

Commercial interests may drown out patients' voices

January 17 2017

Researchers from the University of Sydney and Bond University are urgently calling for greater independence and transparency around industry-sponsored patient advocacy groups, following a growing amount of evidence which raises questions over potential bias in their activities.

Patient [advocacy groups](#) are becoming bigger players in healthcare, promoting certain interventions and shaping public debate about disease more broadly. Yet little is known about how these organisations' commercial interests ultimately influence regulatory decisions and patients' health choices.

In commentary published today in *JAMA Internal Medicine*, Professor Lisa Bero from the University of Sydney's Charles Perkins Centre and Dr Ray Moynihan from Bond University argue that patient advocacy groups should be subject to the same level of scrutiny over conflicts of interest and misleading claims as other medical and pharmaceutical bodies.

"As more research is conducted into patient groups and their influence in medicine, the question remains - are they engaging in potentially deceptive practices by suggesting solutions which better serve the interests of their corporate sponsors, rather than what's best for patients?" said Professor Bero, who is also based at the University of Sydney's Faculty of Pharmacy.

"The very way we think about disease is being subtly distorted because

many of the ostensibly independent players, including patient advocacy groups, are largely singing tunes acceptable to companies seeking to maximise markets for drugs and devices."

Currently in Australia there are no national requirements for patient advocacy groups to disclose their funding sources or industry sponsorships, though some pharmaceutical companies voluntarily disclose payments to these organisations thorough Medicines Australia.

Professor Bero and Dr Moynihan point to an increasing body of evidence suggesting bias in favour of funding source by those patient advocacy groups sponsored by drug manufacturers and other device companies.

A new survey by Dr Susannah Rose and colleagues from the Cleveland Clinic in the United States of 439 patient organisations found that two-thirds of responding groups received some form of [industry funding](#). One in 10 reported half their funding was from industry, with the median amount \$50,000, while approximately 10 percent of groups received \$1 million annually - almost half of that from pharmaceutical and device companies. Some of these groups even reported that they felt pressure from their sponsors to conform to their positions or interests.

"While there is ample evidence across medicine more generally showing that funding has the potential to bias research, education and practice, there is limited data on the possibility of similar associations between industry funding and advocacy group positions or activities," the authors state.

"In our view this new [research] demonstrates an urgent need for patient advocacy organisations to explicitly focus much more on representing the interests of patients and citizens, rather than serving - inadvertently or otherwise - the interests of their industry sponsors."

Another new study led by Dora Lin from the Johns Hopkins Bloomberg School of Public Health reveals that manufacturer-sponsored groups were more likely to oppose draft guidelines aimed at increasing regulation of opioid use (38 percent) compared to those with no industry funding (six percent). The study also revealed that of the 45 groups receiving industry funding, none of these were disclosed in the funding comments as part of the guideline submission.

"Thousands of patient advocacy groups in the United States are reliant on support from pharmaceutical or device industries, and at the system level the aggregation of this influence raises substantial concerns," said Dr Ray Moynihan of Bond University's Centre for Research in Evidence-Based Practice (CREBP).

"To ensure a healthier patient voice in medical research, education, policy and practice, sponsored groups that want to be seen as independent and credible need to decrease their industry sponsorship and ultimately disentangle - gaining in authority what they lose in resources."

More information: Toward a Healthier Patient Voice: More Independence, Less Industry Funding, *JAMA Intern Med*. Published online January 17, 2017. [DOI: 10.1001/jamainternmed.2016.9179](https://doi.org/10.1001/jamainternmed.2016.9179)

Provided by University of Sydney

Citation: Commercial interests may drown out patients' voices (2017, January 17) retrieved 6 May 2024 from <https://medicalxpress.com/news/2017-01-commercial-patients-voices.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.