

Leukaemia Care

Pharmaceutical Code of Practice

Governing how we work with, and accept funding from,
the pharmaceutical industry



How do we work with the pharmaceutical industry?

Introduction

As a charity providing information and support to people affected by blood cancer, we recognise the importance of working collaboratively with all stakeholders with an interest in blood cancers. We work closely with key players in the blood cancer field – including the NHS, the Department of Health, medical professionals and the pharmaceutical industry.

Collaborative working and financial support from pharmaceutical companies is an important resource, enabling us to obtain information, achieve common goals and provide additional support that would not otherwise be possible. It provides opportunities to raise awareness of issues, increase access to treatments and improve the lives of people affected by blood cancer. However, we recognise that such relationships need to be highly regulated and fully transparent to ensure we retain our independence.

Our Code of Practice is a commitment undertaken voluntarily by Leukaemia Care to adhere to specific policies that regulate our involvement with the pharmaceutical industry.

It is intended to minimise the impact of any real, potential or perceived conflict(s) of interest that may arise when we as a patient organisation accept financial support from companies. Our code of practice ensures that we retain our independence and can continue to work with impartiality on behalf of anybody affected by blood cancers.

For more information on why we work with the pharmaceutical industry visit:
<http://www.leukaemiacare.org.uk/working-with-the-pharmaceutical-industry>

Guiding Principles

Our code of practice ensures that we:

- act in accordance with the best interests of patients
- remain independent and free from external influence
- maintain our reputation as a credible, independent source of information
- are as transparent as possible about any funding we receive
- remain impartial and make all decisions on the basis of merit alone
- maintain consistent, appropriate and transparent policies
- continue to work collaboratively with all stakeholders with an interest in blood cancers

Do we accept funding from the pharmaceutical industry?

Types of Funding

We work collaboratively with and receive funding from approximately 10-15 pharmaceutical companies each year. This funding allows us to undertake projects that we would otherwise not be able to afford, enabling us to improve the services we provide to people affected by blood cancer.

The funding we receive from pharmaceutical companies comes in the following forms:

- **Core funding** – where funding is donated to Leukaemia Care as an unrestricted grant to support our ongoing projects and services
- **Project funding** – where funding is donated to support a specific project
- **Donations in kind** – where a company donates services or assets to support a project

Funding Limits

In order to ensure that we remain financially independent, the following limits are placed on all types of funding:

1. We do not allow the total level of funding received from the pharmaceutical industry to exceed 25% of our total annual income
2. We do not allow the funding received from an individual company to exceed 10% of our total annual income

These limits will be calculated based on the previous financial year. The remainder of our funding comes from our own fundraising activities and those of our volunteers.

Disclosure of Funding

In order to ensure that we are completely transparent about how we work, the funds that we receive from the pharmaceutical industry are acknowledged in our annual accounts and on our website.

For more information visit: <http://www.leukaemiacare.org.uk/working-with-the-pharmaceutical-industry>

Any further disclosure of support will be done in an appropriate way following discussions with the company concerned. Where funding is provided as a donation in kind, we will estimate the value of this support and disclose any support worth more than £1,000.

What rules do we place on our relationships with pharmaceutical companies?

General Rules

We apply the following rules to our relationships with pharmaceutical companies. These rules apply to any company wishing to work with Leukaemia Care that develops, manufactures or sells drugs, technologies and other medical devices, or any agency employed to act on their behalf.

Leukaemia Care will:

- Only enter into a relationship with another organisation on the basis of an equal partnership.
- Not endorse, promote or favour individual companies, products or services.
- Not embark upon or continue with any project that might damage our reputation or result in the dissemination of biased or inaccurate information.
- Sign a written agreement with all companies outlining each partner's contribution and responsibilities before accepting funding or embarking on a collaborative project.
- Conduct our relationships with pharmaceutical companies in accordance with this Code of Practice and the Association of British Pharmaceutical Industry (ABPI) Code of Practice where applicable.
- Refer to both scientific and brand names of products in our literature. Where more than one branded version of a product exists, any materials produced by Leukaemia Care will refer to either the scientific name and/or several different brand names.

