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# “Asset exchange”—interactions between patient groups and pharmaceutical industry: Australian qualitative study

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## ABSTRACT

### OBJECTIVE

To understand and report on the nature of patient group interactions with the pharmaceutical industry from the perspective of patient group representatives by exploring the range of attitudes towards pharmaceutical industry sponsorship and how, why, and when interactions occur.

### DESIGN

Empirical qualitative interview study informed by ethics theory.

### SETTING

Australian patient groups.

### PARTICIPANTS

27 participants from 23 Australian patient groups that represented diverse levels of financial engagement with the pharmaceutical industry. Groups were focused on general health consumer issues or disease specific topics, and had regional or national jurisdictions.

### ANALYSIS

Analytic techniques were informed by grounded theory. Interview transcripts were coded into data driven categories. Findings were organised into new conceptual categories to describe and explain the data, and were supported by quotes.

### RESULTS

A range of attitudes towards pharmaceutical industry sponsorship were identified that are presented as four different types of relationship between patient groups and the pharmaceutical industry. The dominant relationship type was of a successful business partnership, and participants described close working relationships with industry personnel.

These participants acknowledged a potential for adverse industry influence, but expressed confidence in existing strategies for avoiding industry influence. Other participants described unsatisfactory or undeveloped relationships, and some participants (all from general health consumer groups) presented their groups' missions as incompatible with the pharmaceutical industry because of fundamentally opposing interests. Participants reported that interactions between their patient group and pharmaceutical companies were more common when companies had new drugs of potential interest to group members. Patient groups that accepted industry funding engaged in exchanges of “assets” with companies. Groups received money, information, and advice in exchange for providing companies with marketing, relationship building opportunities with key opinion leaders, coordinated lobbying with companies about drug access and subsidy, assisting companies with clinical trial recruitment, and enhancing company credibility.

### CONCLUSIONS

An understanding of the range of views patient groups have about pharmaceutical company sponsorship will be useful for groups that seek to identify and manage any ethical concerns about these relationships. Patient groups that receive pharmaceutical industry money should anticipate they might be asked for specific assets in return. Selective industry funding of groups where active product marketing opportunities exist might skew the patient group sector's activity towards pharmaceutical industry interests and allow industry to exert proxy influence over advocacy and subsequent health policy.

### Introduction

Patient groups are increasingly influential advocates in health and pharmaceutical policy.<sup>1-4</sup> These groups also have an important role in patient support, patient and health professional education, and health research.<sup>5 6</sup> Much of the research on patient group relationships with the pharmaceutical industry has focused on the amount and extent of financial donations from companies to patient groups.<sup>1 7-9</sup>

Research consistently suggests that most patient groups receive financial assistance from the pharmaceutical industry. For example, 71% (39/55) of Finnish patient groups reported that they received financial support from the pharmaceutical industry in a 2003 survey<sup>7</sup>; 67% (165/245) of US patient groups reported that they received industry funding from pharmaceutical, device, and biotechnology companies, among others, in a 2013-14 survey<sup>1</sup>; and 83% (86/104) of the most wealthy US patient groups received funding from pharmaceutical, device, or

## WHAT IS ALREADY KNOWN ON THIS TOPIC

Most disease specific patient groups accept funding from pharmaceutical companies

Patient groups have important roles in providing support, advocacy, and information to patients and carers

The pharmaceutical industry exerts influence over the practices and decisions of health professionals through financial sponsorship

## WHAT THIS STUDY ADDS

The attitudes of patient group representatives towards pharmaceutical industry sponsorship range from enthusiasm and open mindedness to unease and philosophical opposition

Patient groups that receive pharmaceutical industry funding should anticipate they might be asked for specific assets in return

Selective industry funding of certain patient groups might allow the pharmaceutical industry to exert unrecognised proxy influence over advocacy and subsequent health policy

biotechnology companies in 2016, with 39% (23/59) of those that reported dollar amounts receiving over \$1 million (€907 300; £772 600) each year.<sup>8</sup>

Industry funding of patient groups appears to be rising. A United Kingdom study showed that total pharmaceutical industry payments to patient groups increased from £8179426 to £20964196 between 2012 and 2016, and the number of companies providing sponsorship rose from 30 to 45.<sup>10</sup>

Concern exists that industry funding could compromise patient group independence,<sup>11</sup> which means that the patient voice might be distorted towards industry interests, therefore ignoring other perspectives and needs. There is evidence of an association between receipt of pharmaceutical company money and a proindustry position on health policy.<sup>12</sup> Some patient group spokespeople have acknowledged that by entering into financial relationships with pharmaceutical companies, their credibility and their objectivity could be threatened.<sup>7</sup>

Study around the nature of patient group interaction with industry sponsors is limited.<sup>13 14</sup> A recent exception is a 2019 UK study of publicly declared pharmaceutical industry payments to patient groups, which showed that company sponsorship concentrated on the diseases and activities likely to provide high commercial returns.<sup>10</sup> The authors found that companies were preferentially funding cancer related groups, concentrating on research and public engagement activities, and giving less money to patient support and group maintenance.

Further research into industry funding of patient groups and the risks and benefits that this might bring is an important issue for groups and the wider public.<sup>10</sup> Our aim was to study the nature of patient group interactions with the pharmaceutical industry from the perspective of patient group representatives by exploring the range of attitudes towards pharmaceutical industry sponsorship, and how, why, and when interactions occur. A clearer understanding of interactions will provide important context for discussions about recognising and managing any ethical issues that might arise from these kinds of financial relationships, including benefits and risks to patient groups, benefits and risks to the wider public, and transparency.

