

Pharmaceuticals and the consumer movement: the ambivalences of ‘patient power’

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Abstract

Consumer and patient advocacy groups (PAGs) are important participants in the politics of pharmaceuticals. Yet very little is known about the precise nature and extent of their influence. It is argued in this article that PAGs fulfil a mixed role within the health system at national and transnational levels, and that they are at times fully incorporated into economic and political power structures. Their frequent dependence on pharmaceutical industry funding is of particular concern. PAGs provide a means of direct industry interaction with the final customer, thereby partially bypassing and putting additional pressure on doctors and regulators. The article presents the case for research to establish a better empirical base for discussions about the role of PAGs within contemporary neoliberal governance structures.

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A DIVERSE RANGE OF CONSUMER and patient advocacy groups (PAGs) has become increasingly influential in the prescription drug domain in Australia and internationally. Their activities include the dissemination of information, advice and counselling, support for disease sufferers and families, lobbying, fund raising for research, and participation in the development and implementation of government programs. They fulfil an important role for many people suffering from particular medical conditions and their families. PAGs have contributed to enhanced medicinal

What is known about the topic?

Consumer and patient advocacy groups are important participants in the politics of pharmaceuticals. Yet very little is known empirically about their resources and about the extent of their influence in Australian policy processes.

What does this paper add?

This article presents the case for research focusing on the role of consumer and patient advocacy groups in Australia. It highlights risks and dilemmas resulting from the incorporation of consumer and patient advocacy groups into contemporary neoliberal governance structures and the marketing strategies of the pharmaceutical industry.

What are the implications for researchers and policymakers?

Policymakers must acknowledge the ambivalences of consumer and patient advocacy groups. It is incumbent upon such groups to make links with pharmaceutical (and other) companies transparent and to develop and make public clear policies in respect of sponsorships.

drug safety and greater industry and government sensitivity to the interests of patients and consumers. They bring substantial resources — budgets, expertise, the capacity to mobilise members and public opinion, and credibility — to interactions with government, research organisations, and the pharmaceutical industry at local, national and international levels. PAGs are commonly perceived as more trustworthy than actors with obvious vested interests such as corporations and public agencies seeking to curtail costs. Australian consumer groups have gained representation within the policy process, including central regulatory bodies such as the Pharmaceutical Benefits Advisory Committee (PBAC) and the Pharmaceutical Benefits Pricing Authority (PBPA). The Consumers’ Health Forum (CHF) reports that “Health consumers are represented on 200 Government, Department of Health &

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Ageing, and professional and research committees" (Consumers' Health Forum of Australia 2003, p. 28). Australian PAGs also participate in 'global' general patient and consumer networks including the International Alliance of Patients' Organizations (IAPO) and Consumers International as well as disease-specific organisations such as the Global Lung Cancer Coalition.

Most health consumer groups — when not set up purely as front organisations — have some of the attributes of the new social movements that emerged in the 1960s. PAGs have often contested the knowledge claims made by established experts and economically powerful actors. But their critical edge, and their autonomy as civil society-based organisations, is likely to be weakened through co-option into government structures and dependence on the health professions and, in particular, the pharmaceutical industry. At times PAGs now resemble corporations, with chief executive officers, large budgets, and business plans, working in partnerships with government departments and mighty pharmaceutical companies. Several observers have noted that they fulfil a rather mixed role within the health system at national and transnational levels, at times fully incorporated into economic and political power structures (Burton & Rowell 2003; Duckenfield 2002; Herxheimer 2003; Jones, Baggot & Allsop 2004; Consumers' Association (UK) 2003; Wood 2000). The *Age* newspaper in December 2003 published a detailed investigation into the funding by pharmaceutical companies of supposedly independent PAGs, highlighting a pattern of non-transparency bordering on corruption (Hughes & Minchin 2003). This article also cautions against a too celebratory assessment of the contribution of PAGs. Its main purpose, however, is to bring to the fore the need for research focusing on the health consumer movement in Australia. Very little is known about the nature and extent of the influence of PAGs in the pharmaceutical domain in Australia. Empirical investigations comparable to those of Allsop, Baggott & Jones (2002), Jones, Baggott & Allsop (2004), Baggott, Allsop & Jones (2004) and Wood (2000) in the UK have not been undertaken. This

