

Consumer-pharmaceutical industry relationships: Building trust and transparency

An outcome of the workshop held on 11 March 2020,
Charles Perkins Centre at The University of Sydney,
convened by the Evidence, Policy and Influence Collaborative
in the Charles Perkins Centre,
Health Consumers NSW,
Consumers Health Forum of Australia,
funded by the Charles Perkins Centre

July 2020

ACKNOWLEDGEMENTS

A number of people contributed to this workshop and report. Thanks to all the participants (listed in Appendix 2) and to the consumer organisations of which they are members.

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ABBREVIATIONS

HCNSW	Health Consumers NSW - peak body for health consumers in NSW.
HCO	Health Consumer Organisation
NHMRC	National Health and Medical Research Council

DEFINITIONS

For the purposes of this workshop, the following definitions were used:

Health Consumers: People who use, have used, or are potential users, of health services including their family and carers.

Principles in Table 2 are worded using terminology in frequent use on the day

BACKGROUND

Building Trust and Transparency

Held on Wednesday 11 March, Charles Perkins Centre at the University of Sydney; convened by Evidence, Policy & Influence Collaborative, Health Consumers NSW, Consumers Health Forum of Australia; funded by the Charles Perkins Centre

This meeting was organised by Health Consumers NSW, the Evidence, Policy & Influence Collaborative at The University of Sydney and Consumers Health Forum of Australia. Funding for consumers to attend was provided by the Charles Perkins Centre.

We invited leaders (Chairs, Board members, and CEOs) of health consumer organisations (HCOs) and individual health consumers to attend a workshop at the Charles Perkins Centre to discuss the risks and benefits of partnering with the pharmaceutical industry. Although guidance already exists for those who wish to work with industry, some produced in collaboration with industry(1, 2) and others developed by HCO governing bodies, the organisers felt there was room for discussion and work towards new resources developed independently from industry funders and across a community of HCOs.

THE WORKSHOP

The Workshop

There were 42 attendees from around the country, including 29 from 23 organisations, nine with academic affiliations and four others (government, individual health consumer, professional organisation). A list of attendees and the program of the event are available in the Appendices. The objectives of the meeting were to stimulate discussion that could inform an independently written set of contemporary principles and suggestions for best practice that health consumer organisations might draw on when considering whether or how to interact with pharmaceutical industry funders (see **Table 1**).

Table 1. Objectives and purpose for the workshop

1.	Discuss risks and benefits of pharmaceutical industry funding for consumer groups
2.	Discuss transparency around pharmaceutical industry funding – what it is, why it is important, how to achieve it
3.	Work towards a discussion document on independent governance around consumer group interactions with pharmaceutical industry

The day was facilitated by Serena Joyner from Health Consumers NSW, the peak group for health consumers in NSW.

Speakers and Discussion

Leanne Wells, from the Consumers Health Forum of Australia, the national peak body representing health consumers, opened the day by describing their advice for Australian health consumer groups who wish to build collaborative relationships with pharmaceutical companies. This Working Together Guide(1) was co-produced by the Consumers Health Forum and Medicines Australia, the industry organisation representing research-based pharmaceutical companies in Australia. Medicines Australia also have their own Code of Conduct,(2) which includes guidance around company interactions with health consumer organisations.

Lisa Bero, researcher in the Evidence, Policy & Influence Collaborative at the University of Sydney, spoke next. She introduced the global movement in the health sector towards financial independence from industries with commercial interests in making or selling health products. (3, 4) Lisa presented evidence showing that industry funding is associated with bias in health research, education and practice,(5) (6, 7) which can result in harms from overtreatment, mistreatment and opportunity costs.