Funding Rules

In order to safeguard our independence, we apply the following rules to all types of funding received from pharmaceutical companies:

- Before accepting funding we conduct sufficient due diligence to ensure that the funding will result in a benefit to Leukaemia Care and the patients it serves.
- We will not knowingly accept any type of funding from a company engaged in business which is in conflict with our charitable objectives.
- We work proactively to maintain our independence by seeking a variety of funding sources and declining any support that threatens to compromise this independence.
- We only accept funding for purposes that are within our charitable aims and strategic objectives.
- Where a company provides a grant for a particular project or event, Leukaemia Care retains full editorial control over all materials produced in connection with the project and has sole discretion on the meeting attendees.

Use of name, logo and quotes

Prior approval must be obtained from an appropriate person of authority within Leukaemia Care:

- Whenever and wherever our name or logo is used in external communications.
- For press releases referring to Leukaemia Care, or containing quotes from members of Leukaemia Care staff.
- For any materials that refer to a project involving Leukaemia Care.

Depending upon the nature of the decision, the appropriate person of authority will be our Campaigns and Advocacy Director, Chief Operating Officer, Chief Executive Officer or Board of Trustees. Adequate time must be allowed for the appropriate person(s) to review the use of our name, logo and the content of quotes.

Disclosure of information

Leukaemia Care considers the confidentiality of member information to be of paramount importance. As such, we do not under any circumstances disclose any confidential information regarding our service users or supporters to any third parties (including pharmaceutical companies) without obtaining prior consent.

Market research

We are sometimes asked to take part in or facilitate market research on behalf of, or in conjunction with, a pharmaceutical company. Under no circumstances will Leukaemia Care take part in or facilitate promotional market research. However, this does not prevent us from conducting or taking part in research designed to better understand the needs of people affected by blood cancer.

Policy and Health Technology Appraisals

Leukaemia Care may sometimes have shared goals with companies, such as the introduction of new treatments for blood cancer. However, under no circumstances will we endorse, promote or favour individual companies, products or services.

Advocacy activities, such as making patient submissions for drug reviews or petitioning governments to fund a particular drug, are not considered promotion because these activities are intended to improve access to the treatment, rather than recommend that it be prescribed. Similarly, providing educational information on available treatments is not considered promotion because it is designed to enable patients to make informed decisions about their use of medicines, rather than recommend the use of a particular product.

The content of any communications originating from Leukaemia Care, such as patient submissions for drug reviews, policy submissions, information for patients and the public, newsletters and presentations are developed entirely by Leukaemia Care. Additionally, submissions for drug reviews or policy recommendations are not shared with sponsors in advance.

Research

Under normal circumstances Leukaemia Care does not get involved with research, but on occasions we have been involved in research that explores quality of life aspects of patients or Carers affected by a diagnosis of blood cancer.

If we do participate in research, for which we receive funding from a pharmaceutical company:

- Leukaemia Care maintains full control over the choice of research organisation, study design and publication of results.
- The sponsor(s) of any research activities will be acknowledged at the presentation and publication of results.
- This funding will be excluded from the funding limits stated above.

Termination

Leukaemia Care reserves the right to terminate any ongoing agreement or project where an attempt has been made by the company to coerce Leukaemia Care to conform to its marketing agenda, where the agreement has been contravened or where the continuation of the relationship may damage our reputation. In such a situation the funds will be returned to the company in accordance with the relevant project's written agreement.

Enforcement

Leukaemia Care accepts full responsibility for ensuring our compliance with this policy and for ensuring that our sponsors are aware of and familiar with this policy. We regularly review this policy and its impact and update our policies accordingly.

This document will be published in full on our website along with the names of those organisations from whom we have had support and those from whom we are currently receiving support.

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Further information is available from Leukaemia Care on **01905 755977** or advocacy@leukaemiacare.org.uk