

P H A R M A C  
C o n s u m e r   A d v i s o r y   C o m m i t t e e   ( C A C )  
P O B o x 1 0 - 2 5 4  
W E L L I N G T O N

10 May 2005

By fax

Dear recipient

**Feedback on Discussion Paper, Health Industry Sponsorship of Consumer Health Organisations**

The Consumer Advisory Committee of PHARMAC is seeking your feedback on a discussion paper on Health Industry Sponsorship of Consumer Health Organisations.

Health industry companies, especially the pharmaceutical industry, are increasingly seeking alliances, or offering donations, to consumer health groups. This is a world-wide trend and such funds can look attractive when access to other sources of funding is increasingly difficult.

There has been some discussion of this trend in overseas journals and publications but very little that we are aware of in the New Zealand context. We hope to stimulate such discussion among New Zealand consumer groups.

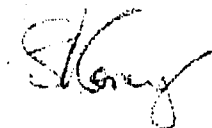
The paper sets out the background and the potential risks involved in accepting industry support, including funding. It outlines the policies and practices of some groups who have addressed the question. It suggests some options for groups to consider and seeks your feedback on these options and other questions about industry support. A questionnaire is attached to help you provide a response.

We will collate the feedback received and report this back to you. Once we have done this, we hope to develop a checklist and/or voluntary guideline for health consumer groups who are considering whether to accept such support.

We need your help with this, and invite you to complete the attached questionnaire and return it to us by 5pm on Friday 3 June 2005.

If you want any further information, please feel free to contact me at :  
S\_coney@xtra.co.nz.

Yours sincerely



Sandra Coney  
Chair, Consumer Advisory Committee

HEALTH INDUSTRY SPONSORSHIP  
OF CONSUMER HEALTH ORGANISATIONS

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**Discussion paper**

Consumer Advisory Committee  
PHARMAC

May 2005

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## INTRODUCTION

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The Consumer Advisory Committee (CAC) of PHARMAC has developed this discussion paper to initiate discussion amongst consumer health groups about health industry sponsorship of consumer organisations.

Although not a new phenomenon, sponsorship of consumer groups by health industries, especially the pharmaceutical industry, is growing. One cause of this is the growth in costs for advocacy groups and the diminution of government and public philanthropy (PatientView 2004). Health industries have emerged as a source of replacement funding. As the number of new drugs being produced by industry declines, competition for a larger market share for existing drugs has become more intense (Medawar & Hardon 2004). Pharmaceutical and other industry groups are increasingly seeking to make alliances with patient groups to build knowledge of and loyalty to their brands, or even to create patient groups (Moynihan 2003; Herxheimer 2003). A survey of European patient groups found that three-quarters accessed funds from pharmaceutical companies, mostly for occasional projects. The larger, national campaigning groups received funds most easily (PatientView 2004). In the US and UK, many national patient groups and others with a national agenda receive pharmaceutical funding, as do some of the most prominent international groups (Herxheimer 2003; Medawar & Hardon 2004).

This trend comes at a time when there is increasing concern about the influence of the pharmaceutical industry. Aside from its well-documented influence on prescribers, the pharmaceutical industry can exercise considerable influence on regulatory agencies, research institutions, the publication of research, and medical journals (Abraham 2002; Horton 2004). Some health organisations have restricted industry sponsorship because of the growing discomfort of members (Lenzer 2004). In the UK the Medicines and Healthcare products Regulatory Agency has restricted what pharmaceutical companies can do in disease awareness campaigns, as it was concerned that these were increasingly thinly disguised promotions for drugs (Jackson 2003).

Some health groups, such as the Cochrane Collaboration and the Medical Council of New Zealand, have policies on relationships with industry organisations (Medical Council of New Zealand 2003; Cochrane Collaboration 2004). However, the CAC is not aware of any attempt to discuss this issue and/or arrive at a consensus among New Zealand consumer health groups. This paper is designed to begin that discussion.

## BENEFITS TO THE INDUSTRY GROUPS

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Grants to and sponsorship of patient groups provide particular benefits to the pharmaceutical and other health industries. Firstly, they get direct access to consumers to promote their products. In disease-focused groups, this may enable direct access to a target market. In broader population groups, such as 'seniors' groups or women's groups, this may enable the promotion of products through "disease awareness" campaigns. Sponsors can exert influence in a number of ways including the use of company logos and displays on web sites and newsletters, displays of products at events such as meetings and conferences, distribution of information about products, involvement in the organisation of conferences, providing speakers at meetings, and disease awareness campaigns. These activities enable the industry to create brand loyalty and widen its influence, especially if its products are promoted or endorsed by consumer health opinion leaders. The ultimate goal is market expansion and increase in profits.