## Methods

### Theoretical framework

We drew on the emerging discipline of empirical ethics,<sup>15</sup> which combines the use of empirical evidence and ethical theory to enable analysis of ethically important issues, and justify recommendations to guide future action.<sup>16</sup> In particular, we understand empirical research and ethics theory to be in a symbiotic relationship, such that each could and should inform the other.<sup>17</sup> According to this approach, empirical methods are used to identify context by providing detailed information on what is currently happening and exploring the circumstances surrounding an ethical issue. Ethics theory is used to inform the research by,

for example, identifying research questions and lines of inquiry, designing study approaches, and informing analysis and discussion of findings. Research findings inform consideration and conversation about whether or not what is currently happening accords with expert and broader societal views on what should be happening. This project was prompted by previously identified ethical concerns about the risks associated with industry funding of patient groups,<sup>11 18</sup> which generated the research questions and informed the analysis.

We used qualitative research methods that involved interviews to collect empirical data because these are well suited to understanding the nature of social interactions.<sup>19</sup> We used sampling, data collection, and analysis methods that were best suited to answering our research questions<sup>20</sup>; we drew particularly on the constructed grounded theory approach as practiced by Kathy Charmaz.<sup>21</sup>

One of our team members (BM) has worked for many years with health and consumer groups. Our team also included healthcare professionals (LP and AF, medical doctors; and QG, a registered nurse), experienced qualitative researchers (LP, QG), a bioethicist (LP), and academic experts in patient group studies (BM, AF) and in industry influence in health (AF, QG, BM, LB). Diversity of backgrounds and deep knowledge of industry influence in other settings led us and enabled us to focus on what might be similar and different about the patient group context. Our methods are reported in accordance with the COREQ (consolidated criteria for reporting qualitative research) reporting guideline.<sup>22</sup>

### Design

We conducted interviews with people working in the patient group sector and used Australia as our geographical case study. Australia has a well established patient group sector, with many similarities to other developed, English speaking countries such as the UK, the United States, and Canada. Some groups in Australia focus on specific health conditions, while others focus more on general consumer health issues, including support and health service delivery for patients (often called “health consumers”). By using Australia as our case study we had access to industry reported information about company funding to patient groups because the trade association for the prescriptions medicine industry, Medicines Australia, requires its members to publicly disclose this spending.<sup>9 23</sup> Therefore, we could recruit participants from patient groups with different levels of industry sponsorship, according to whether and how much money they accepted from the pharmaceutical industry.

### Sampling and recruitment

We used a purposive sampling strategy<sup>24</sup> that aimed for diversity of patient group participants: whether and how much money the group accepted from the pharmaceutical industry; the group’s health focus; the participant’s leadership role within the group;

and the group's geographical location and jurisdiction (eg, regional, national). We reasoned that diversity in these characteristics would allow us to obtain an understanding of the range of patient group experiences.

Our research group had previously compiled a database from publicly disclosed company reports of spending on patient groups,<sup>9</sup> which we used to identify pharmaceutical industry funding of a potential participant's patient group. This database includes the names of all patient groups that received money from the pharmaceutical industry, and how much they received each year from 2013 to 2016 inclusive (freely available at <https://dx.doi.org/10.25910/5bc67fed51798>). We divided the list of patient groups into quarters, according to the amount of industry funding they received. We aimed to include patient groups that received the highest amounts in dollars from industry (that is, groups in the top quarter of industry funded groups) and groups that received less funding (that is, groups in the middle and bottom quarters). To identify patient groups that received no recent industry funding we accessed the membership list of the Consumers Health Forum (chf.org.au), the key national body that represents patient groups in Australia. We searched for organisations not included in our database of industry funded groups and with no declaration of pharmaceutical funding on their website. We also carried out Google searches for regional groups loosely affiliated with national or other regional organisations that were found in our database of industry funded groups; followed up on suggestions from previous participants and colleagues ("snowball sampling"); and carried out Google searches for patient groups focused on a range of health conditions.

We approached 55 people from 49 patient groups by email; we used contact details that were in the public domain. We conducted sampling, data collection, and analysis iteratively, and our sampling strategy evolved as the study progressed to ensure that we had adequate variation of participant characteristics. For example, our initial recruitment efforts provided participants who were mainly working as CEOs in national groups, so in the later stages of recruitment we specifically targeted board members and groups with state or territory affiliation. We continued sampling until we reached thematic saturation; that is, until our analysis revealed no new information or concepts relevant to patient group interactions with the pharmaceutical industry.

#### Data collection and analysis

LP conducted one semistructured individual interview with each participant, either face to face at the participant's or interviewer's workplace or over the phone, between October 2017 and October 2018. Use of telephone interviews when required meant that our study was able to include participants from around the country. LP introduced herself as a researcher interested in exploring the views and experiences of patient groups in relation to pharmaceutical industry

funding. She asked about participants' experiences and interactions with pharmaceutical companies, including whether or not their group received industry funding, and their personal views on that. Interviews were digitally recorded, professionally transcribed, and deidentified. All participants were given pseudonyms to protect their confidentiality, and the names attached to quotes are pseudonyms. Field notes were written after each interview to record contextual data and reflexive thinking.

Data collection and analysis proceeded together; analysis of early interviews occurred during or before recruitment and interviewing of later participants.<sup>21</sup> LP read all interviews repeatedly and made notes about salient concepts and ideas. The other authors independently read two of the early interviews and discussed interpretive findings from these transcripts together. The team's varied experiences and methodological expertise meant a range of analytic interpretations were generated, which enabled team reflection on the data by using a variety of perspectives. Any discrepancies or disagreements were resolved through discussion and consensus agreement. LP used these discussions, her notes, and previous knowledge to develop an initial set of descriptive and thematic codes. LP imported transcripts and field notes into NVivo software and labelled all text with the initial set of codes.

