

Relationships between the pharmaceutical industry and patients' organisations

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Pharmaceutical companies and patients' organisations are unequal partners in a collaboration that has developed over the years—and this raises serious questions

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That different groups of stakeholders in an activity should work together constructively is widely regarded as an ideal. This has brought pharmaceutical companies and patients' organisations together and led them to explore areas of shared interest. Various forms of collaboration between these unequal partners—one usually rich, the other poor—have developed over the years, and have raised serious questions.^{1,2} This article explores the position, mainly in the United Kingdom, which has hundreds of self help groups and support organisations.³ The table lists some of the most prominent. Similar problems exist in other countries where patients' organisations have become important, notably the United States.

Needs and wishes

Like other commercial enterprises, the major companies focus on making a profit, and this determines their priorities. They want to sell their products in large quantities and expand their markets, far into the future. With new drugs this must happen fast, because research is expensive and the costs must be recovered quickly before competing products arrive.

Patients' organisations want adequate care for the people they speak for, usually with specific diseases or health problems—though often they do not represent them. They and the individuals they try to represent want to be listened to, and as far as possible to be treated as equal partners by the health professions and the institutions of the health service.

Box 1 lists the main needs or wishes of each party. The discussions and negotiations between them must of course consider the costs, potential disadvantages,

Summary points

Pharmaceutical companies believe that if patients were aware that their prescription drugs could help them, sales would increase

Advertising drugs to patients is not allowed, so companies try to inform patients in other ways

Patients' organisations may welcome financial and other help from companies

Such relationships must be at arm's length and transparent, and not affect the agenda and priorities of patients' organisations

and harms for each of them as well as the potential benefits of any arrangement.

Guidelines

The Long Term Medical Conditions Alliance, an umbrella body with more than 100 members representing many different conditions, offers guidelines to voluntary health organisations on relations with the pharmaceutical industry (summarised in box 2).⁴ These emphasise that "it is important to maintain cooperative relationships with companies which develop, manufacture, and market medicines and other treatments, so as to foster communication between the patients whose interests we represent and the companies whose decisions will affect their treatment."

These guidelines, which are to be developed further and refined, clarify the alliance's own position to member organisations, to the industry, and to the public. Individual patients' organisations can adopt them and adapt them to their needs. To make them work, however, would need monitoring, enforcement, and sanctions, with compliance as a condition of membership of the alliance—a distant hope. For instance, one big member of the alliance states: "Products highlighted on the Diabetes UK website are not necessarily endorsed by Diabetes UK" and says that it "will make a charge for the use of its logo/name or link to our website [by a] profit-making organisation."

Credibility

A self help organisation or patients' organisation risks its credibility if it becomes identified with one or more companies. Its independence and good name are best protected by explaining its sources of funding, for what

Box 1: Short term [S], medium term [M], and long term [L] wishes

A patients' organisation needs help with:

- [S] Project funding: surveys of members and of services available for them
- [S] [M] Information about treatments and diagnosis; production of information materials
- [M] Lobbying for resources to help people with the disease or problem
- [M] [L] Business know how—fundraising, publicising itself, growing big
- [L] Core funding

A pharmaceutical company would like patients to help with:

- [S] [M] Market expansion:
 - Use of its drugs by all who might benefit
 - More efficient and prompt diagnosis of the problem the drug is intended for
- [S] [M] First line use of its products—rather than competing ones
- [M] Lobbying against restrictive government or health service policies and regulations
- [L] Being seen as a caring and socially responsible business

Some prominent UK patients' organisations

Organisation	Member of LMCA	Likely to have a particular interest in pharmaceuticals
Age Concern		Yes
Alzheimer's Society		Yes
Arthritis Care	Yes	Yes
Blood Pressure Association	Yes	Yes
Breast Cancer Care		Yes
British Colostomy Association		
British Heart Foundation		Yes
British Lung Foundation	Yes	Yes
CancerBACUP	Yes	
Cancerlink		
Changing Faces		
Coeliac Society	Yes	Yes
Cystic Fibrosis Trust		Yes
Diabetes UK	Yes	Yes
Different Strokes		
Down's Syndrome Association		
Haemophilia Society	Yes	Yes
Incontact	Yes	Yes
Insulin Dependent Diabetes Trust	Yes	Yes
Macmillan Cancer Relief	Yes	Yes
Lymphoedema Support Network	Yes	
Migraine Trust	Yes	Yes
MIND		Yes
Motor Neurone Disease Association		
MS Society	Yes	Yes
National Asthma Campaign	Yes	Yes
National Childbirth Trust		Yes
National Eczema Society	Yes	Yes
National Kidney Federation		
National Osteoporosis Society	Yes	Yes
National Endometriosis Society	Yes	Yes
National Schizophrenia Fellowship	Yes	Yes
National Society for Epilepsy	Yes	Yes
Neuropathy Trust		
Ovacome		Yes
Parkinson's Disease Society	Yes	Yes
Patients Association		
Psoriasis Association	Yes	Yes
Scope		
Sickle Cell Society	Yes	Yes
Sjogren's Syndrome Association		
Stroke Association	Yes	