Secondly, the industry company also benefits from association with the "good name" of the consumer organisation. The perception of the company as generous, caring, and public-spirited may be enhanced.

Thirdly, by building partnerships and loyalty with the consumer organisation, the industry creates a potential ally to lobby on its behalf to regulatory or funding agencies or to champion its cause publicly. Thus it can avoid the appearance of self-interest by having another public interest voice speak for its cause (Herxheimer 2003; Medawar & Hardon 2004).

## BENEFITS AND RISKS FOR CONSUMER ORGANISATIONS

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In New Zealand there is a lack of dedicated public funding for consumer health groups even though there is growing recognition internationally of the important role they play in civil society. Many groups seek grants from public funds, usually competing with a wide range of other social service and voluntary groups. There is no dedicated fund of public money for consumer health groups. Compared to larger countries, sources of funds from donations, bequests, private philanthropic trusts and sponsorship are very limited. Consequently, the offer of funding from industry sources can appear attractive.

At the same time, there is an increasing expectation on the part of the public that non-government organisations, including consumer health organisations, will exhibit good governance, employ good practices, especially financial practices, and be accountable to the public for performance. An aspect of accountability is financial accountability, including such things as disclosing sources of funding and having policies around financial management, including conflict-of-interest statements.

Surveys in Europe have shown that few health charities disclose in their annual reports how much of their revenue is derived from corporate giving and none reveal how much of their revenue is derived from the pharmaceutical industry. A survey of patient organisations in the European Union found that only one-third had a conflict of interest statement (PatientView 2004).

As most health consumer groups claim to act in the public interest, there is a risk that public confidence in these groups will be undermined by a lack of ethics around financial practices and accountability. Public trust is critical for health consumer groups. Can it be maintained if the public loses confidence about the independence and integrity of the groups?

As well as access to scarce funds, the other major reason put forward in support of patient organisations having links to the pharmaceutical industry is to access up-to-date information about treatments that may be of interest to their members (Herxheimer 2003). However, this argument has limited weight in the Internet age, when members of the public and groups have access to many of the information sources, such as databases and on-line journals, which previously were restricted to health professionals. Groups such as the Cochrane Collaboration and the New Zealand Guidelines Group are increasingly translating the results of research and systematic reviews into lay language and patient-friendly forms, so that previously inaccessible information is freely available. Projects such as Discern and decision-making aids aim to assist consumers in deciding about treatments from a range of options and to assess the quality of the scientific information supporting claims made for them.

There is a problem in accepting information from a single source, particularly an industry source, as there may be other options that consumers would like to know about. There are particular risks in disease-focused groups receiving funding from industries that supply the main treatments for the disease.

There are also questions about the quality of information that pharmaceutical companies provide for consumers and doctors, as often it is selective and not evidence-based (Lexchin & Mintzes 2002; Tuffs 2004). Companies can suppress or distort information that does not support their products, and this can include efficacy and/or safety data (Braithwaite 1984; Mintz 1985). In addition, pharmaceutical companies 'construct' information, for example, buying space in respected journals to publish results of symposia and other non-peer reviewed information (Horton 2004).

Health industries may seek to promote emerging pharmaceuticals and products to gain market share, but knowledge about the efficacy and risks of these may be incomplete. Consumer groups may run special risks if they join in promoting these new products and they are shown subsequently to be harmful or less effective than promised.

There are particular risks of accepting industry funds in the New Zealand context.

New Zealand is one of only two countries in the world to allow direct-to-consumer advertising of pharmaceuticals (the other being the United States). This means that New Zealand consumers are already directly influenced by pharmaceutical companies. Currently, there is no comprehensive independent health information service for New Zealanders. The need for this was endorsed at the Independent Consumer Health Information Conference held in Christchurch in 2004.

Another issue that has been raised is that of medicalisation. Emphasis on medical solutions may divert attention from other approaches to addressing health and social problems. Groups representing well populations, such as women and older people, may inadvertently facilitate medicalisation of normal processes, life stages or health conditions that are amenable to non-medical prevention strategies, for example, lowering the risk of diseases of aging by smoking cessation, keeping fit and eating a healthy diet.