Team members read and discussed in detail selected coded transcripts to check analytic interpretations. As data collection proceeded, emerging concepts and findings were discussed at fortnightly team meetings, and these discussions informed recruitment and interviewing of subsequent participants. Team discussions also informed new codes that were added to the coding tree, after which LP recoded older transcripts to incorporate these new ideas. At the completion of data collection, the team explored emergent concepts and looked for patterns within and across the full range of participants and groups. Codes were merged into overarching categories that described important findings within the data.<sup>21</sup> We organised the findings into a conceptual typology that described and explained the data, supported by exemplary quotes.

#### Patient and public involvement

One of our research team (BM) has worked for many years with women's health and consumer groups and is a current member of the European network of Health Action International. We are currently working with a local patient group to help us disseminate and comment on our findings in future seminars.

#### Results

We interviewed 27 participants (19 women and eight men) from 23 groups (table 1). Twenty eight people were invited to participate but did not respond to recruitment emails (19), responded initially but did not follow through with an interview (four), refused (four), or did not receive the email (one email send failure). The interviews lasted 60 minutes on average (25-95

minutes), with the 11 face to face interviews tending to last longer (average 72 minutes; median 71 minutes) than the 16 telephone interviews (average 52 minutes; median 50 minutes). Despite the time variance, there was no obvious difference in the quality of data received from face to face and telephone interviews.<sup>25</sup>

<sup>26</sup> One interview was in a noisy environment and was therefore shorter and less informative (25 minutes, with Irene, CEO, disease focused group, top quarter receiver). A second participant was interviewed from the same patient group. All other interview times were longer than 40 minutes and participants were happy to talk in detail.

### Typology of patient group relationships with pharmaceutical companies

We identified a range of attitudes towards pharmaceutical industry sponsorship which we present in terms of four different types of relationship between patient groups and the pharmaceutical industry, drawn from the participants' descriptions and explanations of their group's interactions with companies. Differences related to whether or not the participant's group received any pharmaceutical industry funding, and the participant's attitude towards pharmaceutical industry sponsorship (see fig 1 and case examples in box 1). The most dominant relationship type was a "successful" business partnership.

*Relationship type A: "successful business partners"*—the dominant description (15 participants from 13 groups) of patient group interactions with industry was as a successful business partnership with a commercial entity that had aligned interests. These

participants had a positive attitude towards industry and regularly received funding from selected pharmaceutical companies. They were comfortable with the collaboration and felt able to reject any company attempts to push their own commercial agenda. Many of these participants described access to new drugs for their constituents as an important priority, and one that they openly shared with the pharmaceutical industry. All participants were from disease focused groups and almost all were from groups that were in the top quarter of recipients of pharmaceutical industry funding.

*Relationship type B: "undeveloped"*—some participants were potentially open to industry sponsorship but worked in groups that were not currently receiving industry funding (five participants from five groups). These participants had positive or mixed feelings towards the industry. They were not approached by pharmaceutical companies and did not cultivate relationships with the industry. Four of the five participants explained that their situation had arisen because their group had different priorities to the pharmaceutical industry and were therefore unlikely to be of interest to pharmaceutical companies. Two participants were affiliated with a general health consumer group that did not have a particular disease or drug focus but instead aimed to promote and support consumer engagement in the health sector. The other two were affiliated with a patient group focusing on a disease that was primarily managed by non-drug means. These participants expressed an interest in considering collaboration with the industry if the opportunity arose. One of the five participants

**Table 1 | Characteristics of patient groups invited to participate, participants interviewed, and those invited that did not participate. Values are numbers (percentages) unless stated otherwise**

Patient group characteristics	Participants interviewed (n=27)*	Invited but did not participate (n=28)
<b>Focus</b>		
Specific disease or health condition	21 (77.8)	26 (92.9)
General consumer health	6 (22.2)	2 (7.1)
Body system of specific health condition	Neurological, respiratory, renal, sensorineural, dermatological, musculoskeletal, women's health, multisystem	Neurological, haematological, gastrointestinal, respiratory, mental health, women's health, sensorineural, dermatological, multisystem
Pathological process of specific health condition	Cancer, degenerative, inflammatory, genetic, immunological, infective, other pathological processes	Cancer, inflammatory, genetic, immunological, endocrine, infective, other pathological processes
<b>Geographical scope</b>		
National	15 (55.6)	19 (67.8)
Regional†	12 (44.4)	9 (32.1)
<b>Level of pharmaceutical industry funding (\$A)</b>		
Top quarter (103 001–4 107 981)\$	13 (48.1)	15 (53.6)
Mid to bottom quarter (1–103 000)\$	4 (14.8)	4 (14.3)
No funding¶	10/27 (37.0)	9 (32.1)
<b>Role of participant in group</b>		
Staff, CEO (including acting)	19 (70.4)	NA
Staff, other**	4 (14.8)	NA
Board member	4 (14.8)	NA

NA=not available (recruitment requests were generally sent to generic patient group enquiry email addresses rather than to specific individuals).

\*The four groups from which two participants were interviewed had the following characteristics: (1) general consumer health focus, regional group, no pharmaceutical industry funding; (2, 3) disease specific focus, national group, top quarter pharmaceutical industry funding; (4) disease specific focus, regional group, mid quarter funding.

†Regional groups are based in specific Australian states or territories and serve members living within those states; most are affiliated with a national group with the same health focus but have separate funding sources.

\$£54 300; €63 600.

\$Group's position in list of patient groups that received money from pharmaceutical industry, as listed in our database of funding disclosed by Medicines Australia members during the years 2013–16 inclusive.

¶Not listed on our database of disclosed pharmaceutical funding of consumer health groups and no obvious declaration of pharmaceutical funding on group website.

\*\*Research manager, secretary, fundraising manager.



		Pharmaceutical industry funding of patient group	
		Yes	No
Patient group attitude to pharmaceutical industry	Positive	A: Successful	B: Undeveloped
	Negative	D: Unsatisfactory	C: Incompatible

Fig 1 | Typology of patient group relationships with pharmaceutical companies

worked in a group that focused on health conditions for which there were actively marketed drugs, but did not interact with the industry because of the group's current policy against receiving pharmaceutical company money. This policy arose out of the group's philosophical commitment to financial separation from the industry, but the participant was not personally opposed to receiving industry funding and thought that collaboration might occur in the future if and when the group's policy changed.

