medical research charities group

Unity is our Strength

TEMPLATE

PATIENT ORGANISATION CODE OF PRACTICE:

ENGAGING WITH THE HEALTHCARE INDUSTRY*

This is a template code which can be used by patient organisations to guide their involvement with industry.

We recommend that organisations adapt it, according to their own situation and needs.

**The healthcare industry is defined as commercial manufacturers or providers of healthcare products, devices and services.*

Developed in 2018

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Introduction

Engagement with the healthcare industry has the potential to speed the development and improve the quality of treatments for X condition(s). In many cases industry involvement will be required to undertake the costly later phases of developing treatments for X condition(s). X organisation can add much value to industries with an interest in X condition(s) due to our knowledge of the patient experience and of the X condition(s) community. Representatives of the organisation can provide guidance to industry directly or might facilitate patient involvement in plans for product development.

In engaging with industry however, it is essential that we act according to the highest standards of good governance, in order to best represent patients and to protect our independence and reputation. For this reason, X organisation has adopted the following Code of Practice to guide relations between the charity and the healthcare industry.

The Code should be applied when engaging in a dialogue, working partnership and/or accepting support or funding from the healthcare industry. This Code does not intend to cover every possible funding opportunity or relationship, but rather to define a set of basic principles and recommendations.

Our ethos

To act always in the best interests of patients

To represent patient perspectives in industry-led healthcare product development, when appropriate & feasible

To remain independent from influence by commercial interests

To be transparent about our engagement with the healthcare industry

Recommendations

General recommendations

- In all instances of involvement with the healthcare industry, there must be a clear reason for the involvement, which is directly related to benefit, or potential benefit, for people living with X condition(s).
- In engaging with a company within the healthcare industry, X organisation should investigate whether they abide by a recognised code of practice for involvement with patient organisations. If they do not apply such a code then the reasons for this should be discussed with the company. If there are any concerns about the aims or objectives of the company, futher engagement should not occur.
- X organisation should endevour to provide equal support (on the basis of it being requested) to all companies offering genuine potential for X condition(s) patient benefit. Every effort should be made not to give one company competitive advantage over another.

Funding from the healthcare industry

X organisation should only accept funds for activities that are consistent with its mission and objectives. When receiving funding from the healthcare industry, X organisation should be transparent concerning the amounts and sources of such funding. The terms of funding should be set out in writing in all cases (EFPIA provides a model template for written agreements between the pharmaceutical industry and patient organisations). Public documents e.g. annual reports, accounts and website should clearly illustrate such information and the information should be fully accessible. When accepting funds from the healthcare industry, the following should be applied:

- Funds for **core activities** should only be accepted on an unconditional basis. To avoid undue reliance on any particular company, such funds should be balanced and diversified as much as possible to avoid conflicts of interest and guarantee independence. *Note: patient organisations might wish to put a cap on the percentage of their income that comes from the healthcare industry.*
- Funds or sponsorship for **projects** can only be accepted without any conditions imposed on the design and conduct of the project, guaranteeing the full independence of X organisation.
- X organisation may accept funds, sponsorship or assistance in kind for its own **events**. Funding should ideally come from more than one source, though it is recognised that this will not always be possible. Sponsors should not exercise any control over the programme content or choice of speakers at the events.
- X organisation may accept funds, sponsorship or assistance in kind for its own **communication** activities. The names of the sponsors supporting the materials should be mentioned. The space dedicated to the mention of the company on the communication material (e.g. flyer, website) should be modest in size and logos should be avoided, to avoid being perceived as an advertisement.
- If an X condition(s) healthcare industry offers to provide X organisation with **training/capacity building** programmes, the potential to influence participants way of thinking about commercial products should be considered. It is preferable to find an equivalent programme run by not-for-profit organisations and ask the company to sponsor X organisation's participation.

Communications and marketing

X organisation must be clear to make the distinction between information about healthcare products (or products in development) and promotion of such products. While information can be provided on clinical trials or commercial products for X condition(s) it must be very clear that X organisation does not promote, support or endorse any healthcare product, service or brand. It should be noted that promotional activities related to approved prescription medicines are not permitted under current EU legislation and respective industry codes of ethics. Activities that can be considered promotional include the following:

- Disseminating unbalanced or non-validated information about a product.
- Being quoted in a company's communication in favour of, or against, an X condition(s) product.
- Participating as speaker/participant in a company event.
- Participating in an *ad hoc* meeting sponsored by a single company to inform patients on their products.
- Permitting a company to use X organisation's logo or materials in it's promotional activities/materials.