Consumer groups are looked to by consumers to provide information that is consumer-focused and not biased in favour of particular external sources. If consumer groups receive pharmaceutical funding, consumers may not regard this as independent. Even if the company does not exert direct influence, consumers' perception of the independence of the group may be affected. Consumer groups who endorse industry products may undermine their credibility amongst the public. What consumer groups have to lose is their reputation, which is precisely what makes them attractive to industry.

## EXAMPLES ON POLICIES ON ACCEPTING INDUSTRY FUNDS

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Some consumer and other health organisations have policies not to accept pharmaceutical funding, along with other sources which are viewed as compromising, such as tobacco, alcohol, and gambling industries. Others lack policies or accept funding in some areas of activity or to certain limits.

Some consumer organisations that do accept funding use a number of methods to try to limit or avoid the influence of the company.

### **Long Term Medical Conditions Alliance (UK)**

The UK *Long Term Medical Conditions Alliance* (LMCA) includes the following guidelines for itself and constituent groups:

- The consumer organisation's independence must not be compromised and the relationship must be transparent
- LMCA favours funding consortiums rather than one company
- Accepting the funds will not cause adverse publicity
- The funder does not try to coerce or over-influence LMCA's policy or actions either implicitly or explicitly
- LMCA does not endorse products because people living with long-term medical conditions need the widest range of treatments.

The LMCA encourages active working partnerships between pharmaceutical industry and consumer organisations, advising them to work together on policy development and practical initiatives (Herxheimer 2003). However, it may be naïve to think that this can occur without the patient organisation being influenced by the company. The Medical Council of New Zealand acknowledges in its guideline on commercial sponsorship that research shows doctors are "susceptible to influence, even if it is subconscious" (Medical Council of New Zealand 2003). Although there is a lack of research examining whether patient organisations are influenced by sponsors, there are plenty of anecdotes and there is no reason to think that consumer organisations would be any less susceptible than doctors.

### **National Breast Cancer Coalition (USA)**

The *National Breast Cancer Coalition* (NBCC) in the US has another kind of policy. It wants to ensure that "patient advocacy and education [is] designed, implemented and led by patients to be credible" and says it has always been concerned about "the perceived influence of money on our work".

It will not take any money from Government and although it will accept industry sponsorship; it "will not take more than 15 percent of its annual budget from entities that directly profit from the screening, diagnosis or treatment of breast cancer. Nor will it take more than five percent of its budget from any one entity in this category" (web site for NBCC [www.stopbreastcancer.org](http://www.stopbreastcancer.org)). It must be pointed out that the NBCC has enormous funding by the standards of the average New Zealand consumer group, even national ones.

### **Cochrane Collaboration (UK)**

The *Cochrane Collaboration* policy, arrived at after a consultation with members that drew 156 responses, decided to severely restrict commercial sponsorship by for-profit manufacturers or providers of health care, but not for not-for-profits and for-profit companies that had no real interest in Cochrane reviews (eg banks).

Its policy stated that:

- There should be a clear barrier or 'firewall' between production of Cochrane reviews and any funding from commercial sources with an interest in the conclusions of Cochrane reviews. Thus any such sponsorship of reviews or Review Groups was prohibited.
- Other sponsorship is allowed but the sponsor is not allowed to interfere with, delay or prevent publication.
- The same restrictions apply to the Cochrane Consumer Network.
- A central fund or Foundation is to be established into which unrestricted funds can be put.

### **Health and Social Campaigners' News**

A recent issue of the publication *Health and Social Campaigners' News* recommended that health consumer groups adopt a strategic framework to reassure the public of an ethical approach even if they accepted pharmaceutical industry funding (PatientView 2004). This included:

- Improved governance, including a clear set of objectives, robust systems for financial management, a culture of openness and honesty, and continued contact with the grassroots to obtain feedback on performance.
- Constitutions that specify what the organisation stands for and hopes to achieve, including conflict-of-interest statements. These would define what are considered to be legitimate sources of funding and situations where certain sorts of funding are unacceptable.
- Statements of funding policy. Corporate donors might be required to sign explicit contracts detailing their relationship with the consumer health body.
- Monitoring donors. This would involve scrutinising and policing the ethical reputation and activities of donor companies. It could also involve blacklisting particular companies or industries.

- Refusing to endorse products because this reduces the options of consumers.

## OPTIONS FOR NEW ZEALAND CONSUMER GROUPS

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### Option 1

Independent funding body that distributes aggregated pharmaceutical funding. A number of New Zealand consumer advocates support the concept of a Government funding body that is able to collect funds from the pharmaceutical industry and then make funding available to consumer groups.