Several speakers that are currently or were previously affiliated with health consumer organisations described their organisation's experiences with the pharmaceutical industry. The speakers shared a range of positive and negative views about the industry. For example, Nettie Burke, CEO of Cystic Fibrosis Australia, said that organisation had positive experiences with pharmaceutical industry funding, and that they preferred industry funding to government funding because they felt government funding would inhibit their ability to be a ferocious advocate for drug access. Nettie talked about ensuring industry money is only spent on uses defined by health consumer organisations and provided some recommendations around how to engage effectively with industry while maintaining focus on the organisation's mission (e.g. avoid giving any single company exclusive access to patient data or stories, don't support commercial imperatives that deny patient access to affordable drugs.)

Bridget Haire, immediate past president of Australian Federation of AIDS Organisations, said that, in contrast to Cystic Fibrosis Australia, her organisation's preferred government funding over pharmaceutical industry funding, particularly given the poor track record of industry on global drug pricing for HIV medication. Key elements in this organisation's policy(8) around interactions with the pharmaceutical industry were: they would only accept drug company sponsorship if government funding was not available, inadequate or take too long to obtain; negotiations with pharmaceutical companies would only be considered for projects already conceptualised and assessed; written contracts must clarify that pharmaceutical donors would have no input into publications, projects or staff positions.

Murray McLachlan, Deputy Chair of Cancer Voices NSW spoke about this organisation's 'minimalist approach' to accepting pharmaceutical industry money, whereby they only accept pharmaceutical industry money for exceptional circumstances, for example, to attend important health summits. He referred to the Cancer Voices NSW position statement on pharmaceutical company relationships,(9) which details how the organisation relates to individual pharmaceutical companies and the industry as a whole. Murray advocated for greater transparency around industry spending, so that the public can monitor the movement of money between individual companies and recipients.

The final speaker (who requested anonymity) described their personal experiences with a consumer health organisation. After being diagnosed with a health condition this speaker sought out a group that could provide them with support and education. The group, which on first appearance seemed credible and set up for and by health consumers, did not, however, meet their needs. The organisation provides no patient support and appears to exist only to promote the commercial interests of sponsors and affiliates. The speaker noted that patients can be vulnerable and that health consumer organisations must not exploit this by promoting unsafe treatments or selling member data for no benefit to members; instead organisations must protect their members' interests and be willing and able to act in opposition to the interests of pharmaceutical companies if necessary.

This diversity of health consumer views and experiences around industry funding was echoed by Lisa Parker, researcher in the Evidence, Policy & Influence Collaborative at The University of Sydney, who summarised her recent Australian study on the topic.(10) Lisa also reported on selective industry funding for consumer organisations whose advocacy aligned with company's commercial interests, and suggested this might allow the industry to influence the dominant consumer advocacy message and thereby affect health policy by proxy.

A second researcher, Barbara Mintzes, in the Evidence, Policy & Influence Collaborative at The University of Sydney, presented her and her colleagues' work on pharmaceutical funding of health consumer organisations. She showed that industry funding of this sector is common in Australia⁽¹¹⁾ and internationally.⁽¹²⁾ Participants learnt that the top ten most heavily funded groups in Australia received 45% of all the money provided by the pharmaceutical industry (\$AUD34.5 million over 2013-2016), with the single most well-funded group receiving in excess of \$AUD 4 million. Only half of Australian consumer organisations made public disclosures about accepting money from the pharmaceutical industry,⁽¹³⁾ and Barbara called for organisations to show greater transparency about this in future.

One of the objectives from the day was to encourage discussion towards an independent document that could assist health consumer organisations develop policies and identify good and transparent practices relating to pharmaceutical industry funding.

In order to inform the conversation, three speakers presented examples of institutional guidance around industry funding in the health sectors.

