

L'innovazione di valore: il ruolo delle associazioni a livello europeo

15 March 2022

La sfida dell'innovazione terapeutica centrata sui bisogni della persona: aspetti regolatori e accesso alle terapie.

Marco Greco, Presidente European Patients' Forum



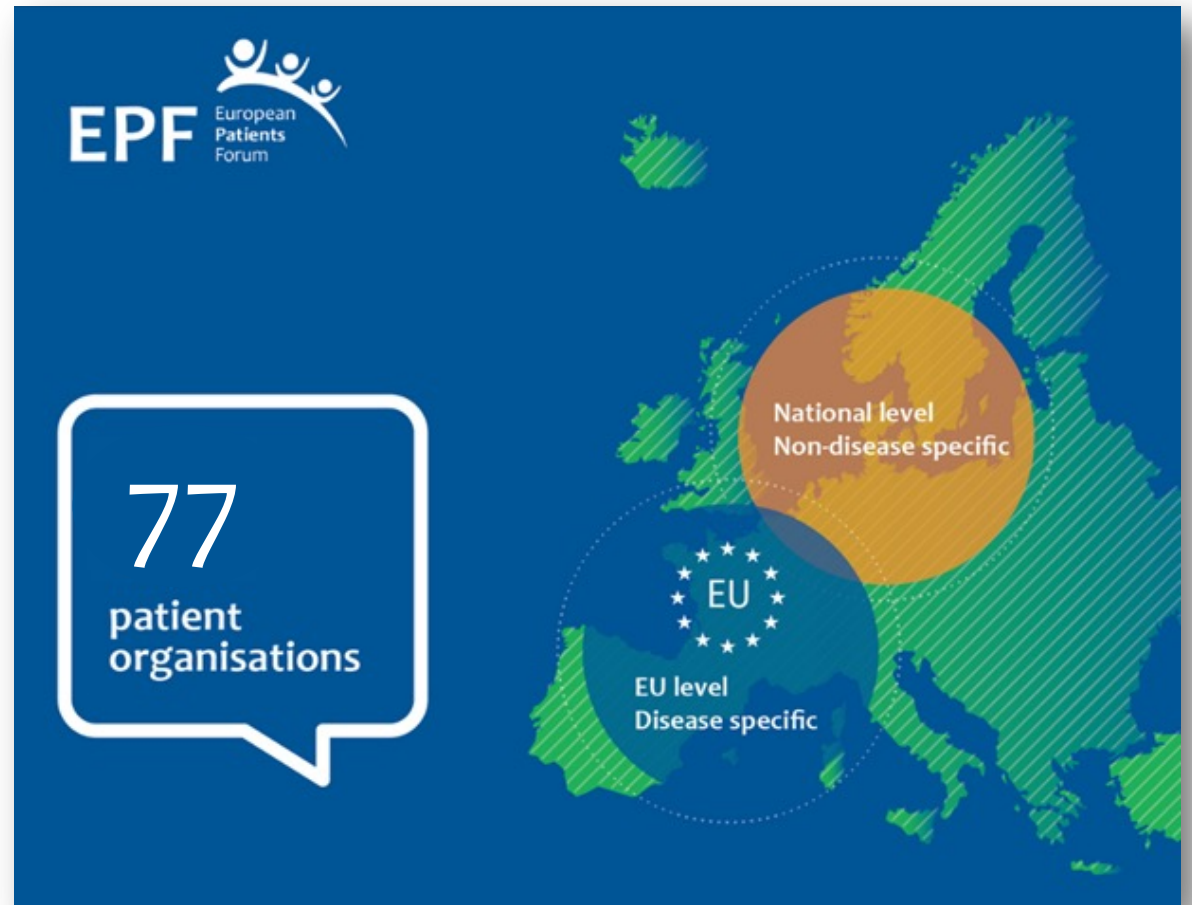
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PATIENTS'
VOICE
TO DRIVE
BETTER
HEALTH
IN EUROPE

About EPF – European Patients’ Forum



Our Vision

A Europe where patient organisations are valued partners in creating equitable, person-centered, accessible, and sustainable healthcare systems, based on patients’ unique expertise



WHAT MATTERS TO US?

Equity of access to high-quality healthcare

- ✓ Investment on technologies that are beneficial
- ✓ Disinvestment from technologies that prove not to be effective as well as reduce quality of life
- ✓ Free resources for meaningful and impactful technologies
- ✓ A new dimension: uncertainty of access!
- ✓ No post code lottery



"First we're going to run some tests to help pay off the machine."

WHAT MATTERS TO US?

Innovation that matters to patients

✓ **TIMELY** access to innovative technologies



✓ **EFFECTIVE** technologies



✓ **IMPROVED** health status and quality of life



Patient centeredness

- Integrate the Patient Perspective to better embed
 - not only individual biological information and experience of living with a diseasebut also
 - patients' needs, beliefs, behaviour, values, wishes, utilities, environment and circumstances



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On Access to innovative technologies

How and what to communicate to the larger target patient population

1. Build a clear **governance** around access management
2. Understanding of **inclusion** and **exclusion** criteria
3. Key role of patient organisations and patient advocates as **information providers**
4. Consider national and cultural variables
5. Education and **empowerment** of patients (use of trainings lay language leaflets)
6. No compromise on **safety**

Reconcile variations of PI across EU countries

- Advocacy to promote common standards
- Sharing good practices and knowledge from country level experiences on methods for Patient Involvement
- Sharing Patient Involvement experiences and impact of Patient Involvement
- Enhance national patient communities' capacity through education
 - Capacity building and educational activities



How patients and POs can be involved

- HTA at national level
- HTA at EU level
- As a patient group to collect data
- As individual patients to provide direct feedback
- As patient experts to inform methodological aspects and early dialogues



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- Patients as trustworthy partners in HTA
- Promote **trust** and the art of **diplomacy**
- Promote respect of common rules and mitigate risks of conflict of interest
- Identify a common ground of understanding and points for cooperation with other stakeholders
- Bring **evidence** and patients **collective experiential knowledge**
- **Support** and **educate** patients to get involved in HTA

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How to mitigate the risk of Conflict of Interest



These tools will support patients in order to take informed decisions before the engagement and help engaging stakeholders to understand the consequences that the act of engagement might have on patients during multi-stakeholder interactions in medicines development.

<https://imi-paradigm.eu/petoolbox/conflict-of-interest/>



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Take away messages

- Education
- Diplomacy and resilience
- Solidarity across patient communities



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