



Best practice guidance: Supporting patient organisations to report industry funding

February 2024

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Foreword

Transparency is essential when pharmaceutical companies work with patient organisations. The Association of the British Pharmaceutical Industry (ABPI) Code of Practice for the Pharmaceutical Industry places requirements on industry to publish annual lists of payments to patient organisations, and we endorse this approach.

Currently, there is no similar requirement for those patient organisations in receipt of grants or funds from industry. While there is no charity commission mandate for patient organisations to declare support from pharmaceutical companies, patient organisations recognise the importance of transparency, as they would with support from any other grant maker, corporate donor, or sponsor.

Therefore, patient organisations already use a range of different approaches to report such funding. For example, some have a dedicated section on their website, others publish funding information in annual reports and others may include details within individual project information. However, many have said to the ABPI that they would value more practical guidance as to what to report and how.

In response, the ABPI has put together some advice for local disclosure mechanisms, based on current practice among industry. We welcome this move, particularly the guidance on the categories of information that should be provided as a minimum (the name of the pharmaceutical company, the value amount, the date, and a short description of the activity to aid public understanding).

There is unlikely to be a one-size-fits-all solution, and different organisations may choose to adapt and tailor their approach, for example, to enable them to explain their collaborations with industry to their communities more effectively or to allow more efficient reporting. However, this guidance will provide a useful starting point.

More work is needed to continue to develop best practice, and the Association of Medical Research Charities (AMRC) will engage with its members to share learning and provide more detailed examples and guidance to support patient organisations in continuing to raise the bar for transparent reporting.

- ABPI Patient Advisory Council (February 2024)

- Clare Jacklin, Chief Executive, **National Rheumatoid Arthritis Society**
- Hilary Evans, Chief Executive, **Alzheimer's Research UK**
- Jacob Iant, Chief Executive, **National Voices**
- John James, Chief Executive, **Sickle Cell Society**
- Nicola Perrin, Chief Executive, **Association of Medical Research Charities**
- Samantha Barber, Chief Executive, **Gene People**
- Tom Nutt, Chief Executive, **Meningitis Now**¹

1. ABPI, 'ABPI Patient Advisory Council', 2024, available at <https://www.abpi.org.uk/partnerships/working-with-patient-organisations/abpi-patient-advisory-council/>

Transparency Principles

There are established principles which underpin all collaborations between patient organisations and the pharmaceutical industry which include commitments to transparency.

Association of Medical Research Charities (AMRC) – Guide for charities working with industry

*"Charities should be entirely open about their collaborations with industry."*²

Association of the British Pharmaceutical Industry (ABPI) – Working with patients and patient organisations sourcebook

*"Transparency – each party should be open and honest about the purpose of the collaboration and be able to account publicly for the associated activities and any exchanges of funding."*³

European Federation of Pharmaceutical Industries and Associations (EFPIA) – Working together with patient groups

*"Transparency of the aims and objectives of any collaboration builds trust and allows for independent external scrutiny. All financial relationships should be transparent and any compensation to patient organisations' representative should be proportional and commensurate with experience, expertise and the time invested."*⁴

Patients Active in Research (PARADIGM) – Code of Conduct

*"All patient engagement partners commit to full transparency about all aspects of the collaboration."*⁵

ABPI Code of Practice for the Pharmaceutical Industry 2021 – Relationships with Patient Organisations

*"In their written contracts with patient organisations, companies are strongly encouraged to include provisions regarding an obligation of the patient organisations to declare that they have provided paid services to the company whenever those concerned write or speak in public about a matter that is the subject of the agreement or any other issue relating to that company."*⁶

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2. AMRC, 'Partnering for patients', 2014, available at <https://www.amrc.org.uk/pages/category/partnering-for-patients>
 3. ABPI, 'Working with patients and patient organisations', 2022, available at <https://www.abpi.org.uk/publications/working-with-patients-and-patient-organisations-a-sourcebook-for-industry-2022>
 4. EFPIA, 'Working together with patient groups', 2017, available at <https://www.efpia.eu/media/412524/working-together-with-patient-groups-23102017.pdf> and the research-based pharmaceutical industry
 5. PARADIGM, 'Code of conduct for all stakeholders involved in patient engagement activities within medicine development', 2020, available at <https://imi-paradigm.eu/petoolbox/code-of-conduct> a Medicine
 6. PMCPA, 'The ABPI Code of Practice for the Pharmaceutical Industry', clause 27, 2021, available at <https://www.pmcpa.org.uk/the-code>

ABPI Code requirements for disclosure by the pharmaceutical industry

The ABPI Code 2021 (Clauses 29 and 31) sets out the requirements for the disclosure of transfers of value to patient organisations, or individuals representing patient organisations, as follows:

- Pharmaceutical companies must make publicly available annually a list of patient organisations together with monetary value and description of each interaction.
- **What?** The ABPI Code lays out the minimum level of information pharmaceutical companies are required to disclose. Values and descriptions will relate to donations, grants, sponsorship, contracted services and non-monetary benefits over the reporting period. Each company must also publish a note of methodologies used to prepare their disclosure declaration.
- **Where?** Information is disclosed by the individual pharmaceutical company on its website. Companies may additionally choose to publish a link to their patient organisation disclosures on the ABPI's existing transparency database, Disclosure UK.⁷
- **When?** In line with European requirements, disclosure reports cover a full calendar (not financial) year and are published by pharmaceutical companies by the end of June after the end of the year in which the payments were made. Companies publish a minimum of three years of information and are required to keep records for at least five years.

Recommended actions for patient organisations

1. Patient organisations should publish a complete list of funding received from pharmaceutical companies by calendar year (preferable to financial year, where possible) on an annual basis.
2. Information should be published on patient organisation websites before the end of June of the following year.
3. Patient organisations may wish to mirror the level of information disclosed by the pharmaceutical industry in line with the ABPI Code of Practice (see ABPI Code requirements above). As a minimum, patient organisations should include the name of the pharmaceutical company, the value amount, the date, and a short description of the activity to aid public understanding.
4. Patient organisations should also include a statement declaring the percentage of their total income received from the pharmaceutical industry and other life-science industries for the same calendar year (preferable to financial year, where possible) on an annual basis.
5. Information should be easily accessible to the public and in a format that supports scrutiny from the public and researchers.
6. Patient organisations could consider placing a dedicated link to transparency of funding information on their organisation's homepage.

7. ABPI 'Disclosure UK database', 2024, available at <https://www.abpi.org.uk/reputation/disclosure-uk>

Example

2022 funding received from pharmaceutical [other life-science] companies by [patient organisation]

Name	Date of activity	Value	Description
Example Pharma Ltd	12 October 2022	£400	Donation/grant description
Medicines UK Ltd	14 April 2022	£10,000	Sponsorship description
Medicines UK Ltd	16 May 2022	£15,000	Contracted service description
Other life-sciences, inc.	18 July 2022	£3,000	Non-monetary description
Pharma Co Ltd	18 January 2022	£5,000	Sponsorship description
Pharma Co Ltd	1 December 2022	£300	Other description
X-Meds Pharma	2 February 2022	£800	Other description
	TOTAL	£34,500	10% of all funding received by [patient organisation] in 2022

Further resources

The ABPI supports industry and patient organisations working together. For more information, see our **Working with patients and patient organisations sourcebook**,⁸ designed to help pharmaceutical companies and patient organisations plan how best to engage and work together successfully.



8. ABPI, 'Working with patients and patient organisations', 2022, available at <https://www.abpi.org.uk/publications/working-with-patients-and-patient-organisations-a-sourcebook-for-industry-2022>



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