article does not remedy this absence of knowledge, but it explores the context and some of the issues that such a research project would have to address. Evidently, future research will have to disentangle more carefully the complexity of PAG activity which encompasses, to different degrees, advocacy, service provision, consumerist lobbying, front activities for the medical profession and the pharmaceutical industry, etc. In this article, groups of different orientation with very different activity patterns are all discussed under the 'grab-all' category of consumer and patient advocacy groups (PAGs).

From corporatist to neo-liberal governance in the pharmaceutical sector

The emergence in the past twenty-five years of consumer groups as influential actors in the pharmaceutical (and other) domains, across the industrially developed countries, forms part of broader processes of cultural and socio-economic change theorised in the social movement literature (Castells 2004; Della Porta & Diani 1999). This transformation has produced citizens less inclined than in the past to trust authorities unquestioningly. The notion of 'risk society' provides a perspective from which this phenomenon can be explored. In a risk society state (regulatory) action revolves around the management of the unpredictable and potentially disastrous consequences of science and technology. The extent and nature of risks, which transcend borders, cannot be objectively determined, and risk assessments can therefore not be delegated to scientists and technocrats (Beck 1992; Lupton 1999). It is no longer acceptable for decisions to be taken behind closed doors by industry and regulatory officials — this mode of operation is bound to generate public apprehension and, at times, organised opposition and social instability. Rather, there must be scope for participation by different social interests including 'consumers'. In this sense, PAGs and other actors in the pharmaceutical domain engage in the politics of risk, that is, they form opinions and participate in delibera-

tions about the risks and benefits of existing and prospective medicinal drugs. A second, perhaps complementary, perspective on the phenomenon of 'patient power' is provided through the notion of neo-liberal governance.

The dynamics of the Australian pharmaceutical sector have certainly been transformed since the early 1980s. This sector used to be characterised by relatively closed, arm's-length interaction between government regulatory agencies, research organisations, the medical and pharmacy professions, and the big pharmaceutical companies. The government, which exercised a high degree of autonomy vis-à-vis producer and professional interests, acknowledged the de facto representational monopolies of the Australian Pharmaceutical Manufacturers' Association (now Medicines Australia), the Pharmacy Guild of Australia (PGA), and the Australian Medical Association (AMA). Marketing approval (safety) regulation was framed by a degree of scepticism on the part of regulators with regard to the industry. Government policy objectives were to ensure public health and safety, and to maximise consumer welfare "without primary concern for the profits of multinational drug manufacturers" (Johnston 1986, p. 44). The concept of corporatism captures this pattern: the government in this perspective is seen as providing a framework and a rationale for orderly bargaining between capital and labour in particular, but at times also other functional interests (Molina & Rhodes 2002). To fulfil this role, the state has to "be relatively independent from too-narrow outside political, social, and economic pressures and influences" (Cerny 1990, p. 156). Thus, regulatory agencies must not be too close to lobby groups and sectional interests, and, by and large, in the period before the mid-1980s relations between the pharmaceutical industry and the Department of Health were not close and cordial.

