

Industry funding of patient groups lacks governance and transparency

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Industry funding of patient groups is common in many high income countries, but few patient groups have formal policies that govern corporate funding and financial transparency is inadequate, warn experts in *The BMJ* today.



They say strategies are needed to prevent biases that could favour the interests of sponsors above those of the public.

Patient groups play an important role in <u>health care</u>, including educating consumers, funding <u>medical research</u>, and contributing to decisions on approval and public coverage of drugs and treatments.

They often rely on multiple sources of financial support, including the pharmaceutical and medical device industries. But concerns have been raised about the financial relationships between industry and patient groups because of conflicts of interest and potential threats to the integrity and independence of groups.

So an international team of researchers set out to investigate industry funding of patient groups.

They analysed the results of 26 <u>observational studies</u>. Most included patient groups from multiple disease areas and were conducted in <u>high</u> <u>income countries</u>, primarily the United States and Europe.

The studies were designed differently, and were of varying quality, but the researchers were able to allow for that in their analysis.

They found that, in general, industry funding of patient groups was common with estimates ranging from 20% to 83%.

Among groups that received industry funding, around a quarter (27%) disclosed this information on their websites. However, the authors note that studies analysing patient group websites were published between 2008 and 2012, so disclosure of financial relationships might have changed since that period.

The proportion of patient groups with formal policies that governed



corporate sponsorship ranged from 2% to 64%.

The few studies that assessed the link between organisational positions and funding, suggest that industry funded groups tended to support sponsors' interests, but the authors say this finding should be interpreted with caution.

These findings are observational, so can't establish cause, and the researchers point out that they might not be applicable to middle or low income countries. Relying on publicly disclosed information could also underestimate the true prevalence of industry funding.

Nevertheless, they say their findings lend weight to the need for patient groups to critically evaluate the role of industry funding on their operations.

"Greater transparency in reporting of industry funding, and policy development to govern corporate sponsorship are steps that are clearly needed and easy to implement," they write.

"In the long term, we would recommend a broader discussion about industry funding in the patient group sector, among patient groups themselves and in the wider society, and exploration of alternate <u>funding</u> mechanisms," they conclude.

These findings "provide yet more evidence that conflicts of interest between <u>patient groups</u> and industry are extensive and run deep," say researchers in a linked editorial.

They welcome moves towards mandatory disclosure of payments to physicians to promote transparency as "providing a starting point from which governments and the public can begin to recognise and interpret industry's influence."



But they argue that voluntary disclosure is not working and it is time for mandatory disclosure. "Only then can stakeholders explore how best to respond to disclosed information and develop additional legislative safeguards as needed to fortify public trust," they conclude.

More information: Industry funding of patient and health consumer organisations: systematic review with meta-analysis, *The BMJ*, <u>DOI:</u> 10.1136/bmj.l6925

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