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THREE REPORTS TO SHAPE PATIENT INVOLVEMENT IN HTA

Health Technology Assessment (HTA) is a multidisciplinary tool that ideally should involve patients' perspectives; however, in reality there is still a long way to go in achieving meaningful patient involvement in HTA. EPF has just released three consecutive reports to help patients gaining a foothold in the HTA process. A comprehensive report will follow.



Three reports, three different stakeholder groups: **HTA agencies (first stage)**, **HTA appraisal committees/policy makers (second stage)** and **patient organisations (third stage)**. Through surveys and discussions, EPF collected the views, needs, ideas and expectations of these stakeholders in order to shape the role and scope of patient involvement in HTA processes.

From the first phase of the research, it emerges that very few **HTA agencies** currently involve and integrate patients' perspectives in their work. Apart from financial resource constraints, the main challenges are perceived to be the lack of capacity, time and good methodologies to involve patients. Above all, the question of the exact stage of HTA where patient engagement is needed or is most useful is still being debated but the respondents have said that ideally they would like to improve patient involvement in the first phases of HTA.

The research made on **decision makers** clearly illustrates the need for EPF to continue advocating for patient involvement in HTA. Despite the fact that involving patients is in general considered beneficial, the bodies or institutions in charge of decision making on health technologies admit not to always do it. And often when there is some form of patient involvement this is not done in a systematic, comprehensive and meaningful way.

The third phase confirmed that **patient organisations** are poorly or not involved in both aspects of HTA and decision-making. They are not enough involved in stages like scoping and prioritisation where decisions are made about which treatments to assess and what aspects. Without this early involvement there is a serious risk that treatments made available do not respond to patients' needs and that crucial needs remain unmet.

Liuska Sanna, EPF programme manager, concludes: *"As most of the respondents we clearly think that patient organisations can have a high impact in helping HTA agencies and decision-makers to better understand technologies' impact in real life context and also the quality of life aspects' and thus, leading to decisions that meet patients' needs".*

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A final comprehensive report, expected to be produced soon, will integrate the results of all phases and therefore provide a complete overview of the three stakeholder groups. The aim is to provide an as accurate as possible state of the art picture of patient involvement in HTA in Europe.

The reports of the three stages of the research are available on [EPF website](#).

The **European Patients' Forum (EPF)** was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement. EPF currently represents 55 member organisations - which are chronic disease specific patient organisations working at European level, and national coalitions of patients organisations. EPF reflects the voice of an estimated 150 million patients affected by various diseases throughout Europe.

EPF's vision for the future is high quality, patient-centred, equitable healthcare throughout the European Union.

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