

European Federation of Allergy and Airways
Diseases Patients' Associations

Code of Ethics and Conduct



Contents

Preface	3
General Principles (A – N)	4
Mission and Activities	7
Annex 1 – Governance & Responsibilities of Board Members	9
Annex 2 – Human Resources	9
Annex 3 – Public Trust & Public Advocacy	9
Annex 4 – Financial & Legal Compliance	10
Annex 5 – Fundraising	10
Annex 6 – Partnerships, collaboration and networking	11

EFA Code Ethics and Conduct

Preface

In recent months, we have witnessed a dramatic increase of the importance of the need for greater transparency of governmental and non governmental institutions in order to impact ethically on policies and advance initiatives that once were exclusive to governments and for-profit organisations. The European Federation of Allergy and Airways Diseases Patients' Associations ensures that its Conduct and that of the Board adhere to the highest standards of probity due diligence and ever increasing transparency in its decisions and overall operations.

However, with increased importance comes increased responsibility. EFA has the responsibility to be transparent, honest, accountable and ethical, to give out accurate information and not to manipulate situations for the personal benefit of the Board and its staff. It has a duty to go beyond the boundaries of race, religion, ethnicity, culture, politics and disability. EFA has the obligation to respect each person's human rights and conduct its business at all times in an ethical manner.

EFA will not align itself with, or stand in opposition to any particular political or health organisation for purely selfish or short sighted means, nor to become controlled by a governmental or corporate body.

In short EFA has the responsibility to dedicate itself for the sake of allergy, asthma and chronic obstructive pulmonary diseases (COPD) patient organisation members and patients and do so according to the highest code of ethical conduct in all transactions of business, including advocacy and providing independent information.

The **EFA Code of Ethics and Conduct** is a set of fundamental principles, operational principles, and standards to guide the actions and management of the organisation. These standards are based on the following selected references:

European Transparency Initiative:

[Green Paper European Transparency Initiative](#), May 2006

[General principles and minimum standards for consultation of interested parties by the Commission](#)

[World Association of Non-governmental Organisations "Codes of Ethics"](#)

[European Patients' Forum \(EPF\) Code of Ethics and Conduct 2005](#)

International Alliance of Patient Organisations (IAPO):

[Patient Involvement in Health Policy, Systems and Delivery](#)

[Policy Statement on Health Literacy](#)

[United Nations Universal Declaration](#) of Human Rights

[United Nations Standard Rules for Equalization of Opportunities for Persons with Disabilities](#)

1. General Principles

EFA operates on the basis of fundamental principles of ethics and code of conduct. It aims to share the same fundamental assumptions or beliefs that will make its governance and operation successful. The following is an articulation of the more important of these shared EFA **Central Values**.

Patient Perspective

Involvement

Sharing Knowledge and Experience

Partnership and Cooperation

Visibility and Presence

Health Equity in Europe

a. **Responsibility, Service and Public Mindedness**

Responsibly to maintain itself to conduct its activities for the sake of patients with Allergies, Asthma and COPD.

Ensuring all income will not be misused for selfish purpose and all assets are treated with the utmost seriousness, as a public trust.

EFA recognises that the organisation, the Board, staff activities and conduct impact on the perceptions of other organisations and that they are corporately responsible for ensuring the public's trust at all times.

EFA will exhibit a responsible, caring attitude towards progress in health and healthy environment in all of its activities.

b. **Cooperation beyond Boundaries**

Significant progress towards improved health and general well being can be fostered through inter-religious, inter-cultural and inter-racial working, and across artificial boundaries of politics and ethnicity that tend to separate people and their institutions. EFA will maintain ethical, cooperative relationships with other like organisations, and partner where possible and appropriate for the sake of the greater public good.

EFA will be willing to work beyond boundaries of politics, religion, culture, race and ethnicity, within the limits of organising documents and with organisations, institutions and individuals that share common values and objectives for improving health and the environment in Europe.

c. **Human Rights and Dignity**

As the United Nations Universal Declaration of Human Rights states, "All human beings are born free and equal dignity and rights are endowed with reason and conscience, and should act towards one another in the spirit of brotherhood." and "the family is the fundamental natural group unit of society promoting human rights and human dignity". ([UN Universal Declaration](#): Article: 16).

