



Roche

Working with patient groups: Good practice guidelines

Introduction

Roche is proud of its history of working with patient groups. The company wishes to ensure that collaborations reflect common values of integrity, maintenance of independence, respect, equity, transparency and mutual benefit. These values act as guiding principles for these guidelines.

Patient groups are increasingly important partners for Roche. We share an interest in helping patients understand and manage their disease/conditions, including having timely and equitable access to the treatment they need. Roche is able to contribute a range of skills, expertise and knowledge which might enhance the patient organisation's activities.

Patient groups are important in helping Roche to gain a greater understanding of what it is like to live with a disease, the challenges facing patients and their families and the role that drug therapies play in the management of the disease. They also provide the company with an insight on how to support healthcare professionals who in turn support patients.

This document sets out the principles which should underlie the relationship between Roche and any patient group. Any agency working with patient groups on behalf of Roche must also follow these guidelines.

Through implementing these guidelines, Roche underscores its role as a true partner working in collaboration with the patient group, where a patient group knows explicitly what it can expect from Roche.

Guidelines

1 *Integrity*

- a. Any activity jointly undertaken with a patient group should benefit the patients whose interests it represents and should fall within the constitution or the articles of association of the group.
- b. Roche should not seek to gain competitor and/or other confidential information from patient groups.
- c. Information about prescription-only medicines which is made available to patient groups must be factual and presented in a balanced way. It must not raise unfounded hopes of successful treatment or be misleading with respect to safety of the product. Statements must not be made for the purpose of encouraging patients to ask their health professional to prescribe a specific prescription-only medicine.

2 *Maintenance of independence*

- a. The patient group's independence should not be compromised or perceived as being compromised because of collaborating with Roche.
- b. Patient groups should not be asked to endorse a specific product.
- c. Any reference to a product should comply with the patient group's practice on nomenclature.
- d. Roche personnel working with patient groups should understand the environment and constraints within which patient groups work. Similarly, Roche must be clear with groups about the boundaries within which they may work with patient groups.

3 *Respect*

- a. Roche and the patient group must respect each other's aims, objectives, priorities, and ways of working.
- b. If Roche is to provide financial support and/or significant non-financial indirect support, there must be a written agreement between the patient group and Roche in place. This may take the form of a letter agreement, a contract or some other mutually agreed upon form. Where patient groups have a standard form of agreement, this should be used, if feasible.
- c. In consultation with the patient group, the written agreement should include some or all of the following: the objectives of the collaboration; the contribution each party will make; the anticipated outputs and timelines; confidentiality, where appropriate; the liability for each party involved in the collaboration; the support provided – how much and when; how both sides will keep in touch about the collaboration (how and how often); how and in what circumstances the partnership

would be terminated; a method for determining how any such termination will be reported; what will happen to any funding which has been provided should the project not go ahead or be completed; how long and in what circumstances the company can refer to the partnership once it has been terminated; how the collaboration can be advertised; and how each party's logo can (or cannot) be used.

- d. One person within a team should be ideally identified as the point of contact with the patient group. A deputy for the contact should be identified to maintain continuity.
- e. If agency support is provided to the patient group, the group should be invited to have a say in the selection of the agency.
- f. There should be formal sign-off mechanisms in place in both parties for any publication or materials produced during a partnership.

4 *Equity*

- a. Both parties in the relationship should be considered to be of equal importance.
- b. Any financial or other benefit offered to a group should be appropriate to the size of the organisation.
- c. Copyright of any publication must be respected and existing content must not be used without explicit written permission.

5 *Transparency*

- a. Roche will be open about its collaboration with patient groups and will expect the patient group to be similarly transparent.
- b. Any collaboration should comply with any legislative or regulatory requirements applying to Roche and/or to the patient organisation.
- c. Roche will make available on its website a list of all patient groups to whom it provides financial support and/or significant non-financial support on an annual basis. The list must include at least a brief description of the type and purpose of the collaboration. The posting of any such information should be agreed between Roche and the patient group concerned. The list will be updated at the beginning of each year.
- d. Any external agency employed by the company to contribute to the collaboration must follow these good practice guidelines.
- e. Permission should be obtained from any patient group whose contact details or logo is to be included in any publication or communication used by the company or

its agency. Any text referring to the patient group should be approved in advance of publication by the patient group concerned.

- f. The editorial authority of the patient group for any information produced under their name should be respected. However, the company is responsible for ensuring that any information about its own products is correct.

6 *Mutual benefit*

- a. For a partnership with a patient group to be successful, there must be benefit to both sides.
- b. In general, time expended and costs associated with travel and accommodation incurred by patient groups working in partnership or on a project should be fairly compensated. With regard to appropriate venue of and reasonable hospitality at events organized or sponsored by Roche, in principle the same rules apply as for the events attended by healthcare professionals.
- c. Financial compensation should be agreed in advance for any time patient groups spend supporting company initiatives. The exception is for patient spokesperson quotes on press releases.
- d. Financial contributions to patient groups can take several forms: donations; one-off sponsorship; educational grants or ongoing general or collaboration funding. Whatever the funding method, financial support should generally be based on and reflect an ongoing relationship with a patient group.
- e. Donations should be used less often but may be an appropriate form of support for small or start-up organisations or to organisations in need of immediate resources. They are generally made once only; if it is feasible, Roche may make a small donation in separate years.
- f. Substantial donations to large organisations are not an appropriate form of continued support. Roche will not request to be the sole funder of a patient organization or any of its major programs.
- g. One-off sponsorship contributions are applied to cover the costs of specific projects such as booklet or video production or meeting costs.
- h. Ongoing or partnership funding is appropriate for activities that are jointly agreed by both sides. Such collaborations are based on mutual benefits which are defined by discussion and agreement.
- i. Where partnerships are in place with patient organizations and meetings are held with these organizations such meetings must be held in an appropriate venue that is conducive to the purpose of the event avoiding touristic/holiday resorts.

7 *Review & Evaluation*

- a. All projects and collaborations should be evaluated at pre-planned time points. The evaluation should be against the outcomes agreed at the outset.
- b. The evaluation should include short, medium and long term objectives. Even if short term objectives were not met, both parties may choose to continue with a relationship.

8. *Implementation*

- a. Roche employees as well as contractors and agencies working for or on behalf of Roche are directly responsible for applying these guidelines.
- b. The responsible Roche Management has to instruct the Roche employees as well as the contractors and agencies working for or on behalf of Roche in an appropriate way.
- c. All Roche Companies have to ensure the guidelines are implemented locally in line with applicable laws and have to ensure compliance. Violations of these guidelines are not tolerated.
- d. All Roche companies have to provide the information as defined in article 5 lit. c. above to the Headquarters in Basel for publication on the corporate website.
- e. Roche will regularly assess the terms and conditions that determine appropriate behavior in engagements with patient organizations; if necessary, Roche will amend these guidelines accordingly.

9. *Entry into Force*

These amended guidelines were proposed by the Corporate Sustainability Committee and approved by the Corporate Executive Committee on September 9, 2008; they entered into force on the same day.