


# Building trust and transparency: health consumer organisation–pharmaceutical industry relationships

Lisa Parker<sup>1,4</sup>  MBBS(Hons), PhD, Post-doctoral Researcher

Anthony Brown<sup>2</sup> BSc, MBA, PhD, Executive Director

Leanne Wells<sup>3</sup> BA, Chief Executive Officer

<sup>1</sup>Evidence, Policy and Influence Collaborative, Charles Perkins Centre, The University of Sydney, Camperdown, NSW 2006, Australia.

<sup>2</sup>Health Consumers NSW, Suite 3/Level 8, 280 Pitt Street, Sydney, NSW 2000, Australia.  
Email: [abrown@hcnsw.org.au](mailto:abrown@hcnsw.org.au)

<sup>3</sup>Consumers Health Forum of Australia, 7B/17 Napier Close, Deakin, ACT 2600, Australia.  
Email: [L.Wells@chf.org.au](mailto:L.Wells@chf.org.au)

<sup>4</sup>Corresponding author. Email: [lisa.parker@sydney.edu.au](mailto:lisa.parker@sydney.edu.au)

**Keywords:** best practice, ethics, funding, health consumer organisation (HCO), health policy, health services, pharmaceutical industry.

Received 5 August 2020, accepted 18 August 2020, published online 3 December 2020

Health consumer organisations (HCOs) have a major and growing voice in health policy, including through submissions and discussions about government subsidy for new medicines. Health consumer organisations are funded in a variety of ways and many accept pharmaceutical industry funding.<sup>1</sup> This supports their work but there is concern over real and perceived conflicts of interest: i.e. HCO acceptance of pharmaceutical industry funding delivers a risk that HCOs will prioritise the interests of the funder over interests of the public, and sector-wide reliance on industry funds might mean that non-industry funded voices are drowned out.<sup>2</sup> If there is a perception amongst health policy makers that HCOs are becoming mouthpieces for industry rather than providing a citizen's rights perspective on health services, they may stop listening to HCOs or stop inviting HCO involvement in policy. Addressing conflicts of interest is an issue of concern for the HCO sector as well as for policy makers.

We report here on a unique initiative of independent, nationwide discussion amongst HCOs to discuss the risks and benefits of partnering with the pharmaceutical industry. We invited HCO leaders from across Australia to a meeting in Sydney in March 2020. The meeting was co-convened by Health Consumers NSW, Consumers Health Forum of Australia and the Evidence, Policy and Influence Collaborative at The University of Sydney.

The aim of the meeting was to work towards a set of principles and suggestions for best practice that HCOs might draw on when considering whether, or how, to interact with pharmaceutical industry funders. The idea is that this independent, collaborative resource will add to existing Australian guidance documents for those who wish to work with industry, which have been produced by industry and/or individual HCO governing bodies.<sup>3,4</sup>

We had 42 attendees from around the country, including 29 people from 22 HCOs, one individual consumer, nine academics and three others (government, professional health organisation). We discussed and collated principles and examples of best practice that might assist HCO considerations about potential pharmaceutical industry funders (see [Box 1](#)). More detail is available in the full report.<sup>5</sup> This material is drawn from the experiences and views of participants as expressed on the day.

This workshop was the start of a conversation and a positive step towards keeping the activities and advocacy of HCOs independent. We welcome comments and suggestions for future work in this area.

## Competing interests

Anthony Brown receives a salary from Health Consumers NSW. He is also a Director of Global Action on Men's Health, a UK based charity which received an education grant from Advanced Accelerator Applications (A Norvatis Co.). He receives no payment from GAMH or AAA. Leanne Wells receives a salary from Consumers Health Forum. Lisa Parker has nothing to declare.

