



ABPI Patient Organisation Forum Terms of Reference



AIMS:

- To identify areas of mutual interest, to promote understanding and, where appropriate, to develop opportunities to partner on policy and practice between industry and organisations that represent patients.

STRUCTURE:

- The Forum seeks to bring together representatives of the pharmaceutical industry with patient organisations. Individuals from both industry and patient groups should be professionally or significantly engaged in policy, government affairs, and public relations, partnerships or similar, where a significant amount of their remit includes industry-patient group engagement. Other interested stakeholders may be included if all parties feel that they can contribute to the Forum.
- The Forum aims to have equal representation of pharmaceutical companies and patient organisations, independent of both size and therapy area. Attendance should usually be limited to two representatives per organisation. Meetings will be co-chaired by one representative from a company and one representative from a charity, usually from the Steering Committee.
- The Forum is supported by an informal Steering Committee of up to seven representatives from each of the industry members and patient groups. The Steering Committee will agree the agenda and co-chairs for each meeting 4-6 weeks in advance and discuss ways of working and a programme of discussion topics in consultation with members of the Forum.

FUNCTION:

The Forum is developed to:

1. Form an on-going two-way dialogue between patient representatives and the pharmaceutical industry, with open discussions and information sharing
 2. Promote partnership and patient engagement
 3. Develop an increasing understanding of each others' perspectives and needs
- Patient organisations and pharmaceutical companies recognise that on a number of UK and International policies both may have common interests. The Forum aims to understand and improve healthcare policy dialogue between the patient groups/health charities and industry, addressing the broad issues. Future outputs may include consensus documents and themed workshops.
 - An essential element is the co-creation and co-chairing of the Forum, to allow all stakeholders who are involved to feel they are part of the development of the Forum as

a stable environment of healthcare discussion, co-creation and collaboration where appropriate.

- The Forum is not a platform for lobbying parliamentarians or other stakeholders; but should be an environment for candid discussion and exchange of diverse views. It is important that participants do not feel that they are obligated through attendance to any external commitment or ABPI/Industry campaigns.
- Representatives should feel comfortable to express their views on a Chatham House basis. The co-chairs of meetings should decide whether a meeting is held on a Chatham House basis, to communicate this, and to agree with speakers about the sharing of presentations and quoting remarks in the published summary.
- The Forum is not designed to address issues effecting a single organisation or company. ABPI will advise should any issues raised for discussion have any implications under anti-competitiveness legislation, either when agreeing the agenda or during Forum meetings. The nature of these meetings will be strictly non-promotional, in line with the requirements of the ABPI Code of Practice 2024.

ABPI role:

- ABPI will act in a secretariat role to the group, providing support and advice to the co-chairs and informal steering committee plus a contact point for enquiries. Meetings will be hosted by the ABPI at its offices in central London and virtually, unless circumstances or Forum members request them to be held elsewhere or entirely virtually.