



Transparency on Industry Relationships

Global Heart Hub (GHH) seeks funding from the Pharma and MedTech industry in support of its mission to promote the role of the patient in healthcare and to advocate for the best possible healthcare outcomes. GHH only engages with industry partners who share the mutual aims of improving awareness and treatment of heart diseases. GHH will always only engage with industry through ethical and transparent collaborations where, at all times, best patient awareness, education and/or outcomes are the sole objective. All industry support of GHH is agreed in advance by way of a written contract of understanding between both parties which outlines the scope of the relationship; the exact nature of the work being supported, the expectations and the deliverables. In all its industry relationships, GHH will maintain its autonomy and independence and is beyond influence.

Global Heart Hub is an alliance of global heart patient organisations. All patient organisations affiliated to GHH, as well as their industry funders, should align to the following guiding principles and code of conduct in relation to patient organisation/industry relationships:

Principles of Engagement

- **Independence:** Patient organisations must retain full control over their activities, decisions, and messaging. Financial support from industry should not compromise the independence of patient organisations or influence their objectives.
- **Transparency:** All interactions between patient organisations and industry must be conducted transparently, with clear documentation of any initiatives. This documentation should reflect a spirit of mutual respect and trust, based on sound medical, educational, and policy principles.
- **Mutual Respect:** Relationships between patient organisations and industry should be based on mutual respect. Each partner's views and contributions should be valued equally, fostering a collaborative environment that prioritises patient welfare.
- **Core Objective of Funding:** Industry funding must always have as its core objective the advancement of patient health and the improved awareness, diagnosis, and treatment of diseases for the benefit of patients.
- **No Promotion of Products:** Patient organisations must not engage in activities that promote any prescription-only medicines or medical products. Any funding received should be used solely for activities aligned with the organisation's mission and objectives.
- **Ethical Conduct:** Both patient organisations and industry partners must adhere to high ethical standards in all interactions. Conduct that undermines the credibility of either party or damages public trust in patient advocacy is unacceptable.

Mutual transparency of funding

- All industry funding should be sought and made in an open and transparent manner.
- Patient organisations should disclose the names and/or logos of its industry funders on its website. The names and/or logos of industry funders should appear on materials related to campaigns or activities which have been funded by an industry sponsor or sponsors.
- Industry funders should disclose on their corporate website the names of any patient organisations they support.
- Patient organisations should always only seek industry support in a fair and transparent manner. Multiple funding partners are essential to avoid real or perceived exclusive relationships.

Manner of funding

- Financial contributions from industry to patient organisations should be made either as unrestricted funding or sponsorship of a specific activity initiated by the patient organisation to support its stated mission.
- Industry should not suggest or offer funding to patient organisations for any implied or actual product promotion activities.
- Industry should not suggest or offer funding to patient organisations to support company-only health policy advocacy.
- Patient organisations should not seek or accept funding from industry that could be perceived as buying special privileges such as directing a meeting agenda, guiding content of educational materials, promoting participation in a specific clinical trial or influencing the outcome of a specific research programme.
- While it is understood that a new patient organisation may need to rely upon a single source of funding in its set-up phase, it should always seek funding from multiple sources and ensure it has multiple funders, within at the latest 24 months of achieving charitable status.
- Patient organisations should only solicit and accept financial contributions that support its stated mission and at all times ensure its independence and autonomy.
- Any transfers of value or benefits provided to a patient organisation by industry should always be documented by a signed agreement between both parties.



Patient organisation and industry interactions

- Patient organisations should always maintain a complete record of all requests for financial or other support from industry. All requests should be submitted on the organisations letterhead, clearly stating its mission and activities and detailing the reasons for the request.
- It is acceptable for patient organisations to seek information and/or education from industry on a disease state and therapies. However, information and/or education provided by industry should always be fair, balanced and non-promotional.
- Patient organisations may provide consultation to industry, if it is consistent with their mission and does not compromise autonomy or independence. The extent and terms of such consultancy services must be documented in a written agreement between the patient organisation and industry.
- It is acceptable that patient organisation leaders, representatives or staff are permitted to attend meetings with industry partners in order to discuss support, secure support or report on activities.
- Travel expenses incurred to participate in industry events, advisory board meetings or disease awareness activities may be reimbursed directly to the individual patient or to the patient organisation.
- Patient organisations should establish metrics to evaluate the effectiveness of an activity or initiative in which it has collaborated with industry. Regular communication with industry funders on the results of a specific project or use of funds is desirable and acceptable.
- Patient organisation leaders will not operate as independent consultants to individual industry outside of their roles within their patient organisation.
- Patient organisations leaders will not accept personal honoraria to speak on behalf of their organisation, but may have the honoraria directed to their organization.

Review and Compliance

This policy will be reviewed regularly to ensure its relevance and effectiveness in guiding interactions between patient organisations and industry partners. Compliance will be monitored, and any breaches will be addressed promptly to uphold the integrity of GHH and its member organisations.