Lisa Bero introduced policies from two different organisations: the Charles Perkins Centre and the Cochrane Collaboration. The Charles Perkins Centre is a health research institute at The University of Sydney. Its Engagement with Industry policy⁽¹⁴⁾ requires a formal risk-benefit analysis for any research projects considering industry linkage. The policy specifically provides examples where industry relationships might be considered too risky to go forward, including when the proposed industry partner has commercial interests that are not aligned with improved public health, has a poor record of corporate governance or responsibility, or has control over any of the design, conduct or dissemination of the project. The Cochrane Collaboration is an independent organisation that synthesises scientific health evidence into publicly accessible review documents. It has strict limits around industry funding; for example, it rejects commercial sponsorship, prohibits employees of interested commercial organisations from authoring its reviews, and limits the number of authors who can have other financial conflicts.⁽¹⁵⁾

Davina Gherzi spoke about the Australian National Health and Medical Research Council (NHMRC), an independent organisation providing research funding and guidelines for clinical medicine and public health practice. NHMRC requires all staff and members of guidelines committees, including health consumers, declare any relevant conflicts of interest.(16) They provide information on how to identify what is a relevant conflict of interest, and give guidance to committees on what to do about members who have them.(17)

Adrian Cosenza, Chair of the Australian Ethical Health Alliance, introduced the Alliance - a collaboration between different groups within health, including the pharmaceutical and medical device sector, healthcare professionals and consumer health groups. The alliance aims to promote collaboration between different sectors and has produced a list of guiding principles to assist organisations wishing to develop policies and practices around working with each other.(18)

In two interactive one-hour sessions, participants met in smaller groups to exchange and develop ideas for principles and suggestions for best practice that might assist health consumer groups' considerations about potential pharmaceutical industry funders. At the end of each session, round table discussions were summarised and shared with the wider group.

Collaborative lists of prominent concepts and suggestions were transposed by the organisers onto a projected computer screen in real time, with opportunity for instant feedback from all participants. We have collated this information, along with additional information drawn from organisers' contemporaneous notes, into a set of overarching concepts (see **Table 2**) and associated examples of best practice (see **Table 3**). This material is drawn from the experiences and views of participants as expressed in discussion on the day. It is not intended to be exhaustive or reflect the views of the organisers.

Table 2. Principles that should guide consumer organisation thinking about whether or how to engage with pharmaceutical industry funders*:

**principles are worded using terminology in frequent use on the day*

1.	<p><u>Consumer centredness</u></p> <p>Making sure that your actions are in keeping with members' views, expectations and interests.</p>
2.	<p><u>Honesty / Transparency</u></p> <p>Being open and upfront with your members about things that may matter to them (e.g. possibly including the organisation's sources of funding, policies around industry funding).</p>
3.	<p><u>Fairness</u></p> <p>Being mindful of the interests of all health consumers, including but not necessarily limited to members of your own organisation.</p>
4.	<p><u>Independence</u></p> <p>Acting in accordance with your organisation's own plans and priorities as per the interests of your members and the health consumer sector, without influence from third parties.</p>
5.	<p><u>Values Alignment</u></p> <p>Being aware of the values, actions and health impact of potential funding organisations.</p>
6.	<p><u>Governance / Accountability</u></p> <p>Accepting responsibility and having measures in place for the oversight of organisational actions to ensure they are in keeping with the organisation's expressed ideals and practices.</p>

Table 3. Participants' suggestions on best practices for operationalising the principles listed in Table 2:

1.	<p>Consumer centredness - as expressed or inferred from a variety of consultative methods; suggested examples of best practice for obtaining this information included:</p> <ul style="list-style-type: none"> a. regular formal surveys b. informal feedback on social media sites or at events.
2.	<p>Honesty / transparency – suggested examples of best practice included public reporting of:</p> <ul style="list-style-type: none"> a. all money received from industry including: actual dollar amounts of each payment, in-kind support including invited attendance at industry-funded meetings, use of funds, rejected funding, any 'strings' attached to funding, percentage of total organisation funds coming from the pharmaceutical industry; b. the organisation's policy on funding c. details about current or previous financial relationships between Board members and the pharmaceutical industry d. all contracts with pharmaceutical industry funders e. all information must be easily accessible including to non-members, e.g. on the website and/or annual reports and newsletters if these are available to non-members.
3.	<p>Fairness – best practice suggestions including:</p> <ul style="list-style-type: none"> a. having a pooled industry fund, possibly from a tax on company profits for distribution to health consumer organisations. The aim is to ensure that voices of all organisations are heard, including those without a pharmaceutical solution, and to support research, including non-drug related research that the pharmaceutical industry would not otherwise be willing to fund. The distribution process must be transparent and organised by non-industry trustees e.g. via a formula incorporating geographic and socio-economic diversity, or on application b. the Pink Meets Teal model (https://pinkmeetsteal.com/) was offered as an example of good practice here, albeit not necessarily in relation to industry funding.