The model they have proposed is the Health Sponsorship Council, which distributes funds gathered through taxation of the tobacco industry. Currently the Government has no mechanism for collecting funds from health industries. It is possible that a voluntary system of donating could be established or that the independent funding body could gather funds from a number of sources.

### Option 2

Group develops its own funding policy/guideline that prohibits acceptance of any funding from any health industry source.

### Option 3

Group develops a funding policy/guideline that prohibits acceptance of funding from specified health industry sources but accepts funding from companies that the group believes could never compromise its independence.

For example, a menopause group might decline ever to accept funding from companies producing pharmaceutical or alternative therapies, but might accept funding from companies producing atomized facial water sprays or bed linen made from natural fibres.

### Option 4

Group develops a policy that proscribes funding from industry sources on a case-by-case effects-based basis. For example, this might prohibit funding that has particular consequences, such as if it:

- enables a company to gain a 'favoured status' with the consumer group;
- influences the group's policies and practices;
- potentially undermines the reputation of the group; or
- has the potential to medicalise the section of the population served by the consumer organisation.

## Option 5

Group develops a policy that places restrictions and constraints around the funds and the relationship with the donor.

- A 'firewall' could be placed between the funds and the use of the funds. For example, a separate entity or trust could collect and distribute the funds.
- Funds are accepted on the basis that the industry organisation has no influence on the use to which the funds are put. This could be stated in a contract with the corporate donor.
- A cap could be placed on the amount of industry funding that is accepted, collectively and from individual sources.
- Products will not be endorsed.
- The consumer group will publicly acknowledge sources of funds, such as on websites and in Annual Reports.

## **F E E D B A C K**

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We invite feedback from consumer organisations on this paper and the options we have outlined. Please note that you can support more than one option. A questionnaire is attached to this paper.

Feedback can be sent to the following address:

Feedback on CAC discussion paper  
C/- CAC Secretary  
PO Box 10-254  
WELLINGTON

## REFERENCES

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HEALTH INDUSTRY SPONSORSHIP  
OF CONSUMER HEALTH ORGANISATIONS

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**Questionnaire**

Consumer Advisory Committee  
PHARMAC



5. Number of members?
6. From the options listed in the Discussion Paper, which option or options do you prefer? (tick as many as you wish)
- Option 1
  - Option 2
  - Option 3
  - Option 4
  - Option 5

Please briefly outline why you have chosen this option or options.

7. Do you have another option (if yes, please outline)? Yes/No
8. Has your organisation been offered industry support?\*
- Yes/No
9. Does your organisation accept industry support?
- Yes/No
10. If your organisation has never been offered industry support, would your group accept it, if offered?
- Yes/No

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\* "Support" can include direct funding, sponsorship of conferences, provision of support materials or services such as advertising or public relations work.

11. If your organisation has received industry support, please specify the sources
- Pharmaceutical industry
  - Other health industry
12. Does your group have a policy on industry support? Yes/No  
If yes, please briefly outline this policy.
13. Would you make your policy available as a resource? Yes/No  
(if yes please attach)
14. Is there any limit on the support that is accepted? Yes/No
15. Can you express the limit as a proportion of total funds received by your organisation? Yes/No
16. Does your organisation accept only unrestricted funds (that is, **not** tied to a specific purpose)? Yes/No
17. If no, please outline the purposes to which funds can be put
18. Does your organisation endorse products or treatments produced by a company from which you receive funding or support? Yes/No
19. Does the industry from which you receive funding or support have any direct input into consumer information or other publications of your organisation? Yes/No

20. Do you disclose the support publicly and, if so, where? (tick as many as you wish)
- Annual report
  - Annual accounts
  - Web site
  - On any specific products, events, resources that have received industry funding
  - Other, please specify
21. Do you have examples from your own experience of the risks of accepting support from the pharmaceutical industry? Please describe briefly.
22. Do you support the development of a checklist and a voluntary guideline on health industry support of consumer health groups?
- Yes/No
23. Would you like us to inform you about the result of the consultation?
- Yes/No
24. Would you like us to continue to inform you of any other developments in this area?
- Yes/No
25. Can we identify information you have provided as coming from your group or would you rather keep it confidential?
- Happy to have information identified
  - Want to keep all information confidential
  - Want to keep some information confidential. (Please write numbers of questions you want kept confidential here)
-