

European Patients' Forum Declaration

As agreed upon by the Council of the European Patients' Forum, 31 January 2003



EPF should be seen as a response to recent calls by the European Commission and other EU institutions to have one pan-European patient body to address and be consulted on issues concerning the interests of patients in the European healthcare debate.

It also addresses the fact that, in this debate, non-patient groups and consumer organisations are currently expressing views supposedly on behalf of European patients in general, but without prior consultation with patients.

It is now time for patients in Europe to have a voice, which is truly representative of their views.

1. Main Objectives:

- To facilitate an open and inclusive Patients Forum enabling ALL pan-European patients' groups to exchange information and points of view in the area of EU Health Policy and all other EU initiatives of interest or concern to patients.
- To share health experiences and examples of good practice in order to strengthen the role and voice of European patients' organisations.
- To offer the views of patients, as external stakeholder in the European healthcare debate, by means of a broad, truly representative and independent patient group resource. To offer the views of patients, as external stakeholders in the European healthcare debate, by means of a broad, truly representative and independent patient group resource.
- To provide a forum for patients' organisations to develop common positions on European health policy issues and to lobby on behalf of those organisations, giving them a central position in the provision of healthcare in Europe.
- To become the natural first point of reference for the European Commission and other European institutions when seeking the opinions of patients and/or when seeking to consult patient groups.
- To co-operate in the formation and execution of joint projects aimed at improving health outcomes and the quality of life of European patients.

2. Working principles

The European Patients Forum may engage in any activities to further the objectives detailed above. The Forum welcomes ALL pan-European patients' groups – both disease-specific as well as umbrella groups – working for patients and/or carers of people unable to represent themselves.

The Forum aims to be as transparent, democratic and inclusive as possible. In furtherance of those aims, full membership of the European Patients Forum shall require the following criteria to be observed:

Legitimacy:

EPF member organisations should have statutes registered in one of the member states of the European Union. If the applicant organisation is not registered in an EU Member State, additional information needs to be provided demonstrating EU focus and activities.

As regards representation:

EPF member organisations should have members of their own in more than half of the member states of the European Union.

Democracy:

EPF member organisations should have governing bodies which are elected by their members, who shall be patients, their careers, or their elected representatives.

Accountability and Consultation:

Statements and opinions of EPF member organisations should reflect the views and opinions of their memberships and consultation procedures with those memberships should be put in place.

Transparency:

European patients' organisations should disclose their sources of funding and generally make available their audited financial accounts.

3. Membership

Pan-European Patients' Groups which fulfil the above criteria may become full members of the European Patients' Forum. All other interested organisations operating on a European level, which do not fulfil the above criteria may apply to become associate members of the Forum.

EPF respects the individuality of its member organisations. It recognises and appreciates the variety of viewpoints among its members. T

he EPF shall aim at developing consensus positions. Where such positions cannot be achieved the Forum encourages the submissions of a majority and a minority point of view. The

adoption of a position does not preclude member organisations from adopting alternative positions and defending their views in an individual capacity.