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| 4. | <p>Independence – there was debate about whether this could be achieved in the context of industry funding or would only ever be an aspirational but unattainable ideal. Some participants suggested that accepting industry funding necessarily entailed a certain level of dependence on the funder while others suggested that independence could still be achieved using practices such as:</p> <ol style="list-style-type: none"> a. only ever accepting money for already-planned projects b. having formal contracts with all funders that clearly lay out expectations and rules including prohibiting any funder involvement in the design, conduct or reporting of the activity c. only allowing industry money for non-drug related activities d. only ever accepting funding as a general donation to the organisation and prohibiting the acceptance of funding provided specifically for a particular purpose or activity e. only ever accept funds tied to a particular purpose or activity that the group has identify a priori and avoiding general donations (i.e. there was debate over whether (d) or (e) was the better way to operationalise independence) f. not allowing staff or Board to accept pharmaceutical industry funded drinks, meals or trips g. limiting the percentage of total funding that the organisation will accept from the pharmaceutical industry sector h. avoiding exclusive funding arrangements with just one pharmaceutical company. |
| 5. | <p>Values alignment – there was debate about what was required to operationalise this concept. Some participants suggested that partial values alignment was sufficient and that it was impossible to assess the entire value set of companies. However some participants rejected this view, saying that consumer organisations should look carefully at company activities and reputations, including internationally, and should avoid relationships with companies whose activities were detrimental to health (for example, through pricing policies that effectively prevented access to medicines for patients in low or middle income countries, or by promoting unsafe products.) Suggested resources to guide best practice here included:</p> <ol style="list-style-type: none"> a. social responsibility league tables of pharmaceutical companies(19) b. putting Medicines Australia members ahead of non-MA members c. suggested rule of thumb: it is not enough if the only thing that a consumer organisation and a pharmaceutical industry have in common is the same target population/market d. values alignment review should be done every time you ask for / consider receiving industry money. |

6. Governance / accountability – suggestions for best practice here included:
- a. Boards setting cultural standards and writing policies around pharmaceutical industry funding that include detail of circumstances under which industry funding is acceptable / unacceptable
 - b. guidance on drawing up policies and practices should be derived from independent sources, not from industry funded sources; options might include pro bono legal teams which may have generic templates for policies around sponsorship, Australian Charities and Not-for-profits Commission(20), resources housed by state and/or federal peak bodies of consumer health organisations
 - c. avoiding having current industry employees on the governing Board
 - d. timely audits of all industry relationships for any resulting benefits and harms, review of values alignment, and for any transgressions of agreed policies and practices
 - e. audits should be by a body that is unconnected to the Board or to people tasked with cultivating funder relationships.

CONCLUDING REMARKS

Ray Moynihan, researcher at Bond University, and Anthony Brown, CEO of Health Consumers NSW, closed the day. Ray talked about his work on the long history of undue pharmaceutical industry influence in health research, education and practice, expressing concern that industry funding of health consumer groups was enabling companies to continue this kind of influence through a less well-recognised route. Anthony acknowledged the importance of research such as Ray's, which allowed health consumer organisations to be better informed about the risks associated with developing financial relationships with the industry, and better able to devise appropriate principles and practices. This workshop was intended as the start of a conversation and the day's open discussions and sharing of ideas was a positive step towards keeping the activities and advocacy of health consumer groups independent.

