

FRAMEWORK OF COOPERATION

between

LUNG CANCER EUROPE (LuCE)

**an association according to the provisions of
Articles 60 et seq. of the Swiss Civil Code**

with seat in Berne, Switzerland

and

SUSTAINING PARTNERS

Lung Cancer Europe and Sustaining Partners: A Framework for cooperation¹

I. Background

Lung Cancer Europe is a non-governmental organisation which was established in 2013 to provide a voice for lung cancer patients and their families at a European level. Through its member organisations (which are lung cancer organisations with a patient focus), LuCE reflects patients' and their carers' and families' unique and direct experience and expertise in healthcare.

LuCE is in its formative years. The founding members have made a decision to seek unrestricted support from commercial organisations to help establish the secretariat, build capacity and knowledge among its board and members, and to start influencing different European policies that have an impact on lung cancer patient outcomes.

Financial support from sustaining partners is crucial to ensure that the organisation will grow and be able to reflect effectively the views of lung cancer patients from across Europe.

This support will also enable LuCE to:

- Be pro-active in and respond effectively to an ever increasing EU health agenda that impacts on lung cancer patients;
- Expand its membership and the services it provides for members;
- Build strong relationships with other stakeholders that have an influence on lung cancer outcomes.

LuCE will endeavour to diversify its funding base by seeking support from a variety of public and private entities. It is hoped that funding from commercial sources will become one component of a broad portfolio of funding. Securing support from different sources will provide LuCE with the baseline resources required to enable it to continue to build and sustain momentum as the voice of lung cancer patients at a European level.

This document outlines how LuCE will work with its sustaining partners. These partnerships are not solely financial but focus also on open and transparent dialogue and the exchange of independent views and opinions between partners.

II. Core principles in relation to acceptance of funding from sustaining partners

In order to make funding partnerships work in practice, the following key principles underpin LuCE's acceptance of funding.

INDEPENDENCE

- LuCE will maintain at all times an independent and strong voice on behalf of its members. Therefore, it will take positions and voice opinions that are in the best interest of lung cancer patients and will feel free to speak out against positions taken by sustaining partners when these positions are not in the interest of lung cancer patients.

¹ This document has been adapted from the framework for financial support that was developed by the European Patient Forum: http://www.eupatient.eu/Documents/Who%20we%20are/Transparency/framework_for_financial_support.pdf

- All events and initiatives will be overseen by an independent LuCE working group established for the purpose. LuCE will maintain complete editorial control over the content of any materials or position papers produced by the organisation.

MUTUAL RESPECT

- LuCE will co-operate and work with its sustaining partners on a basis of mutual respect.

UNRESTRICTED

- In general funding received from commercial organisations will be unrestricted in nature and contribute to the implementation of LuCE's annual work programme.
- LuCE will consider requests from sustaining partners to implement an event or initiative but all LuCE events and initiatives will have to be supported by an unrestricted grant from more than one commercial organisation.
- LuCE will accept funding from non-profit and governmental sources for specific projects provided that these projects are in accordance with its overall strategy and criteria for involvement in projects.

SUSTAINABLE

- The funding provided by sustaining partners should, wherever possible be part of a long term commitment to funding (ideally a minimum of three years) supported by a written agreement. The funding support may also be allocated to building reasonable reserves for LuCE to ensure the long-term sustainability of the organisation.

TRANSPARENT

- A written agreement between the sustaining partner and LuCE will outline the nature and amount of the funding and the period covered.
- The funding sources will be acknowledged with thanks on relevant publications linked to an event or initiative.
- The amount of funding received and the sources will be included in the LuCE Annual Report and published separately on the LuCE website within one month of the Annual Accounts being approved by the Annual General Meeting of the following year.

FUNDING FROM THE PHARMACEUTICAL INDUSTRY

- LuCE will apply the EFPIA Code of Good Practice on working with patients' organisations in relation to any funding received from the pharmaceutical industry whilst also building in the above principles adopted, and other relevant European codes.
- LuCE will ensure that the funding received from one single company will be proportional to the overall budget and reflect its commitment to diversity of funding sources.

FUNDING FROM THE TOBACCO INDUSTRY

- Under no circumstances will LuCE accept any support from the tobacco industry or any entity related to the tobacco industry.

III. Dialogue with Sustaining Partners

In order to promote open and transparent dialogue and to share views and perspectives on issues of common interest and that advance its mission, LuCE undertakes to:

- Distribute its e-newsletters and policy documents/publications to sustaining partners
- Hold an Annual meeting with sustaining partners to share information LuCE's work and to discuss issues of common interest.
- Engage in dialogue on current EU health policy issues.
- Be present at specific company/ federation/ governmental/ Commission events on request to outline its position on one of its policy priority areas.
- Invite sustaining partners to its Annual Conferences, and to selected other events.