EPF Presentation - Patient Perspective on HTA

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

EPF European Patients Forum

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Who we are ? **The united voice of patients in Europe**

- **Founded in 2003**, the European Patients' Forum (EPF) is an independent non-profit, non-governmental umbrella organisation of patient organisations across Europe and across disease-areas.

- **Our 82 members** include disease-specific patient groups active at EU level and national coalitions of patients.

- **Our work**: Policy & advocacy, capacity building, communications and EU projects

- **Our mission**: To advance the interests of patients and patients' communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership.



Quick summary of EPF's work on the HTAR



The HTAR … a long-standing priority for EPF as part of our activity

- ✓ **Active contribution to the negotiations of the EU HTAR**: EPF has helped shape the EU HTAR by advocating for meaningful patient involvement at both European and national levels.
- ✓ **Patient involvement frameworks**: Currently, regarding the HTAR implementation, EPF is contributing to develop standards and best practices to ensure structured and transparent patient participation in HTA.
- ✓ **Capacity-building initiatives**: EPF is supported training programmes, workshops, and educational to strengthen patients' understanding of HTA.
- ✓ **Representation in HTA fora**: EPF is actively participating in international EU-level initiative, expert panels, and is also a member of the HTA stakeholder networks to ensure the patient perspective is integrated into discussions.

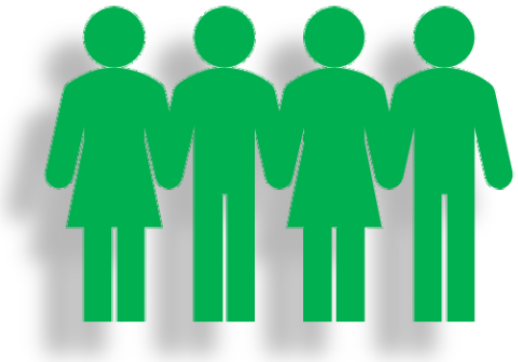


Why does it matter to patients?

1. Patients are the **ultimate users** of health technologies.

2. Decisions taken on the availability and reimbursement of technologies have **an impact on access to quality healthcare.**

3. HTA can prevent the funding of **technologies with limited or no added value.**



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Patient involvement in HTA

Nothing about us without us !!!!!

- **Democratisation** of the decision-making process.
- Contribution to robust evidence **to support informed decision-making.**
- Experiential knowledge of **living with a chronic or lifelong condition.**

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EU HTAR for patients ... in a nutshell

- Patients **can participate** in JCAs and JSCs.
- Patient organisations are invited by the European Commission **to nominate individuals to serve as patient experts.**
- Once nominated, patients must complete a Declaration of Interest (DOI) **to assess any potential conflicts of interest that could affect their participation.**
- If selected, **patients are asked to contribute their lived experience**, including information on their disease journey, treatment history, unmet needs, and expectations for new therapies.
- This input helps ensure that the assessment of the health technology **reflects the perspectives and priorities of patients who are directly affected by the condition.**

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HTA

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Our view on the process so far …

- Patient organisations **recognise the efforts made to involve patients and carers in the assessment process**, including opportunities to contribute to the assessment scope and review draft reports

BUT IMPROVEMENTS ARE NEEDED …

- Involving patients and carers **from the earliest stages** of assessment planning and scoping;
- **Strengthening the role of patient organisations** in representing broader community perspectives;
- **Increasing transparency on how patient input** influences assessments and final conclusions;
- Improving the generation and use of evidence on outcomes that matter most to patients, **such as quality of life and treatment burden**; and
- Ensuring that JCA findings are communicated **in clear, accessible language and made available in all official EU languages**.



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And what about HTA and patient involvement at the national level ?

ANSWERS CAN BE FOUND IN THE FIRST EPF BAROMETER ON PATIENT INVOLVEMENT (published in June 2026)

The Barometer tracks the level of involvement of patient organizations in Europe in various areas of activity (including HTA) !

It also identifies best practices !

And examines the barriers and challenges that patient organisations are facing !

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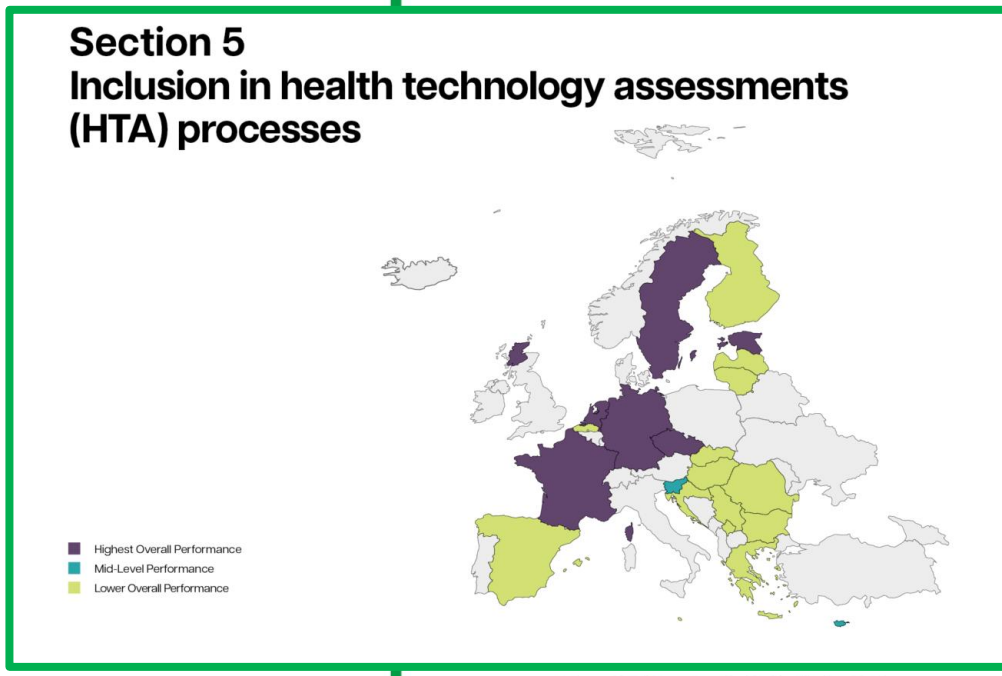
EPF Barometer

And what about HTA and patient involvement at the national level ?

- While the implementation of the EU HTA Regulation is still in its initial phase and foresees the involvement of patient experts throughout the process, with further progress still needed, **the situation at the national level remains uneven**.

- Awareness of HTA procedures among patient organisations, as well as their actual participation, varies considerably across countries. **Although a few Member States have established stronger foundations for patient involvement, this remains the exception rather than the norm.**

- However, some national HTA systems in transition offer a window of opportunity for stronger patient participation … **These reforms, taking place in the broader context of the implementation of the EU HTA Regulation, can represent a valuable opportunity to integrate best practices from other Member States.**



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The link with the HTAR

And what about HTA and patient involvement at the national level ?

Case study

Cyprus, a country reflecting the situation in Europe, where patient organisations' involvement in HTAs is still in its early (promising) stages

In Cyprus, the Ministry of Health and the Pharmaceutical Services [government body within the Ministry of Health] are still developing the national HTA framework, including finalising the specific processes and provisions related to patient involvement. This new development has been in particular driven by the adoption of the EU HTA Regulation and the broader push for greater harmonisation at EU level.

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THANK YOU FOR YOUR ATTENTION



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