

Ethical interaction between Patient Organizations and Health Care Partners

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Treasurer International Alliance of Patients
Organizations



- **IAPO is a Unique Global Alliance of Patients :**
 - Set-up nearly 17 years ago
 - Over 250 national, regional and international members
 - In over 60 countries
 - Cross-disease member organisations covering over 50 main WHO ICD 10 disease classifications
 - Serves interests of over 350 million patients
- **OUR VISION:** To see patients at the centre of healthcare throughout the World
- **OUR MISSION:** To build patient-centred healthcare worldwide.
- **Participation, transparency, accountability and equity essential for a patient-centred health system**

IAPOO has led the way on ethics and transparency

- We established a Consensus Framework for Ethical Collaboration**
- A framework based on four main principles and designed to help healthcare stakeholders work together to deliver high quality patient care.**



Four principles

- Putting patients first
- Supporting ethical research and innovation
- Ensuring independence and ethical conduct
- Promoting transparency and accountability

Key issues covered

- Optimal care- best decisions in patient's interest
- Partnerships-essential for best decisions
- Clinical research-informed consent and ethical
- Objective clinical research-no bias or influence
- Gifts- zero tolerance,
- Sponsorship- has to be transparent, educational and proportionate
- Affiliation-transparent with integrity
- Fee for services- open, contractual and fair value
- Clinical research transparency-transparent, reporting ALL results, patient informed consent, patient centred

The way forward (1)

- IAPO's patient advocates and member organizations working with other stakeholders to ensure that medical representatives globally are no longer rewarded for the number of individual prescriptions written.
- We continue to support medical education but via an arms-length approach

The way forward (2)

- IAPO continues to support investment in the capacity building of HCPs and patient organizations by helping them attend scientific conferences and by acting as a third party partner with the industry
- We continue promote that HCP to speak without any payments on, and specifically to talk about therapeutics etc without mentioning companies and brand names
- We continue to support transparent, accountable and market-tested payments for procurement of clinical research, advisory activities and market research.

Full Copy of Consensus Statement

https://www.iapo.org.uk/sites/default/files/files/Consensus_Framework-vF.pdf