

The European Patients' Forum and Funding Partners

A Framework for Cooperation

APPROVED BY THE EPF BOARD

Update 2018

BACKGROUND

This brief document outlines how EPF works with partners who provide unrestricted sustainable funding to contribute to EPF's strategic plan and annual work programme, and why this is important.

This partnership is not solely financial but focuses on open and transparent dialogue and the exchange of independent views and positions between EPF and its partners. This framework document also describes how this is undertaken in practice, without compromising either party.

INTRODUCING EPF

The European Patients' Forum (EPF) is an umbrella organisation which was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of an emerging EU patients' movement. Through its 75 member organisations (which are chronic disease specific patient organisations operating at European level, and national coalitions of patient organisations), EPF reflects patients' and their carers' and families' unique and direct experience and expertise in healthcare.

VISION

EPF's vision for the future is that all patients with chronic in Europe have access to high quality, patient-centred health and related care.

MISSION

EPF's mission is to be the collective influential patient voice in European health and related policies and a driving force to advance patient empowerment and equitable patient access to care in Europe.

THE NEED FOR A DIVERSIFIED PORTFOLIO OF FUNDING

When EPF was in its formative years, our AGM made a decision in 2005, two years after the foundation of the organisation to seek unrestricted support from industry to establish the secretariat, recruit a staff team, set up an office, build capacity and knowledge among the EPF membership through advocacy seminars, and develop policy influence through an annual conference. This pump-priming was crucial in ensuring the organisation could grow.

- to reflect effectively the views of our diverse members and advance the interests of 150 million patients with chronic diseases and their families across the European Union;
- to be pro-active in and respond effectively to an enlarging EU health agenda;
- to enlarge and support a growing membership;
- to build strong relationships with other health stakeholders.

Three years on, following successful efforts to diversify the funding base, notably by obtaining substantial funding from the European Commission through an operating grant and involvement in key projects, industry funding is now one important component of a broader portfolio of funding. This diversified support from both the public and private arena will continue to be crucial, providing baseline resources to enable EPF to continue to build and sustain momentum as the unique EU umbrella organisation of patients' organisations. To this effect, EPF endeavours to engage with a wide range of eligible partners.

CORE PRINCIPLES IN RELATION TO FUNDING

In order to make funding partnerships work and to ensure the integrity of both the funder and EPF is maintained it is important to demonstrate to other stakeholders that our relationships are absolutely scrupulous. The following key principles underpin our acceptance of funding.

INDEPENDENCE

EPF will maintain at all times an independent and strong patients' voice on behalf of its member organisations. The potential effect of EPF positions on funders (either private or public) will never be a relevant factor in EPF's policy development and decision-making process.

MUTUAL RESPECT

EPF and our sustainable funding partners undertake to cooperate on a basis of mutual respect as fellow stakeholders in healthcare systems and delivery.

UNRESTRICTED

Funding received by EPF for our Operational Programme to fulfil our vision and mission should be unrestricted in nature, to contribute to the operational work programme to fulfil our strategic goals and objectives. When EPF received the Operating Grant from the European Commission (2013-2017) , the ceiling for that funding was 20% of the total budget for operations.

It is expected that between 2018 – 2022 EPF will be required to relax the private funding ceiling to compensate for the loss of the Operating Grant.

EPF will lead and/ or cooperate in specific projects funded by the European Commission and other public/ private sources, where these are in accordance with our policy and criteria for getting involved in projects and occasionally these may also require co-financing in the form of unrestricted funding from sustainable funding partners.

EPF's Operational Programme is part of its annual work plan and includes its day to day activities. External funded projects and initiatives, events such as a Congress and Capacity Building are considered separate work areas.

SUSTAINABLE

The loss of the Operating Grant has meant that EPF has been required to be more agile with its funding strategy. In the short-term the European Patients' Forum has to rely on its private partner funding to be sustainable. However, EPF plans to grow its European Commission project portfolio to ensure its balance of public/ private sources evolves to a 50:50 funding ratio by 2022.

The funding support provided by private partners should be supported by a written agreement, and with a long-term commitment in mind, reflecting EPF's strategic goals.

The funding support may also be allocated to building reasonable reserves for EPF to ensure the sustainability of the organisation.

NO SINGLE COMPANY/ GOVERNMENTAL SOURCE

EPF events and projects should be supported with an unrestricted grant by more than one company, and/ or government; or the European Commission or a Federation composed of

several companies. The content of such events should be developed by an independent EPF working group of members established for the purpose.

TRANSPARENCY

A written agreement between the funder and EPF outlines the nature and amount of the funding and the period covered.

The funding sources will be acknowledged with thanks in relevant publications linked to an event.

The amount of funding received, and the sources are included in the EPF Annual Report and published separately on the EPF website within one month of the Annual Audited Accounts being approved by the Annual General Meeting of the following year.

EPF is listed on the EU Commission Transparency Register, which is updated annually.

FUNDING FROM THE PHARMACEUTICAL INDUSTRY

EPF will apply the EFPIA Code of Good Practice on working with patients' organisations in relation to any funding received from the pharmaceutical industry whilst also building in the above principles adopted, and other relevant European codes.

EPF will ensure that the funding received from one single company for the delivery of its Operational Programme will be proportional to the overall budget and **will not exceed 5%** thereof, reflecting our commitment to diversity of funding sources.

DIALOGUE WITH SUSTAINABLE PARTNERS

In order to ensure and promote open and transparent dialogue to share respective views and perspectives on issues of common interest and that advance our mission, EPF undertakes to:

- Distribute the EPF monthly newsletter with the patients' perspective on EU health developments, and policy documents/publications to funding partners, as fellow stakeholders in EU health debates;
- Hold an Annual Funders' Event, the Industry Round Table, to which partners share information with EPF board and staff members on EPF's progress during the preceding year and core challenges, and our direction for the following year;
- Publish and share an Impact Report/ Summary report as a supplement to the Industry Round Table event;
- Engage in dialogue on current EU health policy issues;

- Be present at specific company/ federation/ governmental/ Commission events on request to outline EPF 's position on one of its policy priority areas;
- Invite funding partners to EPF Congresses, and to selected
- other events;