

## Supplementary File

### Case studies illustrating practices for working with pharmaceutical industry sponsors

#### **Disease specific patient group, mid-range funding from pharmaceutical industry, formal policy (Sally)**

The patient group that Sally works for accepts money from pharmaceutical companies, “predominantly for ... education events for ... GPs [General Practitioners, primary care doctors].” The group recently adopted a formal policy about working with pharmaceutical funders.

*Sponsor exclusivity:* The group tends to have multiple pharmaceutical companies sponsoring their large GP events, but will accept solo sponsorship for smaller events, “so last year we [went to a rural town] and we took a [specialist] in [to speak to the GPs] and we were sponsored by [one pharmaceutical company] to do that, which was great.”

*Brand marketing:* Sally’s group allows pharmaceutical sponsors to provide branded product marketing information to health professionals who attend educational events, “[Pharmaceutical reps] come on the day, have a stand, have their information.” The group does not allow companies to promote their branded products to the public: “[Members of the public] don’t come to an event where there’s a stand and there’s a pharmaceutical rep present.”

*Agenda setting:* The group works hard to prevent pharmaceutical company sponsors having undue influence over its agenda and according to Sally the new policy was adopted with that intention: “We’ve put a policy in place last year, that I got the board to approve saying ... we won’t do anything that we weren’t planning on doing in the first place just because a pharmaceutical company has asked us to.” Sally explained why she drafted this policy: “I was just concerned with the pharmaceutical companies that the direction of what we were doing might be influenced too much, so it was just a clarification from my part to say, ‘That’s not what we’re here for, we’re not going to be mouthpieces for anybody, we’re allowed to push our agenda.’ ... I think, if you don’t have policies in place early on to make it really clear what you will and won’t accept, then it makes it really difficult to say no.” As a result of this new policy, Sally said she has more easily been able to reject pharmaceutical company initiated project ideas: “One of the pharmaceutical companies - recently I was talking to them about sponsorship for [an education project] which they weren’t interested in, but they did say they would be interested if we could send them out to talk to GPs about this specific disease, which is obviously the one that they’ve got the specific medication for ... This policy is great because it’s now very clear what we can and can’t accept ... I can say quite clearly, ‘Well, no, that wasn’t our intention, so we can’t accept that sponsorship, but if you want to make it a general sponsorship, then we can talk about it.’ So it just makes it easier from my point of view, it stops any time wasting or confusion ... if it sits within [the policy], we accept it and if it doesn’t, then we don’t, we don’t have to think about it every single time.”

In general, Sally prefers non-pharmaceutical corporate sponsors because she thinks it is more obvious that the purposes of non-pharmaceutical sponsorship are marketing, “it’s very transparent ... [For example] an electrician company and they wanted to have our logo on the back of their trucks because it made people think they were nicer than the other electrical companies.” In contrast, Sally thinks that pharmaceutical company sponsorship of patient groups is often presented as being non-promotional and she thinks this is misleading: “No matter how much they say they’re not there to sell their product, obviously clearly they are.”

**Disease-specific patient group, high level of funding from pharmaceutical industry, formal policy (Paula)**

The patient group that Paula works for accepts industry money for big programs of activities and for small individual projects: “the industry support really allows us to develop patient resources, [primary care] training, advocacy and awareness across different disease areas.” The group has a formal “working with industry” policy, available on their website, which provides “agreed guidelines for working together ... It just is a way for us to articulate for new staff coming in or for new industry partners about what the relationship should be.”

*Sponsor exclusivity:* The group accepts exclusive sponsorship but only for small projects: “We have no [big] program area that has one sponsor and that’s one of our lines in the sand. For individual projects, I can’t tell you we’ve never done it, I think we did a [small activity] that was supported by one particular company ... but we would always aim to work with more than one company.”

*Brand marketing:* The group allows sponsoring companies to advertise to health professionals and sees this as part of transparency around funding. They sometimes put patients in direct contact with pharmaceutical companies to facilitate industry staff knowledge of the patient perspective: “Often [companies will] come to us and say ‘We’re training our sales group’ and ... [ask us to] approach a patient to go and speak to the staff of the company.”

*Agenda setting:* Paula’s group provides opportunities for existing pharmaceutical company sponsors to suggest activities and will consider each idea on its merits according to whether or not it fits with the group’s strategic plans: “Once we are in a partnership with a company, they may well come to us and say, ‘We had an idea for something and we’d like to partner with you on this.’” Representatives from sponsoring companies are also invited to the group’s annual agenda planning meeting: “They’ll get to come in, raise issues.”

*Advocacy:* The group is willing to consider pharmaceutical company requests for patient group advocacy in support of the company’s application for government subsidy of its products. They might accept company advice on disease awareness campaigns: “They have great suggestions in terms of how we market ourselves, how we raise awareness.” However, the group will not automatically accept a company’s ideas or requests for advocacy if they are not part of the group’s “overall strategy” and the group is guided by the principle that “everything goes through the patient lens and through the evidence lens.” Paula notes, “We certainly have been in a situation where we have not been able to [advocate in] support applications of industry partners for [government] reimbursement for particular treatments if the evidence isn’t there.”

*Content:* Sponsoring companies have “no involvement in the program or who the speakers” are” at educational events. The group’s clinical guidelines are authored by medical experts. Paula stated, “I know that the chair of our guideline committee has no links with industry but we don’t have a policy for the members. It’s probably a good idea actually.”