EFA will not violate and will aim to protect the persons' fundamental rights, with which each person is endowed.

EFA will recognise that all people are born free and equal in dignity.

EFA will be sensitive to the moral values, religion, custom, tradition, and culture of the community it serves.

EFA respects the integrity of Patients, Carers and Families.

d. **Freedom of Thought, Conscience and Religion**

EFA Code Ethics and Conduct

“Everyone has the right of freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.” (UN Universal Declaration, Article 18.)

EFA respects patients and patient organisations and all individuals and organisations that it partners with or ‘comes across in respecting’ freedom of thought, conscience and religion.

e. Equal participation in society, Access to healthy environment, care and non-discrimination due health

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.” ([UN Universal Declaration: Article: 25](#)). ‘Intensified efforts are needed to achieve the full and equal enjoyment of human rights and participation in society by persons with disabilities. They, and their parents, guardians, advocates and organizations, must be active partners with States in the planning and implementation of all measures affecting their civil, political, economic, social and cultural rights’ ([United Nations Standard Rules for Equalization of Opportunities for Persons with Disabilities](#)). ‘Under the principle of the human right to health, everyone has the right to health indoor air’. ([WHO Right to Healthy Indoor Air](#). Report on WHO Meeting: Principle 1)

EFA respects the individual right to equal opportunities and full participation in society and in making decisions about decisions affecting them despite disability or disease, right to healthy environment and access to care and security in case of sickness or disability.

f. Transparency and Accountability

EFA strives for openness and honesty both internally and externally. EFA will be accountable for its actions and decisions to the patient community it represents, but also to the people it serves, members, partner organisations, staff and the public at large.

EFA will be transparent in all its dealings with government and industry institutions, the public, sponsors, partners, members and other interested parties. EFA will provide basic financial information, governance structures, activities, listings of officers, sponsors, members, partnerships and will make proactive efforts to inform the public about its work and the origin of all its resources.

In all activities were EFA, the board, staff or members have been paid in the form of honorariums, expenses, sponsorship, for undertaking work on behalf of an organisation this will be registered for public scrutiny or/and governed by transparent guidelines?.

In all advocacy and other activities of EFA, the board, staff or member will declare who is financing the action and whose interests are being met.

g. Independence and Autonomy

EFA Code Ethics and Conduct

EFA will not be controlled by any governmental or intergovernmental body, or by corporate interests. EFA will ensure that it does not align itself rigidly with, or stand in opposition to any particular governmental body, political party or corporate entity. But, will focus on its principles and policy development for patients with allergy, asthma or COPD.

h. Truthfulness and Legality

EFA will provide accurate information regarding itself and its work, or regarding individual, organisation, project or legislation it opposes or is discussing.

EFA will not engage in any activities that are unlawful in the community it serves, and is strongly opposed to and not to be a willing partner in corruption, bribery and other financial improprieties or illegalities.

EFA has a policy for its membership, partners and employees to confidentially bring evidence to the governing body of misconduct of anyone associated with the organisation.

EFA will meet all of the legal obligations in their country. Such obligations may include laws of incorporation, fundraising legislation, equal employment opportunity principles, health and safety standards, privacy rules, trademark and copyright legislation, and so forth.

EFA will take prompt action whenever a wrongdoing is discovered amongst its staff, governing body, members, contractors, and partners.

i. Integrity

Fundamental to the very character of EFA is that it is a not-for-profit, nongovernmental, organised, independent, self-governing and voluntary organisation. While these criteria appear self evident as the national law codifies and requires such standards, they remain basic to the integrity and conduct of the organisation.

j. Non profit

EFA is organised and operated as a not-for-profit organisation. Any surplus that is generated through its operations will be utilised solely to help the organisation to fulfil its mission and objectives. No part of its net earnings will inure the benefit of Board Members, member organisations, or employees, or any other private persons. EFA will however provide reasonable compensation for services provided, as appropriate to the organisation and this will be disclosed at all times.

EFA will not be operated for the primary purpose of carrying on a trade or business, unrelated to its mission and stated objectives.

