TRANSPARENCY AND ETHICS IN WORKING WITH INDUSTRY

Nicola Bedlington

EPF Secretary General

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LUND

" A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE "

EPF European Patients Forum

Why do we build partnerships?

- "Help meet the organisation's mission and objectives; build a strong organization by strengthening professional capacity and skills; increase awareness and visibility of organisation/fight against a disease/public health issues."

- "corporate donation programmes are seen as a good practice in corporate governance and one of the ways companies can support patients"

- "Collaboration can also allow pairing of diverse strengths and resources, promoting a greater effectiveness in tackling priorities"

Codes of conduct- Principles and Values

Transparency, Independence and autonomy, mutual respect and equal partnerships, accountability

- A number of codes define these principles in more details : the values may be governing conduct beyond relationship with industries.

- But **meanings, emphasis may differ** from one code to another: e.g. *transparency* may encompass financial transparency, **and / or** our collaboration with members and allies, partners, government and healthcare industry organisations, with the public.

Key elements : relations with industry

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Guidelines related to achieving financial transparency:

-*Written agreement* to outline nature and amount of sponsorship.

-Rules for *acknowledging the funding source* (publications the website, in financial reports)

Guidelines related to maintaining independence

-*Independent judgment* in all its decision-making.

-Retaining sole *discretion for the content*, quality, scientific and educational integrity of all sponsored programmes, events and publications.

-Rules on the use of the *logo or name* of the organisation

-On the *endorsement of products* (strictly forbidden)

Examples of codes

Sponsorship guidelines (Alzheimer Europe)	European Patients' Forum code of conduct (2008)
Eurordis policy on financial support by commercial companies (2009)	Code of practice between patient organisations and the healthcare industry (2009)- multiple organisations
EFCCA Commitment to transparency	Corporate relations guiding principle (IPOPI)
Business and Industries guideline (IDF,2009)	Code of ethics and conduct (EFA)
Code of practice (EPDA)	Code of conduct (EMSP)
Code of conduct with the pharmaceutical industry (GAMIAN)	Ethical principles of partnership (PatientPartner Project)

Reputation and credibility

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- No compromise on your core values of independence, integrity and transparency

- Knowing when to say no…

- Diversify your sources of funding so that you never become over dependent on one donor

- Develop your own code of conduct or framework for working with industry (see EPF model)

- Be accountable, effective financial and qualitative reporting

Ethics Check list

- Common sense – if you are not sure whether something is ethical , it probably is not

- If something feels borderline – don't do it

- Any dealings should be able to endure public scrutiny

- Be responsible as PO for content

- Insist on an equal relationship – be confident in your unique expertise, know-how and experience

Reflections

- New climate of **cooperation** and **trust** between industry/patients, and among the health stakeholder community -Not only funding-Public Private Partnerships

- Essential to address **societal challenges**

- These relationships - not '*comfortable*' but dynamic, challenging, ambitious, solution-oriented

- Precious, new and potentially fragile – must be underpinned by **highest level of integrity and ethics**

- External perceptions key- vigilance and rigor
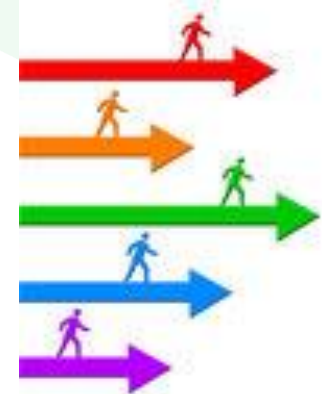
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www.eu-patient.eu
info@eu-patient.eu

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