

Patients' and consumers' meaningful involvement in HTA



Anders Olauson
EPF President

Contents

- 1. EPF main steps in HTA**
- 2. Applying the Value+ Model**
- 3. Report Survey with HTA agencies**
- 4. Report Survey with EU decision makers**
- 5. Survey with Patient Organisations**
- 6. Main recommendations**
- 7. What next**

EPF main steps on HTA (I)

- **Seminar in Brussels, May 2010**

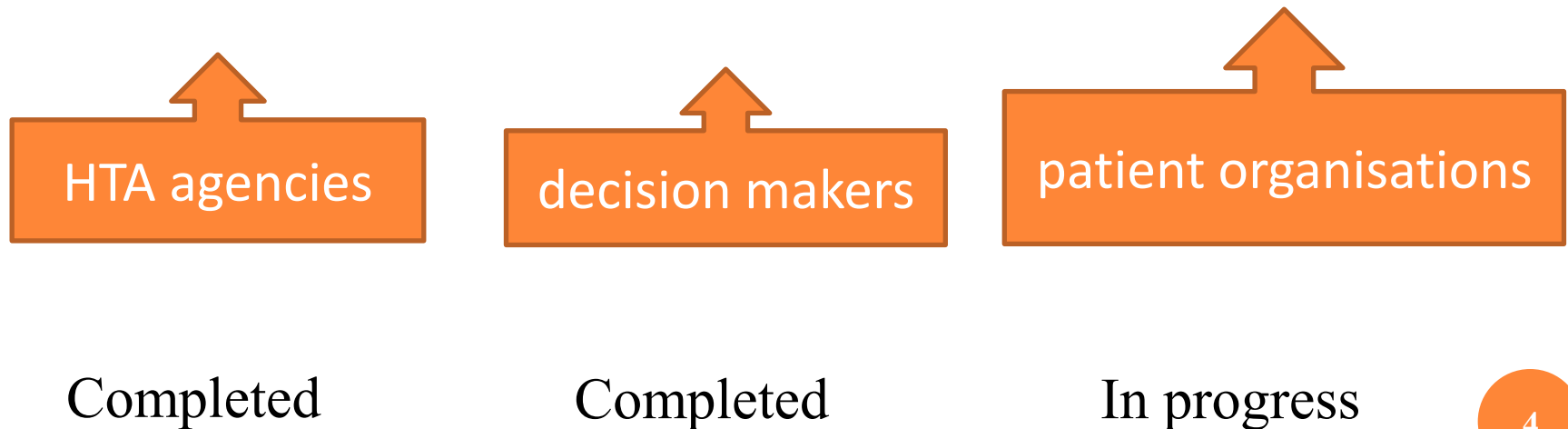
Topics:

- Patient Organisations as equal stakeholders
- Learning how get involved constructively
- Exploring EU policy developments

The Report is available on the EPF website

EPF main steps in HTA(II)

- **Three stage survey:** getting views, needs, ideas and expectations from three main stakeholder groups:



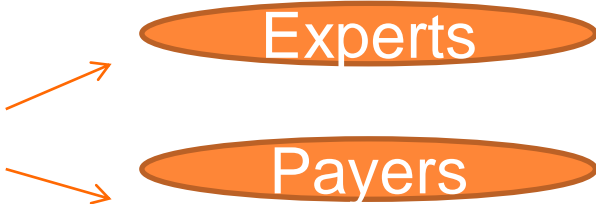
EPF main steps in HTA(III)

- **Participation in various initiatives:**
 - EUnetHTA Joint Action
 - Dialogue (e.g.EFPIA, EUCOMED, EPPOSI)
 - Projects – future Joint Action, FP7 proposals
 - IMI project - EUPATI

Patients' involvement in HTA

WHY?

Patients are concerned with the impact new health technologies have on their personal and professional lives

- Patients are 
 - Experts
 - Payers
- Patients ask for Involvement, Transparency, Accountability to trust HTA

Why cooperate ?

- Avoid duplication of work, reduce costs and improve efficiency:

➔ *No harmonisation of decisions but standard methodologies*

- More informed decision based on patients' evidence & better understanding:

➔ *Patients can tell how the technology better fits into their daily lives*

- Meaningful involvement

➔ *Involving patients from the beginning*

Main Issues and Barriers

- Difficult to access information and communication
- Lack of resources
- Lack of mutual understanding patients-HTA experts (language, lexicon)
- Cost-effectiveness approach vs Quality-of-life approach

Applying the Value+ Model

The EPF-led Project VALUE+: a model for involvement of patients and patient groups - applicable in an HTA context:

- Develop methodologies for patient involvement
- Provide training to both POs and HTA professionals
- Provide tools for dissemination of information on HTA
- Improve social, ethical, quality of life indicators
- Patients involved in decision-making bodies
- HTA agencies improve in qualitative research

Report Survey with HTA Agencies

How and when to get involved: real and ideal

- 40 out 50 respondents in 23 EU countries
- Patient involvement mainly in the final phase: dissemination
- Lack of time and methodology for meaningful involvement
- Few agencies integrate patients' perspectives in the HTA final reports

Report Survey with EU decision makers

A snapshot of patient involvement in HTA and decision making at EU level

- 45 decision makers from 13 EU countries
- Patient involvement quite low
- Unclear how patient input is weighted in final decision making
- Barrier: opportunity of appealing against final recommendations of decision-makers

Report Survey with Patient Organisations

- **Main challenges:**

HTA: patients don't know at which stage they can be involved; lack of resources; lack of interest of HTA agency

Decision-making on health technologies: clearly identified as a **lack of commitment from decision-makers**

- The **IDEAL** type and level of patient involvement in decision-making on HTA includes the possibility of appeal against the final recommendations of the decision makers and to show how patient evidence included in HTA reports was weighted by decision-makers.

Key Messages

- Improve capacity and skills building (training and partnership)
- Set clear methodologies to facilitate patient involvement
- Clear laws and regulations on decision-making for health technologies are essential
- Patient involvement in assessment and prioritisation needs to be improved and it is not simply sufficient to ask patients to give their views in public consultations
- Explore available methodologies to define good practice

What's next for EPF

- To contribute to **informing and building capacity** among patient organisations, HTA agencies and decision-makers
- To develop **appropriate resources** to complement what already exists out there



***THANK YOU FOR
YOUR ATTENTION!***