LMCA=Long Term Medical Conditions Alliance.

purposes each funding stream is used, and any competing interests. At present many voluntary health organisations volunteer minimal information about their structure and funding, and some are reluctant to discuss the subject. Charities that solicit funds from individuals may fear that knowledge of large contributions from industry could undermine appeals to prospective donors.

The Long Term Medical Conditions Alliance's guidelines "favour the use of funding consortia composed of two or more companies from the same industry" but do not consider whether industry funding should be limited to some modest proportion of a voluntary health organisation's total funding. If industry directly or indirectly funds a large part of the budget, say over 20%, the organisation comes to depend on it and this, if nothing else, will influence policies.

An interesting case is the Lymphoma Association, a charity that is somehow linked with Roche. The

portal www.lymphoma.org.uk leads to two sites: /healthcare.htm for professionals and /support for the public. The first is password protected, "is made possible by an educational grant from Roche Products," and links to a Roche site. The second, which is freely accessible, nowhere mentions Roche. One consultancy firm manages both sites.

There have been instances of companies or their public relations agents creating new "patient groups." In 1999 Biogen set up Action for Access in their effort to get the NHS to provide interferon beta for multiple sclerosis.⁵ The Medicines Control Agency stopped this as unlawful promotion. In the United States, activities that are more veiled have succeeded. The National Alliance for the Mentally Ill, "a grassroots organisation of individuals with brain disorders and their family members," between 1996 and 1999 received almost \$12m from 18 drug companies, led by Eli Lilly.⁶ The organisation promotes the nationwide expansion of PACT (Program of Assertive Community Treatment), which includes home deliveries of psychiatric drugs backed by court order.

Lobbying

Two prominent international federations, IAPO (International Alliance of Patients' Organisations) and GAMIAN Europe (Global Alliance of Mental Illness Advocacy), are linked to the pharmaceutical industry and highly visible. IAPO, registered as a foundation in the Netherlands, was founded and is funded by Pharmaceutical Partners for Better Healthcare, a consortium of about 30 major companies; Gamian was founded by Bristol-Myers Squibb (Gamian Europe has since separated from it). The European Commission prefers to hold discussions with these federations rather than patient and consumer groups, apparently because, unlike most voluntary health organisations, they claim to represent patients in many countries. Neither publishes its sources of funds. With other organisations linked to the industry, they successfully lobbied the commission to propose allowing industry to provide direct to consumer "information" about prescription medicines (the European Parliament is opposing this). Early in 2000 the director of the



Patients' groups will go to extreme lengths to raise funds—88 year old Rosina Burson abseils to raise money for Macmillan Cancer Relief

DEMPSEY SEAN/DEMPSEY/PA

Box 2: Guidelines on working with the pharmaceutical industry

Relationships with pharmaceutical companies

- Relationships between voluntary health organisations (VHOs) and pharmaceutical companies can and should be based on equal partnership. Both sides must be prepared to move beyond the VHOs being passive recipients of money to a scenario where the two work together on policy development and practical initiatives, in the interests of the patients whom the VHO represents, while preserving its independence.
- Each party should remember that successful partnerships are those where both partners gain something, and each should make efforts to understand the internal culture of and external pressures on the other.
- VHOs should recognise that pharmaceutical companies have to be profitable, and have their own particular marketing agenda, to which no VHO should ever feel obliged to conform. Funding should be rejected if the alternative is compromising the VHO's independence in any way.