**Relationship type C: "incompatible"**—some participants avoided interacting with the pharmaceutical industry (four participants from three groups). These participants were philosophically opposed to the pharmaceutical industry because they did not agree with the industry's commercial imperative. One participant explained the incompatibility by saying, "It would be very difficult to find an alignment between our due diligence on the effectiveness of pharmaceuticals and . . . their KPIs [key performance indicators] which are all about sales targets" (Euan, general health consumer group, non-receiver). These participants rejected any overtures from companies and did not receive any industry funds. These participants all worked in general (non-disease specific) health consumer groups.

**Relationship type D: "unsatisfactory"**—finally, there were some participants who were uneasy recipients of industry money (three participants from three groups). For two participants the unsatisfactory relationship was because of personal cynicism about the industry's commercial focus, and a feeling that companies were primarily pursuing profit rather than acting for patients or patient groups. Sally (disease focused group, mid quarter receiver) reported, "If they truly were in it for patient support . . . then they would get together as an industry and do something more proactive." For Vicki (disease focused group, top quarter receiver) the dissatisfaction arose from perceived neglect from companies who had previously provided funding but had recently become less interested in interacting with her group. She said, "There's a company called [X], and they actually gave me a serve when they came and met me to say they hadn't felt the love from the organisation and they were decreasing the donation . . . We can't get anyone to deal with us anymore . . . you can call and call and call and call and no one ever

gets back to you." According to Vicki, [company X] was unhappy with the patient group because a community nurse, cosponsored by the company and the patient group, was no longer fulfilling the duties that the company wanted: "Whatever was transpiring with that nurse they hadn't obviously given enough feedback to [company X], and [company X] blamed us . . . And no money from [company X] now." All were in disease specific groups.

### "Give and take": transactional nature of industry interactions

All participants saw that financial interactions between patient groups and the pharmaceutical industry would necessarily entail "give and take" (Sally, disease focused group, mid quarter receiver). Participants said these were fundamentally business transactions, when things of value were traded: "This is about asset exchange" (Robyn, disease focused group, top quarter receiver). If patient groups wanted to accept industry money then the group would have to offer something of value in return because pharmaceutical companies "don't fund for no reason. They don't fund . . . just out of the kindness of their heart" (Cate, general health consumer group, non-receiver) and it was "naïve to think that pharma companies are going to just give away money for public good" (Diane, disease focused group, top quarter receiver). While recognising a commercial driver for the interaction, some participants said that the industry staff they worked with were genuinely interested in helping out. They cited examples such as company staff who undertook personal fundraising activities for the group. A minority of participants said that companies could or should do more to help patients; they claimed that the pharmaceutical industry made so much money out of patients that they should give back some of their profits. Vicki (disease focused group, top quarter receiver) explained this way of thinking by saying that the pharmaceutical industry has a "corporate social responsibility" to give "a percentage of [their] profits" to the "marginalised or vulnerable" patient group sector from whom "they're making a lot of money."

### Who gets money, who misses out: offers of pharmaceutical industry funding appear linked to actively marketed products

In participants' experience, pharmaceutical companies were most likely to be interested in providing money and other assets to patient groups if the company had new drugs that were coming up for review before the government regulator for marketing approval and cost subsidy. If there was no relevant patient group, then companies with new products to market might provide foundational funding to set one up.

Companies were only likely to interact with groups whose members were part of the current or future market for the drug; that is, patient groups that focused on a disease that could potentially be treated by the company's new drug: "So obviously there's no point dealing with a company that doesn't produce one

**Box 1: Case examples of how participants described and explained their interactions with pharmaceutical companies****Successful business partners**

Felicity collaborates regularly with the pharmaceutical industry and sees them as an important part of the health “ecosystem.” Felicity is aware that sponsoring companies might try to influence patient group activities and reports a need for groups to have “a very strong ethical framework about how we engage with these people [so that] it’s not the tail wagging the dog.” Felicity feels empowered to reject attempts at sponsor influence because in her experience pharmaceutical companies need the consumer marketing opportunities that patient groups can provide: “You think about Pharma, they’ve got a drug in the market, and they are limited in how they can market the drug. So they actually really need the patient groups . . . even getting their logo, ‘supported by whatever,’ is actually quite a big deal for them.” When one pharmaceutical company tried to tell her group what they could and couldn’t do she confronted them: “I said, ‘Look, this isn’t okay . . . If you’re really not happy with the way we’re doing it, I’m really happy to give you back your money . . . We will not be dictated to [just] because you’ve been giving money. You cannot buy us like that’ . . . [and they said] ‘Oh, no, no, no. It’s okay. We’ll step back.’” Felicity has previously worked in the pharmaceutical industry (CEO, disease focused group, top quarter receiver of industry money)

**Undeveloped**

Denise works in a disease specific group. She has no regular contact with the pharmaceutical industry. She assumes this is because her members do not use many drugs and therefore companies are not interested: “You can play on [industry] people’s emotions I suppose but . . . there’s not a good argument from a marketing perspective for [pharmaceutical] people to want to support us.” If new products for her members became available, Denise would approach the relevant company for financial assistance. She says, “there are a couple of things in clinical trials now . . . if one of those products came to market then you could see there might be more of a case for asking for pharma company support.” Denise has previously worked in the pharmaceutical industry (CEO, disease focused group, non-receiver of industry money)

