

FOR IMMEDIATE RELEASE

## EPF WELCOMES EUROPEAN PARLIAMENT REPORT – NOW PATIENTS WANT TO SEE ACTION

**BRUSSELS, 2 March 2017 – The own-initiative report of the European Parliament incorporates key recommendations from the patient community regarding a broad range of measures to address access, and the central role played by patients in determining the value of treatments.**

The European Patients' Forum welcomes the own-initiative report of the European Parliament, adopted today in plenary session, as a valuable contribution to the debate on access to medicines.

We welcome the strong **call on Member States and the Commission to develop measures to ensure affordable patient access to medicines and benefit to society whilst avoiding unacceptable impacts to healthcare budgets.** We recall that in our paper on the pricing and value of innovative medicines, published in 2016, EPF called for a framework for “fair access” – one which addresses the affordability challenge but also maximises patient access and the societal benefit derived from therapies. This framework needs to be broad, including exploration of different measures to control prices, such as horizon scanning, early dialogue, innovative pricing models, mechanisms for systematic collection of real-world data, and coordinating joint procurements where appropriate. (1)

The report also answers the patient community's call for **closer EU collaboration in Health Technology Assessment and making the results actionable at national level.** Currently, diverging decisions by national bodies are a source of confusion and frustration for patients. Patients want to see the end of needless duplication and delays due to fragmentation; and they want to know on what criteria decisions are taken.

A meaningful definition of “value” and “added therapeutic value” is only possible with the involvement of patients. We therefore strongly endorse the recommendation to the Commission and Member States to identify or develop appropriate frameworks and methodologies to **meaningfully incorporate patient evidence at all stages of the medicines R&D cycle** – from early dialogue and regulatory approval to HTA, relative effectiveness assessment and pricing and reimbursement decision-making – with the involvement of patients and their representative organisations.

*“Taking a starting point initiatives such as the HTAi patient and citizens' sub-group and existing best practices from HTA and regulatory agencies across the world, we believe these*

*structures can be developed and implemented across the EU,”* said Nicola Bedlington, EPF Secretary-General.

The current situation is unacceptable from a patient perspective and unsustainable for health systems. EPF now asks the Commission to **show leadership and to set up the High Level Strategic Dialogue** mentioned in the report, with a balanced representation of all relevant stakeholders, including patient organisations, to reflect and establish concrete and comprehensive strategies to achieve a framework for fair and equitable access in the short, medium and long term.

Tackling the issue requires a thorough understanding of the causes of unequal access, which may be different in different Member States. The European Commission should put in place a solid methodology for **monitoring patients’ access to medicines and healthcare**, with indicators that reflect the lived reality of patients and families that can shed light to access barriers. It should further monitor and sanction unethical business practices, such as ever-greening, unacceptable price increases for repurposed products, and delays to delay generics entry.

*“At the end of the day, ensuring universal access to medicines for all those who need them is a political choice. We urge decision-makers both at European and national levels to take positive action to show it puts patients’ needs first, and that the European Union’s core values of equity and solidarity are not mere rhetoric but a real political priority,”* said Ms Bedlington.

EPF and our member patient organisations are ready to contribute to taking these actions forward. **EPF has just launched a year-long campaign, “Universal Health Coverage for All”**, which calls for more EU co-operation on access in the framework of the UN Sustainable Development Goal on health and will reinforce the active role of the patient community across the Union in advocating for change. (2)

#### **References:**

- (1) “Core Principles from the Patients’ Perspective on the Value and Pricing of Innovative Medicines” ([European Patients’ Forum, June 2016](#))
- (2) [www.eu-patient.eu/campaign/access-to-healthcare](http://www.eu-patient.eu/campaign/access-to-healthcare)

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The European Patients' Forum (EPF) is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe. Our 67 members are national coalitions of patients and disease-specific groups at EU level.

EPF's vision is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

EPF's mission is to ensure that the patient community drives policies that bring positive change for patients, empowering them to be equal citizens in the EU.

EPF's also supports patient communities through educational seminars, policy initiatives and projects. We coordinate best practice exchanges and provide capacity-building to strengthen patient organisations' advocacy capacity.

[www.eu-patient.eu](http://www.eu-patient.eu)

**Contact Person :**

Mr. Laurent Louette

Communications Officer

[laurent.louette@eu-patient.eu](mailto:laurent.louette@eu-patient.eu)

+32 (0)2 280 23 35



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