

ISSUE FACT SHEET

The patient & consumer voice and pharmaceutical industry sponsorship



Background

Current EU legislation prohibits direct-to-consumer advertising of prescription-only medicines. However, the *Information to Patients Directive and Regulation* could expand the role of the pharmaceutical industry to provide information on prescription medicines directly to patients, beyond the patient information leaflet that is currently distributed with each package. This legislative proposal raises a contentious debate about the role of the pharmaceutical industry as a provider of information about its products. Some patient and consumer organisations seek direct access to information from the pharmaceutical industry, while other groups caution against expanding direct communication between companies and patients.

Overview of the issue

As public interest representatives, patient and consumer organisations play an important role in directing public attention to social problems and voicing the needs of EU citizens in health policy debates. Patient and consumer groups can experience difficulty in securing sustainable funding sources. In order to support their work, some organisations may be financed by pharmaceutical companies, related industries and associations.

Under these conditions, a conflict of interest can arise between the public advocate's primary interest, such as representing the interests of patients and consumers, and a secondary interest, such as securing and maintaining financial sponsorship from companies selling medical products. Previous studies have concluded that the transparency surrounding funding relationships could be enhanced; however no investigation has related this financial support to organisations' policy perspectives and advocacy activities in the field of pharmaceuticals.

The research

This study examines whether there is an association between the opinions of a sample of European patient and consumer organisations on topics related to the *Information to Patients* legislative proposal and the financial support they received from the pharmaceutical industry and related associations. Public interest groups' contrasting opinions, combined with the pharmaceutical industry's clear interest in communicating directly with patients, make this a useful topic to explore stakeholder positions on legislative proposals concerning pharmaceuticals.

The research analysed the responses given by 12 patient and consumer organisations, eligible to work with the European Medicines Agency, to a questionnaire concerning this legislative proposal. Relevant policy documents from 14 organisations were also examined. The overall analysis was then contrasted with the corporate sponsorship these groups received.

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Main findings

Most organisations agreed that the public needs better access to independent and comparative information, and that information generated by the pharmaceutical industry should be approved by drug regulatory authorities before its publication.

An association was observed between receiving sponsorship and support for an expanded role of the pharmaceutical industry as an information provider about its products.

Organisations that received sponsorship also supported new modes of communicating that could be opened up by the *Information to patients* legislative proposal, specifically information in brochures and leaflets, over the internet and on CD-ROMs.

Main conclusions

This study suggests that corporate sponsorship may be associated with civil society perspectives on specific policy debates.

The EU's multi-stakeholder approach in jeopardy

The formation of pharmaceutical policy at the EU level relies on a multi-stakeholder approach where each stakeholder group is given an opportunity to express their unique perspective. These findings suggest that a financial relationship between commercial and civil society groups could jeopardise the uniqueness of the patient and consumer perspective and threaten the integrity of the multi-stakeholder format and the policy formulation process. It is imperative to maintain the distinct view of each stakeholder in order to make balanced decisions about pharmaceutical regulation and health policy.

Sustainable funding from non-commercial sources

The credibility of advocacy organisations sponsored by the pharmaceutical industry has been called into question, such as the case of Europa Donna¹. Sustainable funding from non-commercial sources needs to be prioritised, particularly for patient and consumer organisations engaged in political advocacy. This could be achieved through a funding model that lessens the need for financial support directly from companies or industry associations to sustain the work of public interest organisations and to promote their financial independence.

More research into the relationship between corporate donors and public interest groups

This case study offers insight into the relationship between corporate funding sources and public advocates' political agenda. Additional larger studies could ascertain if these results can be extrapolated to other health policy debates or to a wider population of patient and consumer organisations. Future studies could consider if there is a relationship between the perspectives of public interest organisations on certain policies and the condition or health issue that they work on.

For additional information, please consult the HAI Europe Research Article *The patient & consumer voice and pharmaceutical industry sponsorship* available to download at www.haieurope.org

¹ See article *MEPs shun cancer advocacy group because of industry funding* published in the British Medical Journal, 2008.