

PATIENTS HAVE THE LAST WORD?

Robert Johnstone

European Patients' Forum (EPF)

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

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



Access and equity – a major concern

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

Patients are not only waiting, they are dying...
This is about preserving life, saving lives

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



More efficiency in drug development

Dire need for breakthrough therapies – no room for inertia

- 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
 - Targeted populations – stratified medicines

Better outcomes for less cost....



Patient-centred innovation



Innovation that is important for patients



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



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

- Innovation is often driven by pharmaceutical or technology companies and academia; the end beneficiaries are patients but they are still not involved enough in the innovation process.
- A common understanding of “valuable” innovation must be developed.
- Patient involvement should be integral in HTA processes and also in the development of ICT solutions (eHealth and mHealth).



Patients are individual experts who know precisely how a disease impacts on their daily life and how specific treatments can influence its quality

- Patients' perspective needed in order to define what is a valuable innovation
- Benefit Risk Analysis – understanding the perspective of the patient
 - ✓ Weighing the psychosocial factors
 - ✓ Permissiveness for patients with very serious illness



The importance of taking patients' perspective into account is increasingly acknowledged... **but in practice, patients are still barely involved in HTA processes.**

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

- Lack of an agreed method
- 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



Adaptive pathways seek to foster access to beneficial treatments for the right patient groups at the earliest appropriate time in a sustainable fashion.

- EPF is a partner in **ADAPT SMART**, a project funded under the **Innovative Medicines Initiative (IMI)**. Its aim is to establish a platform for the coordination of all adaptive pathways (MAPPs) related activities within the IMI.
- This project addresses a gap in our knowledge regarding how to integrate patient evidence in the Research & Development process and in regulatory and HTA decisions.

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www.eu-patient.eu

info@eu-patient.eu

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