



IPPOSI MEMBER CODE OF CONDUCT

Guidance for Industry members

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The purpose of this code of conduct is to formally and publicly underline the standards which IPPOSI expects from its industry members. This is designed to promote trust and increase confidence between stakeholders (patients, science and industry) who traditionally operate in distinct arenas with different motivations and agendas.

The intention of this IPPOSI code is to ensure that IPPOSI patient members can participate in IPPOSI activities as 'protected partners' ensuring that their organisation/personal impartiality and independence is protected.

The code is also designed to promote transparency and accountability among the various stakeholders which make up the IPPOSI membership.

The code identifies six key principles, from which a number of specific provisions are drawn.

This IPPOSI code was approved by the IPPOSI Governance Committee on 25 May 2020, and entered into effect on IPPOSI Board approval in June 2020. It will be revised every four years, prior to the adoption of the next IPPOSI strategic plan. The code is not exhaustive or exclusive, and ad hoc additions may be required.

The code was circulated to all existing IPPOSI industry members in early 2020, and will be shared with all new or prospective industry members as the need arises.

If the code contradicts any legislation or codes of conduct/practice by which any IPPOSI industry member is already bound, this element of the code should be disregarded.

Scope of this code

The code applies to all IPPOSI industry members, including large pharmaceutical, bio-tech, diagnostic, medical device companies, technology, genomic companies and individual industry consultants and agencies.

Benefits of IPPOSI membership for industry

The benefits to IPPOSI membership for industry are below:

- Access to an informed, **like-minded community** interested in partnering around patient education and patient involvement
- Opportunities to participate in **multi-stakeholder discussions** on health innovation and research topics
- Access to health innovation and health research **updates and information** via the IPPOSI newsletter
- Opportunities to **co-create positions** via IPPOSI policy working groups and initiatives to address health innovation and health research challenges
- Access to a **network** of health innovation and health research experts available for speaking engagements, workshops and events
- Opportunities to **sponsor** recognised, professional patient education/engagement initiatives, such as the IPPOSI patient education programme.

To promote partnership working and open and transparent dialogue between members, IPPOSI will:

- Distribute the IPPOSI monthly newsletter with our patient-led perspective on Irish and EU-level health developments, and policy documents/publications to industry members.
- Extend invitations to industry members to engage in evidence-based discussions on current Irish and EU health policy issues with our patient and scientific members.
- Speak or attend industry member events, on request, to outline IPPOSI's position on one or more of its policy priority areas.
- Host an annual conference for members (including industry members) to reflect on the ongoing challenges and to strategise for the coming year.

For more information visit <https://www.ipposi.ie/about-us/why-join-ipposi/industry>

Principles informing this code

Patients as partners: IPPOSI is patient-led in all that we do and our work must reflect the needs, values and preferences of patients and their representative groups in Ireland. Issues and topics that are common to our patient members dictate our direction of travel. Issues which do not interest our patient members or do not reap any benefits for our patient members are not pursued.

Consensus: IPPOSI is a partnership of patients, science & industry. We operate in the space where the common interests of these three groups converge. Our strategic goals and our policy positions are based on where consensus can be found. We will not tolerate any efforts to negatively influence or coerce other members.

Partnership: IPPOSI believes that patients are equal and valued partners. We encourage our industry to call out poor practices and that you oppose in the strongest terms any displays of tokenism or paternalism.

Leadership: IPPOSI seeks to drive innovation in healthcare. We want our industry members to be involved in patient education and patient engagement. We ask that you challenge the way you currently do business and look to adopt new ways of working which will help IPPOSI develop and implement continuously improving, high-quality and compassionate health solutions.

Transparency: IPPOSI believes in open and honest communication between members. Where differences are encountered, debate should be cultivated. Where mistakes are made, reparations should be found. We require our industry members to be up front in declaring their interests and in disclosing any conflicts.

Evidence-based: IPPOSI supports evidence-based policy and decision-making. We ask that you represent only the facts, avoiding individual company positions, and bearing in mind that many of the issues we address are complex and often controversial. Misinformation is not helpful.

Interacting with patient members and other members

IPPOSI industry members must NEVER seek to promote a particular product(s) or treatment(s) to other IPPOSI members. Industry members should never offer medical advice to other IPPOSI members. Industry members found in violation will have their membership immediately reviewed by the IPPOSI Board.

Industry members should be mindful that IPPOSI operates within the general health innovation and health research space. IPPOSI does not represent the interests of specific disease or condition communities.

All interactions between industry members and other IPPOSI members must be based on the principles of respect, integrity and honesty.

Industry members should recognise the heterogeneity of the Irish patient community and seek to consult under-represented, hard-to-reach and vulnerable patient communities.

Industry members should be mindful of the way they communicate, avoiding acronyms, unpacking terminology and using accessible language.