The EFA Board will prevent the distributing of profits or assets for the benefit of individuals.

k. Nongovernmental and Independently Organised

EFA will maintain independence and not be aligned, affiliated or controlled rigidly by any political or commercial party, although it may share a common political, commercial or legislative cause within the limits of its mission, stated objectives and legal structure. By itself, being non-governmental or commercial does not prohibit EFA from political activity **only** engaging in doing so within the limits of its mission and stated objectives.

EFA, its Board and staff will not act as an instrument of Government or commercial entities, but act independently of both and be seen and perceived to do so.

EFA Code Ethics and Conduct

EFA does not seek to implement governmental or commercial entities policies, unless it coincides with the stated mission and the organisations independent policy.

l. Organised

EFA has a document outlining its statutes, by-laws which clearly define the mission, objectives, governance structure, membership rights and obligations, rules and procedures.

EFA is a registered legal entity and is recognised by any Government within the EU.

EFA will be transparent in forms of meetings of which a number will be convened in public.

m. Independent and Self Governing

EFA will be independent at all times. Its policies, vision, and activities will not be determined by any profit organisation, sponsor, and government institution, political party or other NGO.

EFA will govern itself autonomously, according to the governance structure and will control its own activities.

n. Voluntary

The voluntary values and principles of EFA will be a reflection of the private initiatives formed by voluntary actions of individuals who have chosen to pursue an interest and concern for the primary force of working for better European health and environments for patients with Allergy, Asthma and COPD.

Those who are part of the EFA Board serve as board members in a voluntary capacity, for no pay.

Volunteers will make meaningful contributions in order to meet the EFA mission and objectives.

2. Mission and Activities

EFA will strive to achieve its 'reason to be', clearly articulating its mission. The mission will serve as the foundation and be the frame of reference for all its activities and be the basis of organisational planning.

a. Mission

EFA will formally and succinctly state its mission in a written statement which clearly states why it exists and what it is endeavouring to achieve which has the approval by its governing body.

- Each board member will fully understand and support the mission and objectives.
- The mission will be publicly available, being accessible to all board members, staff, member organisations, sponsors, partners, beneficiaries, and the public in general.
- EFA will evaluate its mission every two years, to determine if it is still relevant.

Among the issues evaluated:

EFA Code Ethics and Conduct

- Whether the mission has been accomplished, either by EFA or another entity, (and thus whether there is a need for the organisation as it is currently constituted to continue to exist).
- Whether the mission should be revised to reflect societal changes in health and environmental issues.
- Whether there is a desire for EFA to address new needs which require amendments to/or a new mission statement.

b. Activities

All activities will be consistent with the articulated mission, which acts as the foundation and blueprint for EFA strategic and operational planning to ensure objectives are met.

- The objectives and work programmes will ensure EFA works efficiently and effectively toward achieving its mission.
- EFA will regularly seek feedback on its activities from stakeholders, members and beneficiaries of its activities.
- The activities of EFA will periodically be critically examined to determine their relevance to its mission, efficiency, effectiveness, and the value of continuing its work programme, with the aim of revising or establishing new ones as needs dictate.

Among issues to evaluate:

- Whether the activities are consistent with the current mission of EFA or whether they need to be revised or discontinued in light of changes to the mission.
- The efficiency and effectiveness of its work in achieving its stated objectives.
- The outcomes of programme beneficiaries.
- The cost of work relevant to its outcomes.
- Whether new services should be offered.

Evaluations will be open and honest and include input from stakeholders.

EFA will carry out its activities with a high degree of professionalism with a central value of serving patients being paramount.

Related Publications and Selected References

EFA Statutes <http://www.efanet.org/about/documents/EFAStatutes2005.doc>

EFA Internal Rules:

<http://www.efanet.org/about/documents/Annex3EFAInternalRules.doc>

EFA Mission and Objectives and Central Values:

<http://www.efanet.org/about/mission.html>

**European Federation of Allergy and Airways Diseases Patients Organisations
EFA Code of Ethics and Conduct**

**Annex 1
GOVERNANCE & RESPONSIBILITIES OF BOARD MEMBERS**

EFA is committed to enforcing an effective governance structure, a strong and committed governing body which is inspired to achieve its mission and objectives. The plans for governance will reflect the core values, mission, and cultural standards of the organisation.

