

Crohn's and Colitis UK

Policy Statement: working with pharmaceutical and medical device companies.

Crohn's and Colitis UK is the UK's major patient support organisation for people who are affected by Crohn's Disease and Ulcerative Colitis, the two main forms of Inflammatory Bowel Disease (IBD). Our aim is to improve life for all those affected by the conditions. In furthering this aim, we are pleased to be supported by – and sometimes work collaboratively with – pharmaceutical and medical device companies.

The development, availability and proper use of medicines, treatments and devices are an important part of the management of IBD. Our relationships with the companies which produce them bring many benefits to patients and carers, including:

- Information on medicines, treatments and devices to help our Information and Support Service to stay abreast of developments in the field of IBD and give patients and carers information which is accurate, clear and compliant with the rigorous NHS England-supported Information Standard which we are proud to hold.
- Unrestricted donations to help us to maintain and develop our core services such as helplines which are free to callers.
- Grants for specific projects such as nursing awards to raise awareness of the importance of specialist nurses.
- Collaborative research such as a study into the effect of IBD on employment.
- The opportunity for us to make the companies aware of the needs of patients and carers with a view to improving the information, resources and services which the companies produce.

However, in working with pharmaceutical and medical device companies we ensure that we do not compromise our independence, integrity or strategic direction at local or national levels. This policy document explains the principles and terms on which we work with them.

1. Equality

- a) We are equal partners in any relationship.
- b) We will not engage in activity or accept support designed to give one company a competitive advantage over another, or which might tend to endorse specific products or undermine competitor products. Wherever possible, we will work with consortia of two or more companies. We may, however, campaign for equitable access to specific treatments or devices if we feel this is in the best interests of patients and carers. No funding for such campaigning will be accepted from the companies concerned in the production or promotion of those treatments or devices. If we have received – or are receiving – funding from the companies concerned for other activities, we will declare this.
- c) We support the provision of information to patients and carers about the treatments and devices which are available to assist them in making informed choices in collaboration with their health professionals. Where more than one branded version of a treatment exists, any publications we support must use the generic name wherever possible, or refer to all equivalent available branded treatments.

- d) Our name, logo and materials should not be used by companies, their partners or agencies without our prior consent [in writing]. Any press releases referring to us, or containing quotes from any of our staff members, also require our prior [written] approval.

2. Independence

- a) Activity and support must be in the best interests of patients and carers, and fall within our strategic aims and objectives. We will not allow companies to influence those aims and objectives.
- b) We will retain editorial control of the patient information and other materials we produce.
- c) The total amount of financial support we receive from all pharmaceutical and medical device companies will not exceed 10% of our total budgeted income for the financial year. These limits include/do not include gifts in kind, employee fundraising and grants from charitable trusts or foundations which are associated with companies but operate independently of them in accordance with their own charitable objectives.

3. Trust

- a) We will not disclose confidential information about our members, service users or supporters.

4. Openness and transparency

- a) Activity and support must comply with the guidelines of the Association of the British Pharmaceutical Industry, the National Institute for Health and Care Excellence, the Scottish Intercollegiate Guidelines Network and the Association of Medical Research Charities as appropriate.
- b) We will set out in our Annual Report and on our website details of the support we receive from pharmaceutical and medical companies and any collaborative working. We will also respond openly and transparently to any questions about our work with them which may be raised by the public or media.
- c) Our Trustees and Senior Leadership Team are required to declare any financial interests in pharmaceutical and medical device companies.

5. General criteria for funding and collaborative working

- a) Proposals for collaborative working will be considered in relation to ethics, desirability, and practicality bearing in mind timing, our resources and our other activities.
- b) Activity and support will be agreed in writing and with reference to this policy.

6. Specific criteria and guidelines for collaborative working

- a) **Patient education and support** - We do not endorse the publications of other organisations but will consider collaborative working on patient information provided:

- (i) The information is general to IBD, does not constitute explicit or implied product advertising or endorsement, and is not influenced in any way by funding from a company. Our impartiality and objectivity will be rigorously maintained.
 - (ii) It aligns with our thinking on education and support approaches.
 - (iii) It is based on the latest evidence, informed by healthcare professionals and patients.
 - (iv) It does not duplicate existing approaches or risk fragmenting the provision of consistent care to patients.
 - (v) We are consulted at an early stage in the development of the idea.
- b) **Survey and focus groups** – We will consider collaborative working provided there is a commitment to publish the results in an objective (peer-reviewed format) and the surveys and focus groups:
- (i) Have a sufficiently broad focus
 - (ii) Include information which is of value to us
 - (iii) Conform to good market research and ethical standards.
 - (iv) Include a Crohn's and Colitis UK representative at any focus group meeting.
- c) **Research** – We will consider collaborative working provided proposals align with our own objectives.
- d) **Professional and Public Affairs** – We will consider collaborative working when objectives align with ours (an example being the increased allocation of NHS resources for IBD) provided:
- (i) Objectives and the terms of the collaboration are agreed in writing at the outset.
 - (ii) Our independence or perceived independence is not compromised or at risk of compromise.
 - (iii) There is complete transparency.
- e) **Public relations activities** – We will consider collaborative working provided:
- (i) Messages are general to IBD and do not constitute product advertising or endorsement.
 - (ii) They align with our thinking on messaging.
 - (iii) We are consulted at an early stage in the development of the idea.

Date of policy:

Review date:

