

Guidance on working with patient organisations – based on 2008 ABPI Code of Practice for the Pharmaceutical Industry

The following is informal guidance only. There have been few cases in this area so this guidance is based on general principles only. Formal complaints considered under the Code are determined on their own individual merits. It is important that before working with any patient organisation pharmaceutical companies are confident that the patient organisation is genuine and that the patient organisation itself does not in effect advertise prescription-only or unlicensed medicines to the public. Pharmaceutical companies need to be confident that funding etc is only used in accordance with the relevant written agreement. All relevant requirements of the ABPI Code of Practice for the Pharmaceutical Industry must be followed.

In a specific situation it might be helpful to call the PMCPA for informal advice (020 7747 8880 and press '2').

1 Funding websites

Q Given the difficulty of monitoring text on websites, what sort of funding is appropriate? Is it acceptable to fund technical development, a maintenance contract or some other specific part? Does that absolve the company of responsibility for text?

A The acceptability of funding a particular project relating to a website would depend on what the project was. It is more likely to be acceptable to fund certain technical or design features or maintenance. It is too difficult to comply with the Code regarding funding of blogs. It must be very clear in the written agreement what the money is for and that the company has no involvement or influence over the text. Clause 23.6 of the Code prohibits companies from seeking to influence the text of patient organisation material in a manner favourable to its own commercial interests but permits the correction of factual inaccuracies.

2 Referring to websites

Q Can references be made by pharmaceutical companies to patient organisation websites?

A It depends on the circumstances. For example referring to a specific patient group website as part of an advertising campaign or other form of promotion to health professionals should be avoided unless the text of that website always complies with the Code. In an advertisement to health professionals a breach of the Code was ruled in relation to the mention of a patient organisation website as the content of the website which was inappropriate, became part of the advertisement. A corporate style advertisement to the public was similarly ruled in breach of the Code.

The supplementary information to Clause 22.2 of the Code defines reference information as a library resource for the public to consult but it does not specifically allow or prohibit mention of patient organisations. Details of patient organisations could be included as part of reference information provided the company met the requirement that reference information should be a comprehensive up-to-date resource. Companies should therefore list relevant patient

organisations by their home pages. If a choice is made then there must be some reasonable justification for that choice.

The supplementary information to Clause 22.3 of the Code states that requests from the public should be handled with care and enquirers should be referred to other sources where appropriate which might include health professionals, NHS Direct and patient organisations.

3 Funding meetings - for example AGMs and fringe meetings at a party political conferences

Q Given that there is always a possibility that a speaker might say something that in theory ought not be said, what sort of funding is advisable? Is it enough to say in the acknowledgement that the funder/s have had no input into the programme? Do disclaimers protect?

A Meetings with patient organisations or sponsoring of patient organisation meetings are covered by Clause 19 of the Code. Sponsorship must be declared (Clauses 19.3 and 23.8). Disclaimers as described in the question will not necessarily help. When planning to sponsor a meeting all reasonable steps should be taken to ensure that there is no promotion of prescription-only medicines and that all speakers are fully informed about the requirements of the Code. Rulings under the Code are based on the circumstances of the case including the role and involvement of the pharmaceutical company. The brief given to speakers is likely to be requested in the event of a complaint. Companies should ask for comprehensive details of the meeting before agreeing to sponsor any part of it.

Companies can also fund an element of a meeting eg the printing of the programme. However it must be very clear in the written agreement what the money is for and that the company has no involvement or influence over the choice of speakers or the content of the meeting including presentations.

4 Funding meeting attendance/travel/accommodation costs

Q Patient group representatives frequently seek support from pharmaceutical companies to attend meetings. Could the company have a problem if prescription-only medicines are promoted at such meetings (even though the money was requested and the company had no part in the meeting other than supporting the attendee)? Do disclaimers in the written agreement help?

A When considering such a request companies should bear in mind the nature of the meeting and the professional standing of the potential delegate. Disclaimers in the written agreement do not necessarily protect against unintentional exposure of a patient group representative to promotion which, given that the attendee is funded by the company, could be in breach of the Code.

Q If the person from the patient organisation is asking as an individual rather than as a representative of the patient organisation, does there need to be a written agreement?

A There should always be a written agreement. The money should be paid to the patient organisation rather than to the individual directly.

Q If the funding is given to a general education fund ie without a designation being stated, and if the patient organisation chooses to use the fund to send a representative to a specific meeting, is this the responsibility or business of the company?

A The written agreement should state the purpose of the funding in as much detail as possible. It is permissible under the Code to give general funding for patient organisation' staff training etc.

5 Funding patient organisation newsletters

Q Given that newsletters could contain information that a pharmaceutical company might not be able to certify in accordance with Clause 14.3 of the Code (such as a letter to the editor) where does the funding of newsletters stand? Can funding be designated for a specific purpose? For example, can the acknowledgement state that company X has supported the printing/distribution of the publication, and has had no part in the text?

A Funding can be designated for a specific purpose such as printing or distribution. However this must be made clear in the written agreement and it should be stated that the company has no involvement or influence over the text.

6 Positioning of acknowledgements on printed material

Q Where does the acknowledgement of a company's involvement need to be placed on a publication? Must it be on the front cover?

A The acknowledgement must always be sufficiently prominent so that the involvement of any pharmaceutical industry sponsors is clear from the outset ie no content should be read without the reader being aware of the nature of the document. On a two sided document/leaflet the acknowledgement will therefore need to be on the front.

In a longer booklet the acknowledgement should be on the front cover. The acknowledgement must always appear before any of the main text starts.

In addition the nature of the involvement must be accurately reflected.