THE PARTNERS

About Health Consumers NSW

Health Consumers NSW is a membership-based, independent, not-for-profit organisation that promotes and practises consumer engagement in the NSW health sector. We create meaningful partnerships between consumers, the health sector and policy-makers. Our mission: Consumers shaping health in NSW. We promote the best quality, appropriate health outcomes for consumers of health care services. We believe that all perspectives are important and necessary to create better health outcomes for people. Consumer engagement leads to better health outcomes, more efficient and effective services, consumer-centred care and happier patients and staff. We work to ensure that health consumers are involved in the design and delivery of health care in NSW.

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About Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) draws on consumer and community knowledge and experience to relentlessly drive innovation and improvements to the Australian health and human service system. We are the national consumer peak body representing a wide variety of consumer organisations and individuals and organisations with an interest in health care consumer affairs. Our membership is extensive and includes illness groups, disability groups, state peak health consumer organisations, professional, research and other health sector bodies. This diversity ensures we have the capacity, credibility and authenticity to provide deep, well-informed consumer insights and perspectives to governments and other decision makers. CHF's vision is a world class health and social care system centred on consumers and communities.

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About the Evidence, Policy & Influence Collaborative, at Charles Perkins Centre, The University of Sydney

This collaboration between researchers from diverse disciplinary backgrounds works to translate rigorous and unbiased evidence into clinical practice and health policy. The group explores what constitutes evidence and how we can reduce bias in the evidence base. Its work is being used to make new gold standards for synthesising evidence for a wide variety of health policy decisions worldwide and international reforms related to transparency, accessibility of data and stricter standards for managing conflicts of interest.

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Name: Lisa Parker

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APPENDIX 1: AGENDA

Building Trust and Transparency

11 March 2020, Level 6 Seminar room, Charles Perkins Centre, University of Sydney



9.00	Arrival, coffee and welcome	
9.15	Welcome, purpose of meeting & small group introductions	Serena Joyner Health Consumers NSW
9.30	'Where we are at now'	Leanne Wells CEO, Consumers Health Forum of Australia
9.40	Global movement towards independence	Lisa Bero Professor, Chair of Medicines Use & Health Outcomes, Charles Perkins Centre, School of Pharmacy, University of Sydney
9.45	Independence, risks & benefits of industry funding	
	Experiences with pharmaceutical industry, risks of industry funding, how you seek to maintain independence	Murray McLachlan Deputy Chair at Cancer Voices NSW Nettie Burke CEO of Cystic Fibrosis Australia [redacted] Independent consumer Bridget Haire Immediate past president of Australian Federation of AIDS Organisations
10.25	Recent research on consumer group interactions with pharmaceutical industry in Australia	Lisa Parker Research Fellow, Charles Perkins Centre, School of Pharmacy, University of Sydney
10.35	Q&A discussion with panel of speakers	Leanne Wells, Lisa Bero, Murray McLachlan, Nettie Burke, Asher Wolf, Bridget Haire, Lisa Parker

