

FOR IMMEDIATE RELEASE

NEW EPF REPORT CALLS FOR THE RECOGNITION OF THE ADDED VALUE OF PATIENT ORGANISATIONS.

BRUSSELS, 14 November 2017 – For the 1st time, the European Patient’s Forum (EPF) publishes a report on the added-value of patient organisations in Europe, highlighting their importance as legitimate partners and calling all stakeholders to acknowledge their contribution to the common good.

The report gives an overview of the role of patient organisations in Europe, with the objective to emphasise the contribution of patient organisations in representing and voicing the situation of a specific population that would otherwise not be represented.

The 40-page report describes the main activities and roles of patient organisations in four different areas: (1) policy; (2) capacity-building and education; (3) peer support; and (4) research & development (health and pharmaceutical), and uses data collected in a survey conducted by EPF amongst its members.

The document formulates key recommendations for patient organisations but also for other important stakeholders who work with patients: decision-makers (both at the European and the national level); researchers; and academia/ professional educators, to help them understand the potential benefits of enhanced cooperation with patient groups in their daily work.

In a nutshell, **the report recommends all stakeholders to:**

- acknowledge that patient representatives must be treated **on a par** with other types of experts and should be compensated for their expertise and time accordingly;
- recognise that accepting some **funding** from industry does not automatically imply a conflict of interest;
- challenge the tradition of **tokenistic involvement** of patient groups in the development of health policies and the design of health and other essential services;
- invest in **meaningful patient involvement** and work with patient organisations to develop and implement good practices, including on compensation, facilitation/ practical support, and capacity-building on both sides.

Speaking on behalf of EPF, Nicola Bedlington, Secretary General, commented:

“Patient organisations have demonstrated their added-value as a trustworthy partner. Our report proposes avenues for a better collaboration between all stakeholders to strengthen the common good and improve the life of patients in Europe”.

The report is available at http://www.eu-patient.eu/globalassets/library/publications/epf_added_value_report_final.pdf.

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EPF currently represents 74 members, which are national coalitions of patient' organisations and disease-specific patient organisations working at European level. EPF reflects the voice of an estimated 150 million patients affected by various chronic diseases throughout Europe.

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.

The EPF strategic goals focus on areas such as health literacy, healthcare design and delivery, patient involvement, patient empowerment, sustainable patients' organisations and non-discrimination.

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