

Written evidence submitted by Miss Emily Rickard

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Separately, I am currently working on my thesis exploring pharmaceutical industry lobbying in the UK. As part of my PhD project I have looked in detail at the APPG Register, in particular the entries of 146 health related APPGs, and identified a number of payments from the pharmaceutical industry and organisations which separately receive industry funding (and may therefore be prone to having opinions influenced by industry).

On the basis of my research, this submission offers advice for new measures which address three aspects of the inquiry (under subheadings below). Overall, the premise of this evidence submission is that current guidelines for transparency of APPG reporting of financial benefits and benefits in kind do not currently go far enough in terms of the level of information provided. Further, in line with this limited transparency around funding, there is often even less transparency as to what an APPG does. This applies to APPGs generally (in terms of their overall purposes) as well as specific APPGs (their activities and outputs).

Transparency and appropriateness of funding of APPG activities and secretarial support

Purpose of payment. A brief but informative payment description associated with each financial benefit is required. Financial benefits lack the brief details disclosed alongside benefits in kind. Transparency of payments from external donors can be increased, as well as eliminating some of the uncertainty as to what APPGs actually do, by introducing descriptions of the purpose of the payment.

Benefits in kind. When a benefit in kind has been provided by an organisation which has received funding from other organisations for the purposes of the benefit in kind, the relative contribution in terms of the value provided by each indirect funder should be made transparent.

Single source of complete incoming benefits. An Excel or csv document should be available to download annually from the APPG Register webpage. Currently there is no way of identifying all financial benefits and benefits in kind received by an APPG in a given calendar or financial year. The information from the APPG Register should be collated annually into a single, comprehensive and accessible database. This would allow an interested user to calculate the total value of external support an APPG has received in a given year and allow for comparisons between years. Although dates benefits were received and registered are provided in the current APPG Register, identifying unique benefits is not as straightforward as it could be.

The role of external secretariats to APPGs

Function and financial value of secretariats. This suggestion is also relevant to the above question around transparency. Each APPG should provide details of what function their secretariat fulfils for the APPG. The financial value related to secretariat roles varies vastly (by tens of thousands of pounds) from APPG to APPG, causing a lack of clarity as to whether

some secretariats do more work, have more say, or are just generally valued higher than others by APPGs.

Purpose of secretariats. While it is important that external organisations have a voice in important policy issues for which they may have specific expertise, the role and purpose of the secretariat remains relatively unclear. To mitigate against the uncertainty surrounding their role, secretariats could provide bi-annual updates, published as part of the APPG Register, as to the role they have played and the activities they have conducted.

The risk of APPGs being used for access by lobbyists, other organisations or by foreign governments, and how any conflicts of interests arising can be managed

Clarity of the purpose of APPGs. As well as increasing the transparency of financial benefits and benefits in kind provided by external organisations potentially seeking to lobby through APPGs, improving transparency more broadly would help in terms of managing conflicts of interests. More information about the purpose and potential influence of APPGs needs to be published on the Parliamentary website.

Clarity of what APPGs do. It is unclear what many APPGs do, which is exacerbated by the scattered availability of APPG websites (some have their own websites, some have webpages hosted by their secretariats, some do not have websites) and the varied content of the websites (some provide lots of detail of their activities, others provide minimal or no detail, some provide a list of reports published, some provide a selection and others it is unclear if they have any reports). It would be more transparent and informative for the general interested person to be able to access information relevant to the APPG under relevant subsections which could be introduced as part of an APPG's register entry (i.e. links to all meeting minutes, reports, inquiries).

Reasons for financial benefits and benefits in kind. A written indication of why an organisation is providing a financial benefit or benefit in kind. APPG Registers could maintain a record of why an organisation is providing support. This would reduce doubts or misconceptions around ulterior motives. At the very least, descriptions (1-2 sentences) about each financial benefit and benefit in kind should be provided.

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I have published a number of articles alongside my supervisor Dr Ozieranski in the area of transparency and disclosures as part of a project funded by a grant from the Swedish Research Council for Health, Working Life and Welfare (FORTE, #2016-00875), listed below:

Ozieranski, P., Rickard, E. and Mulinari, S., 2019. Exposing drug industry funding of UK patient organisations. *BMJ*, 365:l1806 <https://doi.org/10.1136/bmj.l1806>

Rickard, E., Ozieranski, P. and Mulinari, S., 2019. Evaluating the transparency of pharmaceutical company disclosure of payments to patient organisations in the UK. *Health Policy*, 123(12), pp. 1244-1250, <https://doi.org/10.1016/j.healthpol.2019.08.007>

Ozieranski, P., Csanádi, M, Rickard, E, *et al.*, 2020. Under-reported relationship: a comparative study of pharmaceutical industry and patient organisation payment disclosures in the UK (2012–2016). *BMJ Open*, 10:e037351. <https://doi.org/10.1136/bmjopen-2020-037351>