11.00	Morning tea	
11.20	Transparency	
	Recent research on consumer group interactions and transparency with pharmaceutical industry funders	Barbara Mintzes Associate Professor, Charles Perkins Centre, School of Pharmacy, University of Sydney
11.30	Q&A discussion on transparency	Anthony Brown Executive Director, Health Consumers NSW Barbara Mintzes Associate Professor, Charles Perkins Centre, School of Pharmacy, University of Sydney Edith Lau Doctoral candidate Charles Perkins Centre, School of Pharmacy, University of Sydney
11.50	Workshop 1 – principles: building trust and transparency	
	What should be the principles underpinning consumer group policies about interacting with industry?	Ray Moynihan Assistant Professor, Institute for Evidence-Based Healthcare, Faculty of Health Sciences & Medicine, Bond University Lisa Bero Professor, Chair of Medicines Use & Health Outcomes, Charles Perkins Centre, School of Pharmacy, University of Sydney
12.50	LUNCH	
1.30	Conflict of interest policies & practices	
	Examples of policies on industry funding in other sectors – CPC, NHMRC, RACP, AEHA	Lisa Bero Professor, Chair of Medicines Use & Health Outcomes, Charles Perkins Centre, School of Pharmacy, University of Sydney Davina Gherzi National Health & Medical Research Council (NHMRC) Adrian Cosenza Chair, Australian Ethical Health Alliance
2.30	Workshop 2 – practices: building trust and transparency	
	Operationalising the principles from Workshop 1: best practices for consumer group interactions with industry	Ray Moynihan Assistant Professor, Institute for Evidence-Based Healthcare, Faculty of Health Sciences & Medicine, Bond University Lisa Bero Professor, Chair of Medicines Use & Health Outcomes, Charles Perkins Centre, School of Pharmacy, University of Sydney
3.30	Next steps: meeting report for public dissemination	Anthony Brown, Lisa Bero
3.45	Finish	

Funded by the Charles Perkins Centre at The University of Sydney

APPENDIX 2: LIST OF PEOPLE ATTENDING THE WORKSHOP*

*nb attendees were able to opt out of having their names and details listed

1. Adrian Cosenza, Australian Ethical Health Alliance
2. Alice Bhasale, Charles Perkins Centre, The University of Sydney
3. Anthony Brown, Health Consumers NSW
4. Barbara Mintzes, Charles Perkins Centre, The University of Sydney
5. Benjamin Graham, WayAhead - NSW Mental Health Association
6. Beverley Noble, Cancer Voices
7. Bridget Haire, Australian Federation of AIDS Organisations
8. Davina Ghersi, National Health & Medical Research Council (NHMRC)
9. Dee Hopkins, Macular Disease Foundation Australia
10. Edith Lau, Charles Perkins Centre, The University of Sydney
11. Elisabeth Kochman, Cancer Voices NSW
12. Heather Renton, Syndromes Without A Name (SWAN) Australia
13. Jan Mumford, Genetic Alliance Australia
14. Jan Samuels, Huntingtons Queensland
15. Jane Costello, Positive Life NSW
16. Jane Williams, The University of Sydney
17. Janelle Bowden, Research4Me
18. Jenny Rollo, Cornelia de Lange Syndrome Association Inc
19. Jo Root, Consumers Health Forum of Australia
20. Joel Lexchin, Charles Perkins Centre, The University of Sydney
21. Joni Thomas, Bowel Cancer Australia
22. Julia Overton, Health Consumers Alliance of SA Inc
23. Karen Wong, Allergy & Anaphylaxis Australia

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24. Kellia Chiu, Charles Perkins Centre, The University of Sydney
 25. Kris Pierce, Scn2a Australia\GETA
 26. Leanne Wells, Consumers Health Forum of Australia
 27. Leoni Walton, Macular Disease Foundation Australia
 28. Lewis Kaplan, Huntington's NSW ACT
 29. Lisa Bero, Charles Perkins Centre, The University of Sydney
 30. Lisa Parker, Charles Perkins Centre, The University of Sydney
 31. Maria Said, Allergy & Anaphylaxis Australia
 32. Murray McLachlin, Cancer Voices NSW
 33. Neil Fraser, Positive Life NSW
 34. Nettie Burke, Cystic Fibrosis Australia
 35. Ray Moynihan, Bond University
 36. Richard Brightwell, Health Consumers Council WA
 37. Sally Wortley, Department of Health/The University of Sydney
 38. Sarah Lukman, Cancer Voices Hunter
 39. Sean Murray, Mito Foundation
 40. Serena Joyner, Health Consumers NSW
 41. Steven Drew, Hepatitis NSW Inc

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