All industry members must raise any safety or safeguarding concerns with the relevant authorities.

All industry members must respect the requirements of the General Data Protection Regulation.

Industry members must present all requests to consult with the EUPATI National Platform in Ireland and the graduates of the EUPATI and IPPOSI Patient Education Programmes to the Chair and Vice-Chair of the Platform and the IPPOSI Chief Executive Officer.

Communication with patient members + other members

All use of the IPPOSI logo should be approved by a relevant member of the IPPOSI Executive. Industry members found in

violation of the IPPOSI Communications Policy will have their membership reviewed by the IPPOSI Board.

All external communication quoting IPPOSI or an IPPOSI patient member must be agreed between the industry partner and the individual or organisation. Under no circumstances should an industry member quote a patient member without their explicit consent. Industry members found in violation will have their membership reviewed by the IPPOSI Board.

Industry members should use social media responsibly and appropriately at IPPOSI events and in relation to other IPPOSI members.

Declarations and conflicts of interest

IPPOSI industry members must complete and keep updated a declaration of interests. Any conflicts should be disclosed in full within this declaration. Industry members found in violation will have their membership reviewed by the IPPOSI Board.

IPPOSI industry members in Board positions should exclude themselves from decision-making where a conflict arises. Industry members found in violation will have their membership reviewed by the IPPOSI Board.

Where an IPPOSI industry member is an affiliate, associate or subsidiary of another IPPOSI industry member (either in Ireland or elsewhere), both industry members must make declarations to this effect.

Misconduct and breaches of this code

IPPOSI industry members should familiarise their colleagues with this code to minimise any breaches of behaviour.

If an industry member believes themselves to be in breach of this code, we ask that you acknowledge your concerns and address them to the IPPOSI Chief Executive Officer, who will in

turn consult the IPPOSI Board. Disclosure will be dealt with confidentially and professionally.

Useful resources

- [IPHA Code of Practice for the Pharmaceutical Industry](#)
- [IPHA Code of Advertising Standards for the Consumer Healthcare Industry](#)
- [EFPIA Code of Practice](#)
- [EUPATI Guidance for patient involvement in industry-led medicines R&D](#)

CORE PRINCIPLES IN RELATION TO INDUSTRY SPONSORSHIP

A stated benefit of IPPOSI industry membership is the opportunity to **sponsor** recognised, professional patient education/engagement initiatives, such as the IPPOSI patient education programme.

This sponsorship is considered separate to the IPPOSI industry membership fee and is in the form of a funding partnership.

In order to make these funding partnerships work in practice, to ensure the integrity of both the sponsoring company and IPPOSI is maintained, and to demonstrate to other stakeholders that our relationships are absolutely scrupulous, the following key principles underpin our acceptance of sponsorship funding.

Independence: IPPOSI will maintain at all times an independent and strong patient-led voice on behalf of its member organisations. The potential effect of IPPOSI positions on sponsoring companies will never be a relevant factor in IPPOSI's policy development and decision-making process.

Mutual Respect: IPPOSI and our sponsoring companies undertake to cooperate on a basis of mutual respect as fellow stakeholders in healthcare systems and delivery.

Unconditional: Funding received by IPPOSI for aspects of our operational programme to fulfil our vision and mission should be unconditional in nature.

IPPOSI may also require co-financing in the form of unconditional funding from sponsoring companies to lead and/or cooperate in specific projects funded by the Health Service Executive, the Dept. of Health, the Health Research Board, the European Commission and other public/ private sources.

Sustainable: Sponsoring companies should, wherever possible, provide a long term funding commitment supported by a written agreement. The funding support may also be allocated to building reasonable reserves for IPPOSI to ensure the sustainability of the organisation.

Where a company knows that they will no longer be a member of IPPOSI they should inform IPPOSI at the earliest opportunity. Where notification is not received, IPPOSI will expect membership to roll from year to year.

No single company or governmental source: IPPOSI events should be supported with an unrestricted grant from more than one sponsoring company, or from a company in partnership with another public or private funder. IPPOSI will ensure that the funding received from one single sponsoring company will be proportional to the overall budget and reflect our commitment to diversity of funding sources. The content of such events should be developed by an independent IPPOSI working group of members established for that purpose.

Transparency: A written agreement between the sponsoring company and IPPOSI outlines the nature and amount of the funding and the period covered. IPPOSI will acknowledge sponsoring companies on relevant publications linked to an event. The amount of funding received, and the sources, are included in the IPPOSI Annual Report and published separately on the IPPOSI website within one month of the Annual Audited Accounts being approved by the Annual General Meeting of the following year.

Governance and ethics: IPPOSI will apply the IPHA Code of Good Practice on working with patients' organisations in relation

to any funding received from sponsoring pharmaceutical companies, and other relevant national and European codes.