This pattern of corporatist exchange between a few core stakeholders has been weakened and we now find more 'pluralist' relations, premised on the notion of partnership, between a wider range of actors (Lofgren & de Boer 2004). At both national and transnational levels, relations

between stakeholders are characterised by mutual dependence and the sharing of responsibilities rather than outright bargaining or purely market-driven interaction. Australia and other industrially developed countries, however, retain large public sectors and the building and protection of markets are accepted as essential functions of government. Forms of public power associated with the welfare state have diminished, but state interventions continue to be necessary to sustain a market economy, including appropriate regulation of the pharmaceutical sector (Lewis & Abraham 2001). Complex government controls continue to affect all stages of the pharmaceutical production and distribution chain: basic research, product development, manufacturing, exports and imports, market access, marketing, wholesaling and retail distribution, and most countries also have direct or indirect regulation of drug prices and profits. Certainly, governments prefer market exchange to direct and unilateral state steering to achieve political and social objectives. But the question ultimately is not whether governments should impose rules and regulations in various domains in the economy and society, but precisely how these rules and regulations should be designed in order to facilitate market interaction while retaining social acceptability. Governments then, in the era of neo-liberalism, operate as coordinators and catalysts within horizontal and ever more internationalised networks, particularly in the economic sphere. This trend is particularly marked in high-tech industrial sectors such as pharmaceuticals where science and knowledge play a central role in innovation and policy processes. Here the preferred mode of achieving public policy objectives is through co- and self-regulation, and national arrangements are framed by a rapidly developing international regime which includes as a central component the International Conference of Harmonisation (ICH) process (Abraham 2004; Abraham & Lawton Smith 2003; Braithwaite & Drahos 2000).

Organisational fragmentation and proliferation is a key feature of neo-liberal governance. In the pharmaceutical sector in Australia we find less uniformity than in the past within business and

the pharmacy and medical professions, and within government. The Therapeutic Goods Administration (TGA) and the Pharmaceutical Benefits Branch of the Department of Health & Ageing each pursue distinct objectives which can conflict with those of the Department of Industry, Tourism and Resources and other agencies, and all stakeholders must pay close attention to media reporting and public debates. The capacity of the TGA to impose regulation autonomously and unilaterally has diminished. A plethora of committees and working groups provide mechanisms for collaborative interaction, including, for example, the Australian Pharmaceutical Advisory Council (APAC), established in 1991, with a membership that includes suppliers, health professionals and providers, scientists, pharmacists, and PAGs. What we find in the pharmaceutical sector are “negotiated patterns of public–private co-ordination” (Pierre 2000, p. 3) and PAGs play an increasingly important role within such networks. This has come to be reflected in the language of ‘partnerships’ now popular within both business and government (Buse & Harmer 2004; Richter 2004).

The rise and attributes of the patient advocacy movement

Social movements since the 1960s have contributed significantly to cultural, social and political change (Della Porta & Diani 1999). Patient and consumer health groups in Australia and internationally can be considered an influential and diverse social movement, though not one much studied from the perspective of social movement theory (but see Brown et al. 2004). Wood (2000, p. 8) notes, in a rare study of ‘disease-related patients’ associations’ in the UK, that they are also largely neglected in the pressure-group literature. PAGs emerged when social attitudes were in flux — patients and citizens were becoming less deferential and trustful vis-à-vis doctors and other traditional authorities — and the movement in turn reinforced this change process. Today, patients are generally more aware of the need to be informed about treatments than in the past,

and regulators, health professionals and the industry are also more prepared to engage in consultation with consumers. Consumer representation is a reality across a multitude of public sector agencies and committees in Australia, and to some extent also in the private sector where consumer participation can, for example, add to the legitimacy of mechanisms of self-regulation. The internet provides a new major means of communication used with a high degree of professionalism by many health consumer groups. Functions and activities of PAGs include:

- Mutual support and self-help activities for patients and their families
- Direct service provision (counselling, etc.) and information about treatment options for patients, carers and professionals
- Lobbying for access to medical services and drugs
- Fund raising for research and lobbying to accelerate the development and approval process for new drugs
- Interaction with health professionals, scientists and industry, including assistance with the recruitment of participants for clinical trials
- Participation in the policy process (regulatory agencies and consultative committees, etc.)

