



## **NACC POLICY STATEMENT ON RELATIONS WITH THE PHARMACEUTICAL INDUSTRY.**

One of the principles underpinning the NACC Vision is to forward NACC's objectives through research, development and service activities in partnership with Health Service, professional and other patient organisations and with the pharmaceutical industry.

NACC recognises that the development, availability and proper use of medicines are an important part of the management of Inflammatory Bowel Disease (IBD). As the major IBD patients' organisation in the UK, it is therefore in patients' interests that NACC establishes effective liaison with pharmaceutical companies since the decisions they make will have a major effect on many patients' lives.

The purpose of this policy statement is to

1. explain why it is in patients' interests for NACC to establish an effective working relationship with pharmaceutical companies and indicate to companies that NACC welcomes such a relationship;
2. make clear NACC's view of the principles that must underpin any communication or collaboration so that NACC can work with companies without compromising its independence or reputation;
3. reassure members and the public of NACC's position;
4. enable NACC staff to carry on their work without the need for constant reference to the Trustees.

The basis of the relationship must be:

- integrity and openness on both sides,
- respect by companies for the independence of NACC
- recognition by NACC of the need for commercial confidentiality on some matters,
- equality in any collaborative activities
- acceptance that the ultimate test for cooperation or collaboration will be what NACC considers to be in the best interests of IBD patients.

### **Transparency**

NACC expects collaborative activities to be agreed in writing and declared by both parties. NACC will set out in its Annual Report to the Charity Commission and on its website details of the support it receives from companies and of any collaborative projects.

### **Guidance on Collaborative Working**

- NACC will not collaborate in activities that might tend to endorse a specific product or undermine a competitor product.
- NACC prefers to work on major activities with consortia of two or more companies and seeks to avoid activities that are designed to give one company competitive advantage over another.

NACC will consider proposals against three factors:

- Ethics
- Desirability
- Practicality (timing, resource etc) in relation to NACC's other plans and work.

### **Patient Education and Support**

- NACC supports the provision of information to patients about the treatments that are available and the discussion of available options to assist patients in making informed choices in collaboration with their health professionals.
- Where more than one branded version of a treatment exists, NACC will expect any NACC-supported publication to use the generic name where possible or to refer to all equivalent available branded treatments.
- NACC will consider collaboration on these provided
  - the information given is general to IBD and does not constitute explicit or implied product advertising or endorsement
  - they coincide with the education and support approaches that NACC wishes to see developed
  - they do not duplicate existing approaches and risk fragmenting the provision of consistent care to patients
  - the timing does not jeopardise other NACC activities
  - NACC is consulted at an early stage in the development of the ideas
- NACC does not formally endorse other organisations' literature.

### **Surveys and Research**

- NACC will consider undertaking collaborative patient surveys or focus groups provided these have
  - a sufficiently broad focus,
  - include information of value to NACC as well as the company,
  - conform to good market research standards
  - include a NACC representative at any focus groupand
  - there is a commitment to publish the results in an objective (peer-reviewed) format
- NACC is willing to consider collaborative research proposals provided these coincide with NACC's own research objectives.

### **Professional and Public Affairs**

- There will be times when NACC and Companies have shared policy objectives (e.g. increased allocation of resources for IBD or the introduction of new treatments)
- NACC will consider joint working or collaboration in this area, but will require
  - objectives and the terms of the relationship to be agreed in writing at the outset
  - that independence or perceived independence of NACC should not be compromised
  - that there is complete transparency

### **Public Relations Activities**

- NACC will consider collaboration on these provided
  - the messages are general to IBD and do not constitute product advertising or endorsement
  - coincide with the messages NACC wishes to convey
  - the timing does not conflict with other NACC media activities
  - NACC is consulted at an early stage in the development of the ideas

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