**Incompatible**

Helen works in a general health consumer group that does not have any financial interactions with the pharmaceutical industry. She says her group’s priorities for consumer health are in philosophical opposition to the profit motive of the industry. She considers the industry has poor transparency about efficacy and side effects, excessively high drug prices and inadequate social justice programmes for people who cannot afford medication. For Helen, accepting industry money was “a threat to your independence or your ability to take a particular position.” She cited the experiences of colleagues in other groups who found that pharmaceutical sponsors prevented groups from informing members about competitor drugs: “They thought they would be able to publish the material they wanted . . . on a particular form of medication, but there was push back from the pharmaceutical company because that medication they did not manufacture” (CEO, general health consumer group, non-receiver of industry money)

**Unsatisfactory**

Gina and her group have philosophical objections to the industry. Gina criticises industry drug pricing policies and views companies’ attempts to give money to patient groups as just a public relations exercise: “one of the ways that they present a glowing face to the world while on the other hand they are performing actions that have highly deleterious effects.” She occasionally and reluctantly works with the industry but tries to minimise accepting money: “You get dinner invitations . . . breakfast . . . big boozy do’s. We don’t [go] . . . Look even if we have a work meeting . . . we try to ensure that we even pay for the coffee” (board president, disease focused group, bottom quarter receiver of industry money)

of our medications . . . If we’re not a big slice of their market . . . then they’re probably not wanting to put a lot of funds into [our patient group]” (Lyn, disease focused group, top quarter receiver).

Some participants reported their group had been receiving substantive pharmaceutical industry sponsorship for many years while others were newly experiencing interest and money from the industry: “So there’s a new drug on the horizon, the [company] kind of want[s] to really get into the [disease x] market, so they really want to work with us, so we’re loving them” (Lyn, disease focused group, top quarter receiver). Several participants reported no industry interest or a recent decline in interest, particularly those groups focused on diseases managed by non-drug interventions, or where there were no new drugs.

Neil (disease specific group, top quarter receiver) worked in a pharmaceutical company at a time when the patient group he now works with was first set up in Australia. He described the impetus for starting the group: the company wanted to build “patient awareness” and “enhance the actual understanding of the disease,” and “also due to the fact that one of the first [disease related] drugs which actually made a difference came to Australia.” Since “pharmaceutical companies cannot go directly to patients or consumers”

they provided foundational funding to set up “the independent consumer body to be in Australia.” More recently, according to Neil, financial support from the industry was shrinking, “in the past we had potentially, what, five, six companies with products and interests in [disease x]. Now we really have maybe one or two serious companies only.” According to Neil, the reason for this is that the drugs “are either not reimbursed or they’re out of patent in Australia,” which would mean that cheaper generic products would likely be available, reducing sales and profit margins on branded drugs.

**Asset exchanges between patient groups and pharmaceutical companies**

Participants described a range of assets that their groups exchanged with pharmaceutical companies (box 2). One asset that was commonly discussed as being provided to pharmaceutical companies was assistance with advocacy. Irene (disease focused group, top quarter receiver) spoke about how her group coordinated their drug lobbying efforts with companies: “If a company approaches us that they’ve got a new drug coming up for the consumer submission [to the government regulator] then we reach out to our consumers to say, ‘This is what it is, this is what it does, here’s some information about it. If you’d like to make

a submission, please do.' And then we just do a very brief, if we think it's a good thing, we do a very brief submission ourselves."

Others rejected this kind of behaviour, saying "I do know that some health consumer organisations, in the past and now, are funded by pharmaceutical companies and then lobby for medications to be listed on the PBS [pharmaceutical benefits scheme, subsidised by the government]. We've never done that" (Diane, disease focused group, top quarter receiver).

### Crossing the line

Participants discussed several kinds of interactions with the pharmaceutical industry that they perceived had crossed an ethical line (box 2). These interactions were described as practices that happened "when I first came here" (Robyn, disease focused group, top quarter receiver) months or years ago, but have since been stopped by the participant, or things that other groups were doing, particularly "some of the small groups" (Emily, disease focused group, top quarter receiver). A couple of participants talked about company requests for the names and contact details of health professionals who attended educational events run by their patient group: "[T]he pharmaceutical company sponsor[s] . . . come on the day, have a stand, have their information . . . pay their bill, they always try and get the list of people who have attended out of us, and we refuse and give them deidentified information" (Sally, disease focused group, mid quarter receiver).

One participant also said that a sponsoring pharmaceutical company asked (unsuccessfully) for contact details of members of the public attending consumer education seminars run by her group.

### Interconnectedness

There is an overlap of personnel between pharmaceutical industry and patient groups. Four participants from three groups had previously worked in the pharmaceutical industry. Of these four, two had worked in pharmaceutical companies at a time when their company had provided foundational funding to set up a new patient group and had subsequently changed their employment to work in that patient group. One of the four had moved from working with health consumer advocacy into the pharmaceutical industry and then into a disease specific patient group.

Groups and the industry interacted in many ways besides formal business meetings. They met serendipitously at educational events and stakeholder meetings. Participants also described meeting purposively over drinks and meals paid for by the industry and at patient group fundraisers attended by industry staff. Some patient group staff described close relationships with industry staff.

## Discussion

### Principal findings

Many patient groups interact with industry and express varying degrees of enthusiasm and satisfaction with the relationship. Interactions are largely transactional

in nature, with patient groups providing a range of assets such as advocacy assistance, marketing opportunities, and credibility in exchange for financial and in-kind support. Some groups work separately or in opposition to the industry. The timing and amount of interaction largely depends on the companies and the kinds of products they are actively marketing, with more frequent and substantial offers of funding going to patient groups when a company has a new product for which the group is a potential market. Thus patient groups have limited agency to engage in funding relationships with pharmaceutical companies: while they can veto industry advances, they are not able to insist on industry funding to support their activities. Frequent opportunities exist for interaction and multiple levels of interconnectedness.

