

Revealed: Large discrepancies in accounting for the funding sources of some UK patient organisations

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Large discrepancies in payments disclosed by patient groups and major drug companies are highlighted in a new report published today—Sunday 20 September 2020.

The research, which appears in *BMJ Open* from an international research collaboration led by University of Bath academic Dr. Piotr Ozieranski, analysed the disclosure of payments made by drug companies and patient organisations covering a period from 2012—2016. The research is covered exclusively in *The Sunday Times*.

It covers a large sample of 425 [patient groups](#) registered as charities in the UK, campaigning on issues ranging from disease awareness, research into new treatments, to patient support; and a sample of 87 drugs companies signed up to the Code of Practice of the Association of the British Pharmaceutical Industry (ABPI).

By comparing and contrasting drugs companies' own reporting of payments made, against how much patient groups claimed they had received, the study reveals large discrepancies between the two. In total, it found drugs companies disclosed 3235 payments worth over £54 million. By comparison, patient organisations, disclosed just 772 payments worth over £33 million—a shortfall of over £21 million.

Although 63 drug companies reported payments, 84 were mentioned by

patient organisations. In addition, drug companies disclosed payments to 425 patient organisations, yet only 200—less than half—reported receiving such funds.

Reaching these conclusions required the research team to spend hundreds of hours trawling through 220 disclosure reports published by drug companies, as well as 1,428 annual financial accounts published by patient organisations.

Their analysis raises important questions about transparency in patient organisation finances, which the team say requires swift policy action. They say this should focus on creating a single state-run, permanent database which would integrate payments reported by both drug companies and patient organisations in order to eliminate any underreporting and provide full clarity about funding sources.

Dr. Ozieranski from the Centre for the Analysis of Social Policy at the University of Bath explains: "Whilst aspects of this report might appear technical, these are transparency issues which affect us all given how much patient organisations can influence and shape decisions about how diseases should be treated, including new drugs that can have huge cost implications for the NHS.

"Patient organisations play an important role and we expect them to be their true, authentic voice. This is why their members, policymakers, individual and institutional donors, as well as the broader public, need to know about who funds them as funding relationships can create potential conflicts of interest. The same applies to any expert voices in public debates."

Marcell Csanadi, a study co-author from Syreon Research Institute in Hungary, noted: "In the current economic climate, it is unavoidable that patient organisations accept drug company funding. But especially in this

context, transparency is a powerful way of reassuring everyone that the receipt of industry support is managed carefully. This is important because perceived conflicts of interests may be just as important as the 'real ones'."

In their conclusions, the authors suggest that careful disclosure of funding information represents good governance and the general ability of patient organisations to report their finances transparently. It also best demonstrates that a [drug company](#) and patient organisation is serious about potential conflicts of interest.

As an interim step towards a state-run unified system, the researchers suggest the Association of the British Pharmaceutical Industry (the trade group representing [drug companies](#) in the UK) could create a single database of payments which companies following its Code of Practice make to patient organisations. This solution would be much more user-friendly than allowing individual companies to publish [payment](#) reports on their websites, they say, and a similar, industry-run, centralised disclosure database of payments to patient organisations is already in operation in Sweden.

Finally, the team suggest charity regulators could introduce tailored solutions related to reporting corporate funding in annual accounts. This could include a simple template which might comprise a short payment description, its value, and donor name in order to help standardise the process. Patient organisation websites should report this information separately or include clear signposting to the annual accounts, they also argue.

More information: Piotr Ozieranski et al, Under-reported relationship: a comparative study of pharmaceutical industry and patient organisation payment disclosures in the UK (2012–2016), *BMJ Open* (2020). [DOI: 10.1136/bmjopen-2020-037351](https://doi.org/10.1136/bmjopen-2020-037351)

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