As it is a diverse movement, PAG perspectives on existing drugs and medical devices and the risks and promises of new product developments can range from deep distrust to lobbying for fast-tracked access to new therapies. Yet when PAGs first emerged in the 1960s their focus was typically on building pressure for more stringent regulatory controls, and the formation of many groups was associated with the thalidomide calamity and other drug disasters (Mintzes & Hodgkin 1996). Paralleling the story of the environmental movement, relations with industry were characterised in this period by both a lack of mutual trust and, at times, confrontation. Cox (2002, p. 9) notes that “Most corporations were uncomfortable with the idea of ‘partnering’ with advocacy groups, because they often saw them as activists, unsympathetic to the profit interests of big business”. Health Action International (HAI), established in 1981 as a transnational network of

consumer activists, was denounced by the industry as extremist and “attempts were made to discredit them as Moscow-funded communists” (Mintzes & Hodgkin 1996, p. 79). The early activism of the AIDS community in the US was framed by distrust with regard to the pharmaceutical industry and government regulators, and radical activism was initially a hallmark also of many breast cancer groups. “At that time, only a few forward-thinking pharma companies recognized the potential return in building true alliances with patient groups” (Cox 2002, p. 9).

Conflict between PAGs and the industry remains a regular occurrence. Such tensions, however, more commonly involve groups with a broad consumer and social equity focus than disease-specific PAGs. Cases in point include the US non-profit consumer advocacy organisation Public Citizen, which regularly issues research-based studies critical of the pharmaceutical industry, Consumer Project on Technology and some of the groups associated with HAI such as the German BUKO Pharma-Kampagne. The CHF and the Australian Consumers' Association (ACA) emphasise their independence from the industry; indeed, the ACA on its website provides an explicit warning against “high-profile support groups . . . created and/or funded” by pharmaceutical companies. PAGs as discussed in this article cannot be readily separated from various public interest and social justice organisations in which health professionals play a prominent role. For example, Healthy Skepticism, an Australian initiative that commenced in 1982 as the Medical Lobby for Appropriate Marketing (MaLAM), monitors the techniques and impact of pharmaceutical promotion through an excellent website (<http://www.healthyskepticism.org>).

As PAGs proliferated from the early 1980s, relations with industry, government, and the medical research sector became more diverse and ambivalent. The quantitative expansion has been documented for the US and the UK, and Australia in all likelihood presents a similar picture (Jones, Baggett & Allsop 2004; Wood 2000). Many groups developed “a highly sophisticated analytical and policy framework” and have acquired substantial

resources (Davis 1997, p. 109). Sources of funding include membership fees and donations, federal and state government grants, charitable trusts, and in many cases sponsorships from drug and medical device companies. Duckenfield (2002, p. 3), studying the UK, notes that some PAGs

share the organizational characteristics that have enabled business associations and trade unions to pursue political solutions to their economic concerns. In terms of . . . financial resources, capacity for mobilising members, political access, and control over an issue space, many patient groups are quite comparable to major labour and business groups.

The hostility of the pharmaceutical industry towards the consumer movement has long been abandoned and PAGs are now seen as posing opportunities rather than threats. In particular, PAGs provide a means of direct interaction with the final customer, thereby partially bypassing, and putting additional pressure on, traditional intermediaries: prescribing doctors, regulatory agencies, and third-party payers. Disease awareness campaigns developed in partnership with PAGs weaken the impact of the prohibition of direct-to-consumer advertising (which is however legal in the US). The notion of ‘empowering’ the patient was a term with a radical and critical edge in the early days of the health consumer movement; today ‘personal choice’ and ‘patient power’ are catchphrases embraced by industry marketing experts (Hayes 1999; Mintzes 1998). There are at least four reasons for industry funding of patient groups:

- Patient groups enable companies to spread awareness of new drugs at a pre-launch stage and help to prepare the market;
- They provide a more credible endorsement of a product than could be achieved if the information was coming directly from the company;
- They can aid industry in arguing for fewer controls on drug licensing and pricing; and
- It enables companies to reach consumers directly. (Mintzes 1998, p. 17)

