



## EDITORIALS

# Corporate sponsorship of patient groups

It's time for mandatory disclosure

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Non-profit patient groups provide support services to patients and families, increase public awareness through educational outreach, participate in the development of clinical guidelines, lobby on policies affecting access and care, and invest in novel research on therapeutics. Although many focus on a particular disease, others focus on the needs and interests of healthcare consumers more generally.

Various sources provide financial assistance, including pharmaceutical and medical device companies. Given the considerable power of patient groups to influence healthcare policy and individual medical decision making, and given research documenting the effects of even small payments on physician practices,<sup>1</sup> monetary relationships between patient groups and industry have prompted recent concern. In the linked paper (doi:10.1136/bmj.l6925), Fabbri and colleagues provide the first systematic review on this topic to examine the extent of ties between patient groups and industry, the policies of patient groups surrounding corporate sponsorship, and the effect of industry support on the public position statements made by patient groups.<sup>2</sup> This builds on a recent qualitative study in *The BMJ* by Parker and colleagues exploring the attitudes of patient groups towards industry.<sup>3</sup>

Fabbri and colleagues performed a comprehensive meta-analysis of 26 cross sectional studies. Fifteen publications examined the prevalence of corporate sponsorship: between 20% and 83% of patient groups were estimated to have relationships with industry, supplying anywhere from a few per cent to near totality of annual operating expenses. Only a quarter of organizations receiving monetary support disclosed this relationship online, and transparency policies were insufficient. At most, only two thirds had organizational policies to regulate industry funding. The results of four studies examining the association between group positions and corporate sponsorship show substantial divergence between funded and non-funded groups, which largely reflect differences in industry versus patient interests.<sup>2</sup>

These findings reveal the breadth and depth of relationships between patient groups and pharmaceutical and medical device companies. The issue is likely even more widespread than

portrayed, as included studies only examined relationships with pharmaceutical and medical device companies, excluding connections with the food industry, health insurers, and other companies in the wellness sphere.<sup>2</sup> Additionally, patient groups are not the only patient voices affected—individuals can become corporate sponsored influencers with no public disclosure of their commercial relationships.<sup>4</sup>

More importantly, these results suggest that financial relationships pose real, not potential, conflicts of interest—with alignment between organizational positions and industry interests even when contrary to patient welfare. This is of particular concern given the power of patient groups internationally. When pharmaceutical and medical device companies lobby political leaders, the financial motivation is readily apparent, but when patient groups or individual patients engage in similar efforts, government and society assume they are acting independently in the interests of patients.<sup>5</sup>

Patient groups also may provide a channel through which companies can target patients in the many countries where direct-to-consumer advertising is illegal. As Parker and colleagues noted in their previous study, when a patient group does not already exist, companies have been known to establish one, placing carefully selected leaders at the top. In qualitative interviews with patient group staff, the leaders readily acknowledged the “give and take,” transactional nature of corporate sponsorship.<sup>3</sup> Patient organizations have been slow to regulate their own conflicts of interest; perhaps these intimate connections explain the holdup. Society's sympathy for patients' lived experiences might also underpin hesitancy to legislate in this sphere.

Fortunately, the beginnings of a solution have already been developed and implemented by governments in another context. Patient groups are not the only branch of corporate influence in medicine; about 48% of American physicians receive a total of \$2.4bn (£1.8bn; €2.1bn) annually in payments from industry.<sup>6</sup> Acknowledging the potential for undue influence as well as the failure of voluntary policies, particularly among those receiving large payments,<sup>7</sup> “sunshine” acts in the US and several European

countries mandate disclosure of payments to physicians to promote transparency.<sup>8,9</sup> Although not a cure-all, disclosure upholds moral commitments to honesty and integrity while providing a starting point from which governments and the public can begin to recognize and interpret industry's influence.<sup>10</sup>

Fabbri's and Parker's teams provide yet more evidence that conflicts of interest between patient groups and industry are extensive and run deep. Voluntary disclosure is not working. 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.

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She also served on the ethics committee for the American Society of Clinical Oncology, a non-profit professional organization in the US, for a two year term ending in fall 2019.

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