



Acute Leukemia Advocates Network

Code of Conduct and Ethical Framework

Introduction

The Acute Leukemia Advocates Network (ALAN) is an independent global network of patient organisations, dedicated to changing outcomes of patients with acute leukemias by strengthening patient advocacy in that area. It aims to build capacity in the members of the network to deliver tailored services to acute leukemia patients and carers on the national level, while joining forces between organisations on the policy and research level across countries.

ALAN acts as a network of organisations and does not target patients and carers directly.

Activities of ALAN

- Developing patient information and specific support for patients with acute leukemias and their carers in all countries
- Strengthening patient organisations by sharing best practices and providing toolkits in patient advocacy
- Creating awareness about acute leukemias and how to better support leukemia patients
- Advocating for better treatment, care & access to healthcare services
- Improving education for healthcare professionals serving leukemia patients
- Collaborating with other initiatives and stakeholders with similar goals

ALAN is involved and working with various stakeholders such as (but not limited to):

- not-for-profit and patient organisations
- pharmaceutical industry
- healthcare professionals
- academia
- medical societies
- third parties supporting ALAN with its projects
- other committees

Information is available on www.acuteleuk.org

Scope

The Code of Conduct outlines the working culture and spirit of “assumed good intent” within ALAN, while the Ethical Framework outlines the ethical ground rules.

This document applies to all those involved in carrying out work for ALAN. For the purpose of this document, they will be referred throughout as “contributors”. This includes staff, committee members, contractors and members.

Code of Conduct

1. Rational

The Code of Conduct is based on the conviction that

- A strong collaboration between contributors of a multi-stakeholder project is likely to generate benefits for all parties involved.
- The integrity, credibility, and independence of all involved contributors, as well as the constraints and obligations under which all contributors operate, should be respected at all times.
- A collaboration in which the integrity and credibility of all parties concerned are upheld should be underpinned by core principles and values.
- The perspective of patients and patient advocates is unique in nature and therefore should be valued as specialist knowledge and complementary to knowledge of other experts, academia and industry.

2. Principles

○ Mutual Respect

All contributors act in accordance with the principles of mutual respect. This implies that all contributors' competences, capabilities, working culture and environment shall be taken into account, understood and respected.

○ Trust

All contributors work together in a spirit of mutual trust and assumed good intent. This is underpinned by openness and clarity of communication, and genuinely shared efforts and responsibilities to contribute to common goals, although the methodology and rationale may differ across the collaboration.

○ Reliability and Responsibility

All contributors commit to adhere to the code of conduct and to rely on each other in order to achieve the ALAN goals,

In the event of conflict or dispute between contributors, it will be addressed by the ALAN Steering Committee, which attempts to resolve it collectively, reflecting the spirit and principles of this code of conduct.

○ Transparency

All contributors agree to open, honest, fair and transparent communication between each other and to public at large. This includes:

- Clarity about each other's roles and responsibilities;
- Being open about the constraints under which each party is operating;
- Any activity jointly undertaken with a patient organization should operate within their constitution, articles and codes of practice;
- Contributors' independence should not be compromised or perceived as being compromised because of collaboration with other contributors;
- No contributor should seek to gain competitive advantage/or use confidential information from the work performed for its own gain.

○ Accountability

All contributors are accountable for their work and should agree on the ways in which they will report back to their members, colleagues, and others.

- **Proprietary material**
- Use of ALAN material

Ownership and intellectual property rights of materials produced in the collaboration should be agreed upon upfront.

The terms for the use of the ALAN name, brand and / or logo by any collaborator must be discussed ex ante.

- Use of other material

Patent protection rules for all material collected for ALAN purposes is respected.

- Acknowledgement

The terms for acknowledgement of any resources, product, material and / or any other outcomes developed in the framework of the collaboration should be discussed before and an agreement is reached on how the contributors individually and collectively acknowledge them.

- **Sustainability**

All contributors explore opportunities for a sustainable and long-term relationship, beyond the lifetime of the collaboration.

Ethical Framework

1. Rational

The Ethical Framework is based on the convictions that:

- A strong collaboration between contributors of a multi-stakeholder work is likely to generate benefits for all parties involved in their attempts to accelerate the new treatment options.
- The integrity, credibility and independence of all involved contributors, as well as the constraints and obligations under which all contributors operate, should be respected at all times.
- A collaboration in which the integrity and credibility of all parties concerned are upheld should be underpinned by core principles and values.
- The perspective of patients and patient advocates is unique in nature and therefore should be valued as specialist knowledge and complementary to knowledge of other experts, academia and industry.
- The perspective of patient is frequently represented by patient organisations which integrate the experience of their members and disseminate this combined knowledge to help improve the disease conditions and quality of life of their members. Incorporating this patient expertise into the clinical development process will lead to clinical research and treatments that are more adapted to the real needs of patients.

2. Principles

The Ethical Framework sets additional principles to the ones outlined in the section of the Code of Conduct.

- **Non-maleficence:**

No physical, social or psychological harm to all those involved in ALAN projects, particularly when vulnerable by virtue of age, social status, disability or medical condition.

Decisions that primarily protect the health and well-being of patients and also advance medical knowledge for scientific and wider public benefit are taken. No financial gains or other material benefits from this project for contributors, their families or friends

- **Equality:** all contributors are treated as equals by not being biased
- **Independence, objectivity, and neutrality**

Independence in selection of training / education / information material, objectivity, and neutrality in its adaptation to the different patient audiences' needs, in dissemination and in allocation of resources for production and dissemination is ensured.

- **Integrity**– of behavior, processes, activities. Falsification or misrepresentation of evidence, data, findings or conclusions are avoided.
- **Declaration of Conflicts of Interest**

Conflicts of interest may arise when an individual's personal, business, economic, occupational or professional interests or loyalties conflict with the interests of ALAN, in the course of their ALAN activities.

Therefore, declaration and management of potential conflicts of interest are important. All contributors involved in ALAN should disclose their potential conflict of interest to ALAN. Identified potential conflicts of interest are reported to the ALAN Steering Committee for resolution.

- **Data privacy**

All activities are conducted in compliance with the data privacy laws in place. Project records are kept confidential, with appropriate data protection measures.