### What this study adds and implications

There is a growing body of research that identifies the extent and frequency of financial contributions from the pharmaceutical industry to the patient group sector.<sup>7-10</sup> This research is being replicated in studies on patient group interactions with other health related industries.<sup>3</sup> Our work fleshes out the detail of interactions between patient groups and the industry, helps us to understand what it is that patient groups value about relationships with industry, and highlights pockets of ambivalence and resistance to industry. We identify how, why, and when interactions occur. We explain the kinds of assets that are exchanged and expose unevenness in sponsorship patterns. Our results lay the groundwork for working with patient groups to better identify and manage any ethical concerns about existing relationships. Our study has raised the possibility that pharmaceutical industry interest and financial support of patient groups are tied to whether or not active product marketing to patients and advocacy to regulators are currently profitable. This area warrants further study.

Patient groups who receive pharmaceutical industry money are more likely to advocate in a way that aligns with the interests of their commercial sponsors.<sup>12 27 28</sup>

The patient group sector asserts its independence from industry funders,<sup>29</sup> and so the mechanism behind the alignment of advocacy positions has been unclear. A variety of explanations have been suggested for this phenomenon and our work supports many of these, suggesting a multifactorial mechanism. For example, groups whose views and advocacy naturally align with industry might be preferentially funded by pharmaceutical companies<sup>30</sup>; industry supports the setup of new patient groups to assist advocacy around new products<sup>31</sup>; and some companies could exert pressure on patient groups to act in a particular way.<sup>7</sup> Whatever the mechanism, there is a need to ensure balance and objectivity in the patient group sector with regard to advocacy around medicinal drug use. For example, recent recognition of the scale of the opioid crisis has highlighted the need to actively watch for harms associated with drug prescribing and use.<sup>32</sup>

**Box 2: Assets exchanged between pharmaceutical companies and patient groups and illustrative quotes****Assets that patient groups receive from pharmaceutical companies***Money for educational events for prescribing health professionals*

"Last year we did [town A] . . . and we took a [specialist] in and we were sponsored by [company x] to do that, which was great, so [x] dollars of sponsorship allows us to get out there, give a community seminar without recognising their sponsorship, but recognise their sponsorship at a . . . dinner for GPs" (Sally)

*Money for patient group research programmes*

"It is not unusual for pharma to provide funding for research grants, so they're supporting the research grants and they might give anything from 50 to 150 000 simply as a donation to [our group] and that money is treated like any donation or bequest we receive for research . . . Pharma does not have any involvement in the selection [of applications], they're supporting the research program" (Robyn)

*Money for disease awareness campaigns*

"We actually had funding from [company A] and then later from [company B] to run TV promotion of [disease x] and, again, just pushing the need to get your [body system] tested and highlighting this is a disease that can affect your [body system], and so these were typically either 15 or 30 second TV ads which we had funding to both produce them and to then run them" (Ian)

*Money for updating patient group website*

"Let's say I want to . . . refresh our website . . . we'll work out and let's say we need \$30 000 to do that, then I will write a grants application to them . . . I would talk to a few of them, I'll ring them up and say 'We want to do this, would you be interested in supporting it, would you be interested in receiving a grant [application]?' And . . . they will generally say, 'Yeah ship it in and we'll put it before the grants committee,' or and usually sometimes they'll say, 'Yeah I think that's a really good idea,' and the people that I talk to will have an idea of whether they have money in the budget available for the year" (Chris)

*Money for newsletters and information booklets for members*

"I put their logo on the inside back cover [of the report that the company funded]" (Fiona)

*Money for setting up aligned patient groups elsewhere*

"Part of the funding we've had was to help set up other organisations like us in other countries, so we actually got industry funding to do several of these, we did one in [region A], one in [region B] and one in [region C] because I think they could see the benefit that we were doing, and again, at no stage was it about selling drugs, it was about educating the public and about raising awareness" (Ian)

*Foundational funding to set up the group*

"[Our group] actually came about when there was a particular doctor . . . who could see from the discussions he was having with his patients that there was very low awareness, very low understanding, education and that there was a need for an organisation to advocate on behalf of patients. It was also at the time when there was starting to be a couple of new treatments that were coming online and it was considered important to help, again, advocate for funding for these . . . and also to help promulgate information out to the public which the industry can't do . . . Actually I was working for one of the companies in the area at the time and we were about to introduce one of the earlier treatments for this and we provided a bit of funding" (Ian)

*Money through patient group's fundraising activities*

"They bought some tickets and came to our ball, they bought three or four tickets and came to the ball" (Chris)

*Information about new drugs and drug delivery systems*

"I'm having lunch with one of the drug companies down there, just to catch up. We've caught up every year, so just for a coffee, they've got drugs that are in the development pipeline which I'm keen to know about" (Alan)

*In kind assistance, for example, with patient group's research activities*

"We wanted to have a look at distribution of [our disease] by geographic area . . . this happened over a cup of coffee actually. We were talking about it and they said, 'Oh we can probably do that,' and they went back to their, the epidemiological research in the organisation and it was fairly easily done. It was probably a day, two day's work for them; it would have taken me a year" (Alan)

*Access to company staff who might grant access or reduced price medications for specific patients*

"I can pick up the phone to the CEO [of the pharmaceutical company] and go, 'What the hell? What's going on?' Or like, I had a call, [I was] on the phone to a guy last Friday and his son . . . can't get onto [drug x] because it's, he's not sick enough, but he's getting sicker. And so I've organised for him to speak to the drug company about paying for it personally. And if I didn't have the contacts at the drug company I wouldn't be able to do that. And I said to him, 'Look, it's going to cost you this much money per month, and what you need to do, this is the process'" (Fiona)

*Training and marketing advice on how to run a successful patient group*

"We don't just take money but often they have great suggestions in terms of how we market ourselves, how we raise awareness, they're very sophisticated marketers so they can help us in those ways" (Paula)

*Meals and entertainment*

"You get dinner invitations . . . big boozy do's" (Gina)

