Acute Leukemia Advocates Network

Code of Practice between ALAN and pharmaceutical industry

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 Practice outlines the working culture between ALAN and pharmaceutical industry.

Rationale

People should be at the heart of healthcare. From, prevention and awareness, through research and development, regulatory and Health Technology Assessment (HTA) processes, to service design and outcomes measurement.

Patients bring invaluable knowledge and experience of living with a condition, while patient representatives are making sure to have the voices of their communities heard, how disease impacts them, what really matters to them, their families and their carers.

- Role of patient organisations

Patients' organisations have the role to ensure that the patients' voice is heard at all levels of decision making, implementation and monitoring of policies and actions that concern health and healthcare and that the existing system achieves the best outcome for society. Patients' organisations have an interest in interacting and communicating with these different stakeholders, including industry, in the interest of their patients. Good communication will embrace trust, integrity, honesty and openness.

The valuable and serious work of patients' groups and the service they provide needs to be recognised, valued and supported. However, most groups are struggling to find sufficient, diversified resources, to fulfil their mission and objectives and remain independent, whether funding comes from corporate or public sources.

Credibility, transparency, and democracy are the most treasured assets of patients' organisations. Patients' organisations are keen to work in a constructive manner together with all stakeholders to ensure that the credibility of patients' groups is safeguarded.

- Role of pharmaceutical industry

Listening to patient experiences, understanding their challenges and exchanging insights can shape future of medical research and disease management to more adequately address the unmet needs of patients. It is only through open and transparent dialogue between patients and industry that we can ensure that the patient perspective becomes an integral part of how medicines are researched, developed and delivered to patients.

Appropriate inclusion of the patient's perspective across the life-cycle of the medicine has the potential to co-create and co-develop better health care management and patient outcomes, delivering greater efficiencies in healthcare utilization.

Working principles

- ALAN only accept funds for activities that are consistent with its mission and objectives.
- Funds always come from more than one source and ALAN does not accept funding from a single organization exceeding 20-25% of total operating budget.
- For transparency's sake, funders are acknowledged for their support on ALAN website and materials when appropriate.
- ALAN ensures that none of their activities will be associated with promotional activities.
    - Funds for activities are always received on the basis that ALAN does not accept funds aimed at promoting the use of any specific product and/or service.
    - No information in relation to projects should ever be used to promote the use of any specific product or business of the funders.
- Funds, sponsorships for projects or for ALAN's events are accepted without any conditions imposed on the design and conduct of the project and/or influence of the programme, guaranteeing full independence of ALAN.
- Any ensuing findings, publication, etc. will be the property of ALAN and these may not be used or quoted by the funders without the explicit permission of ALAN.
- When ALAN representative participates in an industry activity (adboard, consulting, participation in a company even, review of documents, etc.), a written agreement is set up between the 2 parties and includes honoraria.

References

1. Working together with patient groups – EFPIA Code of Conduct- https://www.efpia.eu/media/288492/working-together-with-patient-groups-23102017.pdf - Accessed Aug 2021
2. Code of practice between patient organisations and healthcare industry - https://www.eurordis.org/sites/default/files/thumbnails/0904-PO-Code%20of%20practice.pdf - Accessed Aug 2021