The credibility that PAGs carry with patients, the general public and government is probably

their key resource. At times PAGs strengthened by direct and indirect pharma industry funding serve to “diffuse industry critics by delivering positive messages about the health-care contributions of pharma companies to legislators, the media, and other key stakeholders” (Cox 2002, p. 8). Positive information about prospective new drugs builds demand for products before they may even have been approved. The importance of PAGs in industry marketing strategies is evident from the trade literature. Reuters Business Insight in January 2004 published *Harnessing Patient Power: Strategies for Speeding Drug Approval, Building and Retaining Market Share* (available for US\$1,219). Its content is described as follows (see <http://www.biz-lib.com/ZRBHPP.html>):

Relationships between the pharmaceutical industry and patient groups have changed drastically during the past two decades, they are no longer restricted to financial contributions to create goodwill, with no expectation of a measurable return for the company. The ... report ... outlines the developments in pharma-patient group alliances and provides a guide for maximizing their impact across a range of pharma activities: clinical trial recruitment, product launches, CME programs, disease awareness and education initiatives. Advocacy groups are now more aware of how to leverage their influence, but still seek financial assistance, cutting-edge information about clinical trials, new therapies, professional or technical support, and other in-kind contributions that help them better serve their patient communities. The report uses detailed case studies to pinpoint how pharma companies can convert such relationships into important business tools to meet their corporate objectives.

Similarly, PJB Publications (publisher of *Scrip Magazine* and *Scrip World Pharmaceutical News*) has published (2004) *Maximising Patient Power: Commercial opportunities for the pharma industry* (available for US\$1,670). The executive summary reads:

In recent years, it has been recognized that many pharmaceutical companies are taking

more of a consumer-oriented approach to marketing. The wide network of patient advocacy groups that exist to inform disease sufferers of drug information as well as lifestyle changes to cope with disease has prompted this. As a consequence, patients are finding extensive information about their disease conditions, thus empowering themselves. The advent of the Internet and subsequently healthcare portals has slowly moved the paternalistic patient-physician relationship towards one resembling increased free exchange of information. Healthcare professionals have critiqued the impact of patient empowerment on physician prescribing decisions in some depth. Until now, chronic disease patients and members of advocacy groups have had limited power. However, patients are advocating that they be perceived as experts in their disease condition. As a consequence, pharmaceutical companies are canvassing patient opinion on routes of drug administration and patients' requirements of a drug in advance of any marketing strategy being put into place. With a large number of drugs being marketed of the same classes the importance of patient opinion and needs has never been so important to the success of a drug.

The globalisation of the prescription drug sector — worldwide innovation, production, and marketing networks, a global regulatory regime centred around the ICH process, the politics of HIV/AIDS and generic medicines played out in the world media and on the internet, the monitoring across borders of drug access and pricing arrangements, etc. — has catapulted consumer groups into the sphere of global politics. The industry is investing resources in international consumer networks, notably the International Alliance of Patients' Organizations (IAPO) — see Herxheimer (2003) and reply from IAPO (van der Zeijden 2003). Braithwaite and Drahos (2000, p. 501) note that “knowledgeable advocates” associated with HAI, Health Skepticism and Consumers International participate, and wield a degree of influence, in the process of constructing global regulatory arrangements.

Consumer and patient advocacy groups in Australia

Early misgivings vis-à-vis the consumer movement are illustrated by the following exhortation by the then chairman of the APMA (now Medicines Australia) to the association's 1992 annual conference:

Remember with all resources the tobacco industry threw at their own survival, admittedly at the very last minute, the industry has been decimated . . . Frequently, the very ineptitude that these consumer lobby groups share works in their favour not against. They shape the agenda and their role to serve self-seeking purposes with little consciousness of the effect and impact of their efforts . . . They have little regard for the maintenance of a viable pharmaceutical industry . . . Concerted action is needed now to address all the elements — identified and obscure — that are challenging our industry. We must treat them seriously, no matter how absurd they may seem to our logical classic and scientific minds. (Exact quote from unpublished conference proceedings.)

