)
- ▶ Current medicine policy frameworks in European countries fail to remove existing **barriers for generic medicines**
- ▶ Access to Generics –**not solely on economic** grounds – importance of **high quality and comparative information**
- ▶ **Competitiveness wrangles** between originators and the generic industry **not helpful**

Addressing discrepancies

- ▶ EPF active in **Pharmaceutical Forum** – information, pricing & reimbursement, relative effectiveness
- ▶ **Platform on Access to Medicines in Europe**: EPF involved on Steering Group and in specific projects aiming to speed up availability of medicines after market authorisation
- ▶ EU legislation on **Pharmacovigilance, Anti-Counterfeiting, Cross-Border Healthcare**: EPF's input ensured the draft legislation addresses patients' needs, and creates opportunities for patient involvement e.g **Direct Patient Reporting**
- ▶ **Information to patients**: EPF influence on the draft legislative proposal shifted the focus on **patients' rights to access quality information on medicines**

Addressing discrepancies (2)

- ▶ **Innovation Partnership on Active and Healthy Ageing:** focus on the needs of older patients with chronic conditions, including medication safety issues
- ▶ **Review of EU Transparency Directive:** an opportunity to ensure that the governance and tools are in place to promote real advances in pricing and reimbursement
- ▶ Patient involvement in **the Innovative Medicines Initiative** – input in the Scientific Advisory Board – good examples from first Calls Third Call– Fostering Awareness among patients regarding pharmaceutical research

Better communication **between European Generic Medicines Association** and EPF – Joint meeting foreseen in 2011

Addressing discrepancies (3)

- ▶ Cooperation and **exchange of good practices** between Member States – with meaningful patient involvement – is key to an effective medicine policy that offers patients safe and affordable medicine
- ▶ The Value+ project, led by EPF developed a **model of meaningful patient involvement** in health policy, and practical resources to support patient involvement



Patient Involvement in HTA: EPF action to date

- ▶ EPF HTA Seminar – May 2010 -Toolkit and **comprehensive report**
- ▶ Collaboration with **EUnetHTA**
- ▶ Need for **patient led research** : to gather **good practice** on HTA patient involvement and **to inform effective engagement of patients in HTA**
- ▶ **3 phases** – HTA Agencies launched last autumn; Patient Organisations and Decision makers – this year
- ▶ **Survey with HTA agencies** now completed – 50 HTA agencies contacted, **40 responded**
- ▶ Of those, **18 involve patients** in HTA
- ▶ Few agencies involve patients in EU -12

The story so far.....

- ▶ When we asked the HTA agencies what are the challenges for patient involvement.....
 - “We do not have infrastructure to involve patients in the HTA process. Our system does not allow it.”
 - “Basically we don't know how – we use quite complex methodologies to evaluate new health technologies (i.e. GRADE, RAND etc.)”
 - “We have limited resources. Patient involvement only in Clinical Practice Guidelines (CPG)”
 - “At the moment no decisions on patient involvement have been made.”
 - “Actually there are not standardized methods in order to involve patients.”
 - “Currently, the direct involvement of individual patients doesn't form part of the established HTA process.”

EPF's research on patient involvement in HTA with HTA agencies- interim results

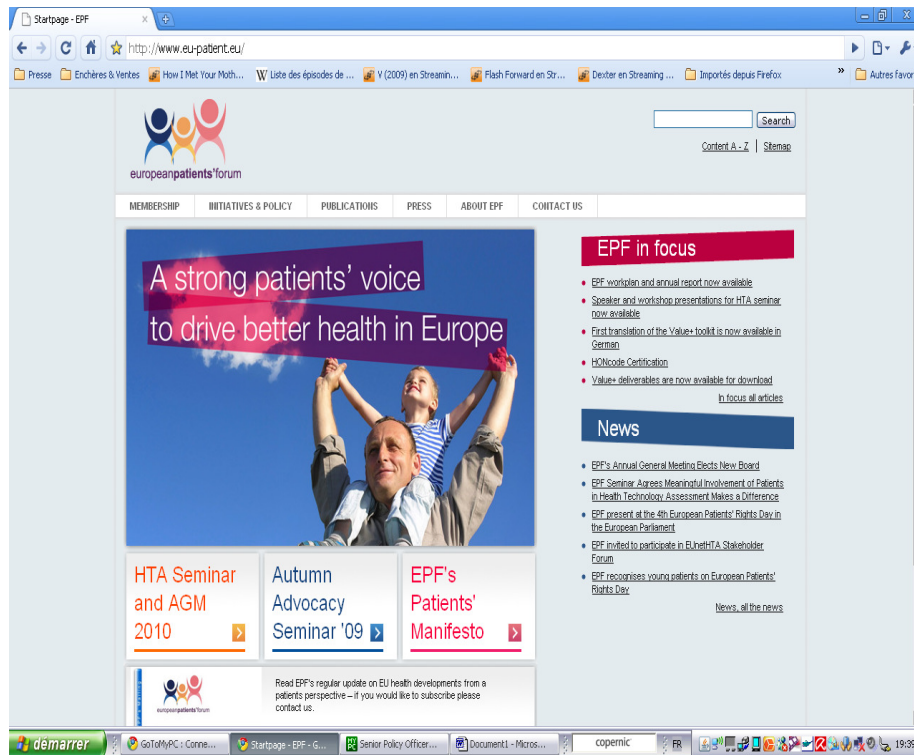
- ▶ Main challenges for patient involvement in HTA: lack of legal framework and methodologies to collect patient information; lack of knowledge about which stage of HTA to involve patients
- ▶ Patient participation in HTA is 'optional'
 - Next steps
- ▶ Review of outcomes – forthcoming EPF Annual General Meeting in April.
- ▶ Policy impetus– Directive in Patients Rights in Cross Border Healthcare
- ▶ New Joint Action on HTA

Some Reflections

- ▶ **Patients** and their organisations need to be involved - **pharmaceutical research, policy and practice interface**
- ▶ **Pharmaceutical policy** -anchored in **broader public health needs and challenges**
- ▶ **Transparency** remains absolute **bedrock** -pre and post market approval polices, pricing and reimbursement and safety/quality issues
- ▶ Greater **awareness and understanding of pharmaceutical policy** among patients and the General Public -**positive political environment to break down existing barriers**
- ▶ Need for further **concerted EU collaboration on HTA** methodologies and policies, including **patient involvement**

EPF is ready to play our part

More information?



europeanpatients'forum

www.eu-patient.eu

info@eu-patient.eu