**Assets that patient groups provide to pharmaceutical companies, directly related to company's products***Advocacy assistance, for example, responding to company requests to lodge patient group submissions to government regulators for approval and cost subsidy of new drugs; collaborating on public advocacy events*

"If a company approaches us that they've got a new drug coming up for the consumer submission [to the government regulator] then we reach out to our consumers to say, 'This is what it is, this is what it does, here's some information about it. If you'd like to make a submission, please do.' And then we just do a very brief, if we think it's a good thing, we do a very brief submission ourselves" (Irene)



**Box 2: Continued**

*Marketing opportunities, for example, product marketing to prescribers, company brand marketing to patient group members*

"You think about pharma, they've got a drug in the market and they are limited in how they can market the drug [to consumers]. So they actually really need the patient groups . . . even getting their logo, 'supported by whatever' is actually quite a big deal for them" (Felicity)

**Assets that patient groups provide to pharmaceutical companies, not directly related to company's products**

*Credibility, for example, building trust in a company run project when patient group partners with company*

"[We offer] credibility . . . if anything is attached to a health consumer organisation the research shows people immediately think there's integrity and it's a viable proposition as opposed to from a business . . . We're respected by the health professionals . . . there will be some health professionals that won't, for example, recommend to their patient that they do a particular programme that's developed by a pharmaceutical company" (Robyn)

*Raising disease awareness, for example, through patient group media campaigns, founding and supporting new, aligned patient groups in other places*

"What we're trying to do is to ensure that people do get, are aware of the disease, get diagnosed, get regular [body system] checks for example . . . The companies, in almost all cases they've been very, very accepting and they get it because what we're doing really is we're just ensuring that there is good disease awareness and ultimately that will benefit them of course . . . For our work with [the disease A] awareness [campaign], [company A] funded that for many, many years . . . Part of the funding we've had was to help set up other organisations like us in other countries, so we actually got industry funding to do several of these, we did one in [region A], one in [region B], and one in [region C] because I think they could see the benefit that we were doing, and again, at no stage was it about selling drugs, it was about educating the public and about raising awareness" (Ian)

*Relationship building opportunities with key opinion leaders in the medical profession, for example, when company staff attend patient group's clinical advisory meetings and educational events*

"We recognise that our partnerships with industry have to have benefits both ways and part of the benefits that the industry partners get is that for each disease area we have a clinical advisory group that oversees the planning and the delivery of the annual plan of the year and we'll include industry for part of the meeting. They'll get to come in, raise issues, understand how we're delivering on the programme and they get a change to meet the key opinion leaders in the area" (Paula)

*Information to company on patients' experiences and views about diseases, drugs*

"They get access to patients too, often they'll come to us and say, 'We're training our sales group and none of these people'—I shouldn't say none of them, but—'They don't know patients particularly well.' So to get a patient to go and talk about their experiences as a disease are, for people who are out in the field, is important" (Paula)

*Opportunity to channel money through patient groups, for example, by giving money to a patient group to pay for a medical speaker at an educational event so that the speaker is not officially funded by the industry*

"One of the pharmas . . . did the wrong thing by us . . . We had an education seminar for consumers in [town A] a couple of weeks ago and we were aiming to do a GP forum with it . . . They pulled out a week before . . . [and instead] they did some one on ones [between some of the GPs and the specialist] that we flew up through their money because they can't fly the [specialists] up themselves. I don't think they're allowed to. So they funnelled the money through us to fly the [specialist] to talk at the consumer event and then they used them to go and see some of the GPs without me, and I went, 'So . . . you've just funnelled the money through us to get that [specialist] there!'" (Vicki)

*Assistance with recruitment for clinical trials*

"Our newsletter that goes out four times a year, we have a section that will say, 'Ok, there's some clinical trials going on, here's some things that might interest you.' And we don't push it, but it's up to them to, they have a read of that and have a talk about it with their doctor" (Emily)

**Assets that pharmaceutical companies ask for but which some participants did not provide ("crossing the line")**

*Influence over content of patient group's communications, for example, newsletter, press releases, conference slides*

"Once a publication that I edited ended up getting funded by pharmaceutical companies . . . A staff member [was] just chatting away to a pharmaceutical rep about something that was in a story [in that publication] and that pharmaceutical rep then said, 'Well, we want to stop that story.' And it didn't happen, the story wasn't stopped . . . but [some] people [do] not have an awareness that you have lines and they need to be very sharp and very, very clear" (Gina)

*Influence over the process and content of patient group's advocacy about access and subsidy for new drugs*

"Sometimes, in trying to help a charity that has no money, [a company] will, for example, offer—and it's quite innocent and they won't do it twice—but they'll occasionally offer, for example, to have their PR people help you with a media release . . . [One company] well, I think their PR company had worked out in their heads that [Chris] from [patient group A] going out and making a statement about . . . I can't remember the issue but it was around a particular thing . . . would be really good and, 'Chris's busy so why don't we write the press release for him?' . . . I rang them up and said, 'Look, this is not appropriate, I'm not doing it,' and they were just totally apologetic" (Chris)

*Names and contact details of attendees (including members of the public, health professionals) at educational events organised by a patient group and sponsored by a company*

"[T]he pharmaceutical company sponsor[s] [of GP seminars] . . . come on the day, have a stand, have their information . . . pay their bill, they always try and get the list of people who have attended out of us, and we refuse and give them deidentified information" (Sally)

*Assistance with setting up aligned patient groups in other countries for the express purpose of marketing new drugs in that country*

"One of the guys from one of the [pharma] companies said to me, 'I really want you to [help me set up a patient group in a certain country] because we've got this drug we really want to get listed up there,' and I said, 'Well, that's great, good on you, good luck, that's not what I do'" (Chris)

*Influence over a patient group's agenda to match company interests*

"On the one very brief occasion where there has been a bit of a push to make . . . the work we do tied with their results, we've said, 'No, that's not what we do' . . . There has been some [funding] pushback for a while there, but generally it is getting harder to get funding from industry overall" (Ian)