But this attitude has been well and truly overturned. Australian PAG-industry relations are now extensive and diversified, paralleling developments in the UK and the US. Yet the precise extent of PAG participation and influence in the policy network in Australia is largely unknown. The most detailed investigation is the report published by *The Age* last year which concluded that “Many groups have become largely reliant on pharmaceutical money to keep going” (Hughes & Minchin 2003). The journalists detailed industry entanglements with consumer groups in a range of disease areas, including hepatitis, hormone replacement therapy, herpes, diabetes, depression and arthritis. The executive director of one PAG was quoted as saying that the “vast majority” of patient groups in Australia are heavily dependent on drug company money” (Hughes & Minchin 2003).

The membership listing of the CHF provides an indication of the range of local, state and national organisations in Australia providing support and advocacy for people with a particular disease.

This is by no means however a complete list; Alzheimer's Australia, Australian Cystic Fibrosis Association, Eczema Association of Australia, Multiple Sclerosis Australia, and others, are not listed as CHF members. Medicines Australia on its website also lists a large number of health consumer groups. Federal and state governments provide grants to a wide range of PAGs and draw on their participation in consultative processes. As already noted, the CHF in its annual report enumerates consumer representation on around 200 governmental working groups and committees. As in other fields of complex policy, government agencies in the pharmaceutical sector must be able to enlist the expertise of external organisations in the design and implementation of policy. Importantly, consumer consultation and representation bring added legitimacy to the policy process. Conversely, of course, participation provides opportunities for PAGs to exercise a degree of influence.

The major non-disease-specific consumer groups are, as mentioned, the ACA and the CHF, and the Combined Pensioners' and Superannuants Association of New South Wales (CPSA) also takes an active interest in pharmaceutical matters. They are not necessarily wholly detached from the pharmaceutical industry (Merck Sharp & Dohme and Pfizer are associate members of the CHF), but the primary focus of their activities — consumer access to quality drugs, appropriate prescription practices, and issues of affordable pricing — make them somewhat less interesting as ‘partners’ to the industry than the disease-specific groups. Yet CHF and “a representative of a patient support group (with specialist qualifications)” have representation on the Medicines Australia Code of Conduct Committee (Medicines Australia 2003a).

Both types of consumer groups are the recipients of federal and state government funding and have historically operated as allies of the Health Department on regulatory matters. A major focus has been on equity and accessibility issues, notably the role of the Pharmaceutical Benefits Scheme (PBS), and consumer groups were also early champions of the notions of ‘rational drug policy’ and appropriate prescribing. What has

happened in the past decade, however, is that the pharmaceutical industry has sought purposefully to weaken this connection, with associated scepticism vis-à-vis the industry, through dialogue and sponsorships. Medicines Australia maintains a database of PAGs and distributes a regular newsletter entitled *Medicines Matter* to more than 300 health consumer groups, and the significance of consumer dialogue is emphasised throughout the organisation's annual report (Medicines Australia 2003b). There are many cases of consumer groups becoming intertwined with drug company marketing. For example, the Arthritis Foundation of Australia on its website declares major sponsorships by Aventis, Merck Sharpe & Dohme, and Pfizer. Similarly, the Haemophilia Foundation Australia acknowledges (in its annual report) support from four companies (Baxter Healthcare, Bayer, CSL and Wyeth). At times, such groups are little more than front organisations for the drug industry, for example Impotence Australia was funded by Pfizer and several other companies to inform about Viagra and similar products. As concluded by Herxheimer (2003, p. 1210):

Grants from and joint projects with pharmaceutical companies can help [patient organisations] 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.

In the order of thirty Australian PAG websites (mainly national organisations listed as members of CHF) were explored for this article. Some have the feel of self-help groups with quite limited resources, but most have a highly professional design and contain large volumes of information. Indeed, Heart Support — Australia, ACCESS Australia National Infertility Network, Multiple Sclerosis Australia, and many others, have the appearance of business enterprises. Clear policy statements on sponsorships and transparency of relations with the pharmaceutical industry are, however, exceedingly rare. Proactive disclosure of possible conflicts of interest is by no means the norm.