Funding

- The Long Term Medical Conditions Alliance (LMCA) encourages the use of available funding so long as the VHO's independence is not compromised in any way and so long as the relationship is totally transparent. Contracts between the parties help in this respect.
- LMCA frowns on relationships designed to give one company competitive advantage over another, and, where possible, it favours the use of funding consortiums composed of two or more companies from the same industry.
- Joint research initiatives must ensure that independence is not unwittingly eroded and the policies of the Association of Medical Research Charities are not contravened.
- LMCA itself accepts funding from pharmaceutical industry groupings or companies when:
 - It believes it will result in benefit to LMCA and at least some of its member organisations;
 - The director is satisfied that accepting the funds will not court adverse publicity; in case of doubt the board's advice is asked before accepting;
 - The funder does not try to coerce or over-influence LMCA's policy or actions either explicitly or implicitly.
- A charity's good name is its most valuable asset. Both charity law and agreed best practice preclude the exploitation of a charity's name for non-charitable purposes. LMCA's name must not be used to imply approval or endorsement of any of the donor's products or policies, without the director's prior written approval.

Product endorsement

- LMCA endorses no individual treatments, because people living with long term medical conditions need the widest possible range of treatment options, to integrate them as they wish. These may include medicines, complementary therapies, lifestyle changes, and non-therapeutic products such as vacuum cleaners.
- We encourage active partnership between patient and health professional and discussion of all available options, to promote informed choice by the patient.
- Where a drug exists in more than one version we encourage the use, in communications by VHOs with patients, of either the scientific name or the several different brand names. Publications should show impartiality.
- LMCA supports the proper licensing of medicines and believes that the marketing of non-drug treatments to the public requires similar rules and standards.

Association of the British Pharmaceutical Industry had privately described the association's "carefully thought-out campaign." The ABPI battle plan is "to employ ground troops in the form of patient support groups, sympathetic medical opinion and healthcare professionals ... which will lead the debate on the informed patient issue. This will have the effect of weakening political, ideological and professional defences ... Then

the ABPI will follow through with high level precision strikes on specific regulatory enclaves in both Whitehall and Brussels.³⁷ The battle is still going on.

Conclusions

Most patients' organisations are poor and have little independent funding. Grants from and joint projects with pharmaceutical companies can help them grow and be more influential, but can also distort and misrepresent their agendas. Relationships must therefore be fully acknowledged and open, without public relations flummery.

Society as a whole should do more to enable patients' voices to be heard. Various recent initiatives in the NHS show that this is recognised, but some modest public funding for patients' organisations should also be considered. This seems at least as important as public funding for political parties, and it should cost very much less.

Meanwhile regulatory agencies have to distinguish between independent and extensively funded patient groups, and they must realise that many groups have a tiny base and cannot be representative.

Competing interests: For over 40 years AH has tried to help the pharmaceutical industry, with notably little success; he has long worked with Consumers' Association, Consumers International, Health Action International, and the International Society of Drug Bulletins. AH is co-founder of DIPEX (www.dipex.org) and a participant in the Cochrane Consumer Network.

- 1 Hogan B. Pulling strings from afar: drug industry finances non-profit groups that claim to speak for older Americans. *AARP Bulletin* 2003 February. www.aarp.org/bulletin/departments/2003/consumer/0205_consumer_1.html (accessed 16 May 2003).
- 2 Consumers' Association. Who's injecting the cash? Money from drugs companies could do patient groups—and patients—more harm than good. *Which?* 2003 April: 24-5.
- 3 *Help! Guide to national self help groups*. 9th ed. Blackpool: G-text, 2002.
- 4 LMCA Board of Trustees. Working with the pharmaceutical industry. Guidelines for voluntary health organisations on developing a policy. June 2000. www.lmca.org.uk/docs/pharmgds.htm (accessed 2 May 2003).
- 5 Boseley S. Drug firm asks public to insist NHS buys its product. *Guardian* 1999 Sept 29.
- 6 Silverstein K. Prozac.org. *Mother Jones* 1999 Nov-Dec. www.motherjones.com/mother_jones/ND99/outfront.html#name (accessed 16 May).
- 7 Jeffries M. The mark of Zorro. *Pharmaceutical Marketing* 2000 May:4-5.

Endpiece

The atmosphere of London

In London, when a man receives into his lungs a draught of air, he cannot be sure that it has not been in some other person's lungs before. This second hand atmosphere cannot but be injurious to health, as the idea of it is offensive to the imagination.

J Reid in
Essays on hypochondria and other nervous affections,
1816

Jeremy Hugh Baron,
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