## Acknowledgements

We thank all the attendees at the meeting, and the consumer organisations of which they are members. Thank you to Serena Joyner, from Health Consumers NSW, who facilitated the meeting on the day. Thank you to Barbara Mintzes, Alice Fabbri, Kellia Chiu, Zhicheng Wang, Lisa Bero and the staff at the Charles Perkins Centre for their assistance in planning and convening the meeting. Thank you to speakers on the day, including Murray McLachlan from Cancer Voices NSW, Nettie Burke from Cystic Fibrosis Australia, Bridget Haire from the Australian Federation of AIDS Organisations, Lisa Bero, Barbara Mintzes and Edith Lau from the Charles Perkins Centre, Ray

**Box 1. Principles to guide consumer organisations thinking about engaging with pharmaceutical industry funders and participant suggestions on best practices for operationalising the principles<sup>A</sup>****1. Consumer centredness**

Making sure that your actions are in keeping with members' views, expectations and interests, as determined from regular consultation and feedback.

**2. Honesty/transparency**

Being open and upfront with your members about things that may matter to them (e.g. providing easily accessible information on: funding sources including dollar amounts and uses; policies around industry funding; any financial relationships between Board members and the pharmaceutical industry).

**3. Fairness**

Being mindful of the interests of all health consumers, including but not necessarily limited to members of your own organisation (e.g. advocating for a pooled industry fund to ensure voices of all organisations are heard including those without a pharmaceutical solution and to support non-drug related research that the pharmaceutical industry would not otherwise be willing to fund).

**4. Independence**

Acting in accordance with your organisation's own plans and priorities in the interests of your members and the health consumer sector, without influence from third parties (e.g. only accepting money for already-planned projects, having formal contracts with funders, refusing gifts of food and travel, limiting the percentage of total funding the organisations will accept from the pharmaceutical industry).

**5. Values alignment**

Being aware of the values, actions and health impact of potential funding organisations and avoiding or limiting relationships with less socially responsible companies (e.g. those with unfair pricing policies that effectively prevent access to medicines or that promote unsafe products; assessed through Access to Medicine Foundation league tables or membership of Medicines Australia).

**6. Governance/accountability**

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 (e.g. avoiding current industry personnel on Boards, regular audits of industry relationships by people unconnected to the Board or fund-raising activities).

<sup>A</sup>Principles are worded using terminology in frequent use on the day.

Moynihan from Bond University, Davina Ghersi from the National Health and Medical Research Council and Adrian Cozens from the Australian Ethical Health Alliance. The meeting was supported by the Charles Perkins Centre at The University of Sydney, who provided the venue, food and funding for consumers to attend, with in-kind support from Health Consumers NSW and Consumers Health Forum of Australia.

**References**

- 1 Fabbri A, Swandari S, Lau E, Vitry A, Mintzes B. Pharmaceutical industry funding of health consumer groups in Australia: a cross-sectional analysis. *Int J Health Serv* 2019; 49(2), 273–93. doi:10.1177/0020731418823376
- 2 Parker L, Fabbri A, Grundy Q, Mintzes B, Bero L. “Asset exchange”—interactions between patient groups and pharmaceutical industry: Australian qualitative study. *BMJ* 2019; 367: l6694. doi:10.1136/bmj.l6694
- 3 Consumers Health Forum. Medicines Australia. Working Together Guide, 3rd edn. 2015. Available at <https://medicinesaustralia.com.au/community/working-together-guide/> [verified 24 March 2020].
- 4 Medicines Australia. Code of Conduct, 19th edition 2019. Available at: <https://medicinesaustralia.com.au/wp-content/uploads/sites/52/2020/01/20200108-PUB-Edition-19-FINAL.pdf> [verified 3 August 2020].
- 5 Evidence & Policy & Influence Collaborative, Health Consumers NSW, Consumers Health Forum. Consumer-pharmaceutical industry relationships: Building trust and transparency 2020. Available at: [www.hcnsw.org.au/trust-and-transparency/](http://www.hcnsw.org.au/trust-and-transparency/) [verified 9 August 2020].