Enshrined will be democratic principles for the election of governing body and entrusted to its officers the ultimate responsibility for all activities and resource utilisation for the organisation. This includes establishing the direction of EFA beginning with the mission statement, and ensuring that the mission statement is current, appropriate, and relevant as times change.

The governing body also determines the activities and monitors their compliance with the mission. The governing body exercises responsibility for obtaining and securing appropriately the employment of human and financial resources, to carry out the organisations mission and sustain the organisation in an ethically sound manner, whilst overseeing fiducially and legal requirements.

**European Federation of Allergy and Airways Diseases Patients Organisations
EFA Code of Ethics and Conduct**

**Annex 2
HUMAN RESOURCES**

EFA is committed to ensure it has capable and responsible staff to bring about success of the organisation. As the organisation develops it is committed to develop effective human resource policies. This will address all staff including volunteers who play a major role in management and programme implementation. EFA will seek suitably qualified staff and offer them proper training and supervision, treat them fairly and with equity, providing them with opportunities for growth and development.

EFA will expect employees and volunteers to maintain the highest standards of professional conduct, use information and resources responsibly, and avoid conflicts of interest.

**European Federation of Allergy and Airways Diseases Patients Organisations
EFA Code of Ethics and Conduct**

**Annex 3
PUBLIC TRUST AND PUBLIC ADVOCACY**

EFA Code Ethics and Conduct

EFA regards its good reputation as sacred to the principles of the organisation. It regards the trust of others as the lifeblood of the organisation – trust by the members, public, media, governmental and commercial organisations, sponsors, other similar organisations, employees and volunteers are crucial for it to succeed. To ensure trust EFA will exhibit genuine public accountability and transparency, it will therefore be honest in the information that it makes available to the public and those it works with to ensure better health for patients in Europe.

European Federation of Allergy and Airways Diseases Patients Organisations EFA Code of Ethics and Conduct

Annex 4 FINANCIAL AND LEGAL COMPLIANCE

EFA will have proper financial and legal procedures and safeguards in place, not only to stay within the law, but also to measure the organisations health and to assure sponsors, members, and the general public that investments in EFA are safe and being correctly used. For this to reason EFA board will employ sound and robust financial procedures, maintaining transparent financial records of donations, fundraising activities, where they come from and how the resources have been utilised.

The organisation will produce financial statements for public scrutiny and have its financial records reviewed periodically by a qualified, independent, outside examiner who can certify that the organisation is operating legally and according generally accepted accounting practices within European and national laws.

European Federation of Allergy and Airways Diseases Patients Organisations EFA Code of Ethics and Conduct

Annex 5 FUNDRAISING

As the European Federation of Allergy and Airways Diseases Patients' Associations intends to fund their operations, activities and programmes by seeking voluntary financial support from mainly outside the organisation, through foundations, corporations, individual sponsors, membership and governmental agencies, this financial support is not simply a movement of money from these sources to itself. It is a two or three way process, involving value for the obligations of sponsors and partners. EFA as a recipient of such funding will ensure that it is open and transparent, accountable to its sponsors and partners, it will ensure that the use of funds are used responsibly and according to the original, agreed intent with the sponsor, partners and members and within the scope of the overall mission and objectives of the organisation.

At all times EFA will ensure that the EFA framework documents for membership and working with industry and governmental agencies are used to establish transparency and insight in to activities undertaken and resources utilised for core funding.

European Federation of Allergy and Airways Diseases Patients Organisations EFA Code of Ethics and Conduct

Annex 6
PARTNERSHIPS, COLLABORATION AND NETWORKING

EFA will seek cooperation with other organisations in the health and environmental sectors or when appropriate other civil society organisations, governmental and intergovernmental organisations, and for-profit organisations that will be beneficial in advancing the EFA's mission and related objectives. Such collaboration for the common good will reduce duplication of effort and eliminate the use of finite resources for competitive purposes rather than serving constituencies. Collaboration will allow pairing of diverse strengths and resources, promoting a greater effectiveness in tackling priorities. However EFA will only enter into such relationships if they are beneficial and consistent with the mission of the organisation.