When providing information on the management of X condition(s) that refers to particular X condition(s) products, X organisation must endeavour to ensure that:

- Any actions that could be interpreted as promotional (such as the above examples) are avoided.
- A clear statement of how any information provided on X condition(s) products or services was arrived at.
- The accuracy of the information is checked by experts that are independent from the commercial interests of the company and that details of any such consultation are provided.
- Any medical description of the product is based on the 'Summary of Product Characteristics' or another commercially-independent and validated source of information.
- Where possible, medical descriptions of the product should be based on active ingredients, rather than brand name.
- Any information provided is free from any commerical advertising.
- Any breach of this code by industry (e.g. unauthorised use of the charity's logo) is dealt with and objected to (it might be necessary to alert industry umbrella groups if the company has breached a code of practice).

Campaigning

In the case that it is necessary to campaign for X condition(s) patient access to a specific drug, treatment or device, X organisation will not accept funding from industry to support such campaigns. X organisation should ensure that our campaigns are guided by the best interests of patients, are not influenced by commercial interests and are based on evidence from reliable and transparent sources.

Paid services to the health care industry

There are several situations where industry may propose payment/honoraria to X organisation's volunteers or staff members and it is permitted by healthcare industry codes of practice to do so. Examples of such situations include payment for:

- Travel expenses to participate in a meeting or conference
- Reviewing industry materials, leaflets, protocols etc.
- Consultancy on industry policy, advisory committees etc.

To ensure that the independence of X organisation is maintained, **it is usually preferable to provide advisory services to industry on a non-payment basis**. However, it is also important that patients and their representatives are recognised as valuable experts, akin to healthcare professionals. For this reason, it might sometimes be appropriate that individuals within X organisation are funded for their expertise and their time or to cover expenses incurred during participation in industry activities. X organisation should be fully transparent about any such honoraria or payments.

The arrangements that cover paid services should fulfil all the following criteria:

- The services should be directly related to the purpose of supporting X condition(s) research and improved X condition(s) healthcare. A legitimate need for the services should be clearly identified and documented by X organisation.
- A written contract/agreement should be agreed in advance, specifying the nature of the services to be provided and the basis for payment for those services. X organisation should make it clear in this contract that payment for services is not an inducement to recommend a particular medicinal product.
- The extent of the service should not be greater than is reasonably necessary to achieve the identified need and the compensation should be reasonable and not exceed the fair market value. Equally, codes of practice must not be used to justify not appropriately compensating X organisation representatives.
- Payment for any services provided by X organisation should ideally be paid directly to the organisation and used to support core activities. Failing that, it is the responsibility of the representative to transfer the honoraria to X organisation.
- Payments or honoriums by industry to people living with X condition(s), for patient involvement activities, are permitted and should be arranged directly, between those parties.

***Note**: this should be considered a dynamic document and reviewed on an annual basis.*

Source and guidance material

1. Working together, delivering for patients: A guide to collaboration between charities and pharmaceutical companies in the UK. (2014) The Association of the British Pharmaceutical Industry. http://www.abpi.org.uk/our-work/library/Documents/ABPI_NV_Guide_FINAL.pdf

2. An Essential Partnership: A guide for charities working with industry. (2014) Association of Medical Research Charities, UK. http://www.amrc.org.uk/sites/default/files/doc_lib/Essential_Partnership.pdf

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4. EFPIA code of practice on relationships between the pharmaceutical industry and patient organisations. (2011) European Federation of Pharmaceutical Industries and Associations. http://transparency.efpia.eu/uploads/Modules/Documents/code_po2011.pdf

5. Guidance for patient involvement in industry-led medicines R&D. (2016) European Patients' Academy on Therapeutic Innovation (EUPATI). https://www.eupati.eu/patient-involvement/guidance-for-patient-involvement-in-industry-led-medicines-rd/

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