There is also concern about the broad impact of industry funding in the patient group sector.<sup>33</sup> If we accept the premise that industry funding enhances the ability of groups to achieve their goals (and our results suggest that patient groups certainly see this kind of benefit flowing from industry relationships), then selective pharmaceutical industry funding of aligned patient groups will boost the impact of some groups over others. The end result could be a patient group sector that is heavily focused on industry favoured issues. This focus could mean inequity in disease awareness and patient support, favouring health conditions that are amenable to drug treatment.<sup>34</sup> Additionally, advocacy efforts might be preferentially directed at drug access and subsidy rather than prevention or non-pharmacological interventions,<sup>14</sup> and a research agenda that prioritises the study of new drugs.<sup>35</sup> In sum, the unintended consequences of having a patient group sector heavily reliant on industry funding could be to prioritise industry agendas.

### Strengths and limitations of this study

The strengths of this study are the depth and breadth of detailed information we obtained about patient group interactions with the pharmaceutical industry. A limitation is that we only spoke with patient group personnel and did not speak to industry staff. It is possible that participants misinterpreted some of the industry reasons and patterns around pharmaceutical company interest in interacting with patient groups. Although we spoke to a group of diverse participants who probably had a wide range of experiences and views, we did not cover all types of patient groups. Additionally we did not speak to individual patients or health consumer advocates who were not affiliated with any patient group, so we could have missed some issues or ideas. In particular we might not have heard the full range of experiences from participants who felt that they or their affiliated patient group had engaged in improper relationships with industry funders or had “crossed the line” according to their own moral compass; these people might have been less likely to agree to an interview. Another limitation is that our study is based in Australia. Although the topic of patient group relationships with industry funders is of global interest,<sup>7 10 11</sup> there could be some local contextual differences that affect the ethical issues. For example, the USA and New Zealand have a unique context in which the pharmaceutical industry is able to advertise directly to consumers, which could lead to more industry interactions with individual members of patient groups beyond the scope of organisational actions. Furthermore, Australian pharmaceutical companies that belong to the umbrella trade organisation Medicines Australia are bound by a code of conduct.<sup>36</sup> This code of conduct includes a list of principles and practices that guide relationships with patient groups, such as respecting independence of patient groups and not seeking to influence patient group materials for commercial interests. Companies in other countries might adhere to a different set of principles.

The database that we used to source relative amounts of pharmaceutical industry payments for named patient groups (eg, whether a group’s funding level was in the top quarter) was derived from public reports. These reports contained data from pharmaceutical companies that were members of Medicines Australia over the four years from January 2013 to December 2016. The database might not accurately reflect the relative amount of industry funding during the time that we conducted the interviews (October 2017–October 2018). However, our review of the database showed that most patient groups tended to remain in the same quarter from year to year: 67% (38/57) of patient groups from the top quarter over 2013–16 were also in the top quarter in 2016; 95% were in the top or second quarter. In addition, some industry funding might have been missed because companies that are not members of Medicines Australia are not bound by any codes of conduct to disclose their spending on patient groups.

### Further research and recommendations

Our results will probably be of interest to patient groups that are seeking to review their policies and practices governing commercial sponsorship. Our research provides details on the kinds of assets that industry funders have asked patient groups to provide in return for their support. Strategies to help groups mitigate conflicts of interest that arise from industry funding could include increasing awareness among groups about the kinds of assets they might be offered and that industry funders might request, so that they can discuss and prepare responses; improved transparency about industry funding of patient group activities; and education targeted at patient groups and their constituencies around the risks of industry funding, which draws on evidence from other stakeholders; for example, doctors’ acceptance of even low cost industry funded meals could alter their prescribing habits.<sup>37</sup>

We are planning a meeting with patient groups to share our data, discuss the risks associated with receiving industry funding, and to develop standards and strategies for mitigating those risks. Educational materials are available for health professionals<sup>38</sup> and these kinds of teachings could be adapted for patient groups. The authors have conducted public workshops to alert patient groups to the influence of pharmaceutical industry over evidence creation and use, and these could be rolled out to a broader audience.

Our results are also of interest at a broader health policy level. They show that the industry practice of selective funding for patient groups where active product marketing opportunities exist could skew representation of patient interests towards issues that align with pharmaceutical industry interests. Because the patient group sector plays a powerful role in advocacy and health policy development, including pharmaceutical policy, this could mean that the pharmaceutical industry is exerting unrecognised proxy influence over health policy. Strategies to help mitigate industry influence across the broader sector

include more robust public funding of the patient group sector, and pooled industry funding to the sector.<sup>10</sup> Companies could be required by industry codes of conduct to donate money to a centralised collection, independently managed and reserved for patient group funding so that companies and groups have no direct financial interactions. The outcomes of patient group activities might be quite different if the patient group sector were to collaborate and build a list of priority groups and projects, and had access to pooled industry funds that could be distributed according to that agenda.

## Conclusions

An understanding of the range of views that patient groups have about pharmaceutical company sponsorship will be useful for groups that are seeking to identify and manage any ethical concerns about these interactions. Patient group interactions with the pharmaceutical industry are predominantly business transactions and groups receiving pharmaceutical industry money should anticipate they might be asked for specific assets in return. Selective industry funding of groups in which active product marketing opportunities exist is widespread. This funding could skew the patient group sector's activity towards pharmaceutical industry interests and allow industry to exert proxy influence over advocacy and subsequent health policy.

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**Ethical approval:** The study was approved by the University of Sydney Human Research Ethics Committee (project No 2017/758).

**Data sharing:** The database of publicly declared industry payments to patient groups is available at: <https://researchdata.andis.org.au/pharmaceutical-industry-funding-december-2016/1330638>.

The lead author (LP) affirms that the manuscript is an honest, accurate and transparent account of the study being reported.

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