The dilemma of inclusion and exclusion

Australian governments (at federal and state levels) in recent decades have provided plenty of opportunities for PAGs to participate in policy processes in the medicinal drug area and beyond, and much of their funding derives from governments. In their dealings with this movement, governments have been “actively inclusive” (Dryzek 1996, p. 478). (This may parallel the incorporation of feminism into the public sector; see Sawer 1990). As noted, within the policy networks of neo-liberal governance, consumer groups bring substantial resources to their interchange with regulatory agencies and the health professions, and they are also extensively entangled with the pharmaceutical industry. Clearly, they are not located unambiguously within the oppositional sphere of civil society, where many of them originally emerged as spontaneous, critical and sometimes radical groups, but have instead to an extent become part of the state itself.

Dryzek argues that inclusion into the state is benign for a social movement only under restrictive conditions. The key condition is that it must be possible to associate the objectives of the movement “with an established or emerging state imperative” (Dryzek 1996, p. 486). If there is no such overlap of ‘imperatives’ the outcome will be co-option that nullifies the original critical and oppositional edge of the movement. In contrast, Braithwaite and Drahos (2000) consider participation by consumer groups in ‘global epistemic communities’, and presumably also national policy processes, unquestionably to be the key means of monitoring and restraining transnational pharmaceutical companies and of achieving better public policy outcomes. Consumer groups from this perspective must become “part of the information flows and tacit workings of technical committees, drafting committees and standards committees” (Braithwaite & Drahos 2000, p. 625).

The safety regulation undertaken by agencies such as Australia's Therapeutic Goods Administration (TGA) is, perhaps, a case of public policy where a fundamental state imperative (the com-

mercial, social and political imperative of stringent risk management) coincides with the objectives of PAGs and the broader health consumer movement. It is not so clear whether the objectives of, say, rational, cost-effective and socially equitable use of medicinal drugs can be pursued most effectively by groups with a solid 'insider' status within the established structures of government and business. For such participation to be effective, it would seem necessary, at the very least, that a capacity is retained to confront state and business from a basis in civil society. Consumer groups and activists in the Australian pharmaceutical domain are to some extent engaged precisely in such autonomous capacity building and lobbying, but pressures for co-optation into the state, and cosy relationships with the industry, are indeed strong.

Conclusion

It is clear that health consumer groups play a significant role in the politics of pharmaceuticals at national and transnational levels. Coalition building and a degree of trust between stakeholders, and a capacity to influence public opinion, can be critical to success in the policy process. The pharmaceutical industry has taken this insight fully on board and now operates sophisticated strategies to directly and indirectly make use of PAGs to strengthen its hand vis-à-vis government regulators and for marketing and other purposes. It is therefore incumbent upon PAGs to actively make its links with pharmaceutical (and other) companies public and transparent (including support received in kind), as well as their policy in respect of sponsorships. The suggestion is not that such links are necessarily inappropriate, but it must be possible for consumers and the general public to readily establish their extent and nature. The aim must be adherence to high ethical standards, and the proof of this will be 'in the pudding' rather than in formal announcements. As noted by the *British Medical Journal*, "Codes of practice are mere window dressing unless they are explicit and vigorously observed" (Abbasi & Smith 2003).

Abundantly clear also is the need for research in Australia to establish more precisely the magnitude of PAG activity in terms of their number and memberships, sources of funding, pattern of activity, relations with other stakeholders, and the extent and nature of their influence. Investigations are necessary to separate genuine consumers' groups that retain some social movement attributes from industry front organisations, though many PAGs will probably be shown to be located in a grey zone in between. Deliberations about the risks and benefits of 'inclusion' and 'exclusion' also require better empirical data.

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