

EU drugs agency working with patient groups bankrolled by big pharma

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European patients' groups, set up to represent the interests of the subjects of medical procedures in their dealings with healthcare systems, insurance firms and drug companies are in many cases bankrolled by pharmaceutical firms, according to a new report.

Complicating the situation, many such groups working with and on the board of the European Medicines Agency - the very EU agency charged with evaluation of medicines in the bloc.

A fresh report from transparency watchdog Corporate Europe Observatory accuses the EMA of mis-administrating conflict of interest guidelines allowing individuals and groups to falsely say that they are not sponsored by the pharmaceutical industry.

The document makes four accusations of conflict of interest non-disclosure.

The report notes that the representative of the European Federation of Neurological Associations (EFNA), a patient group that also sits on the EMA's management board, failed to disclose the corporate funding of EFNA on her EMA conflict of interest statement even though 91 percent of the group's total income stems from corporate sponsors, including GlaxoSmithKline, Novartis and Solvay.

A second group that also maintains a representative on the EMA board, the European Patients Forum (EPF), receives hundreds of thousands of euros every year from industry, including AstraZeneca, Novartis and Pfizer.

Additionally the vice-chair of the Committee for Orphan Medicinal Products (COMP), a working group of the the EMA, represents Eurordis, the rare diseases patients' umbrella organisation, which receives 23 percent of its income from pharmaceutical companies. But the vice-chair also does not declare this interest in the mandatory annual disclosure statement.

Lastly, the European AIDS Treatment Group (EATG) representative on the EMA's Paediatric Committee (PDCO) also made no disclosures despite receiving more than 80 percent of its funding from corporate sponsors such as Pfizer and Roche.

Moreover, says the report, only six of 22 the patient groups - who engage in lobbying of European institutions - that work under with the EMA have taken it upon themselves to register with the European Commission's lobby register.

"In fact, more than half of the patient groups in EMA committees are sponsored by industry," the report's author, Jens Clausen, told EUobserver.

"This widespread practice of accepting funding from business can have serious implications. There is a fundamental risk that the patient group does not actually represent patient interests but instead puts forward the views of industry."

" Disclosure of funding sources is key if society is to be able to prevent corporate capture of public health policies."

The EMA for its part concedes that there is a problem, but with the conflict-of-interest declaration forms, which spokesman Martin Harvey concedes are not sufficiently clear.

"The declaration of interest forms we give aren't very helpful.

Neither of the two individuals on the board are employed by the patient groups, and that is what the form asks."

"There's nothing sinister going on. They thought they were being truthful on the forms. We've had similar complaints on our end about the confusion of the forms, so we are considering changing them to solve this problem."

Mr Harvey said that such representatives are nominated by the European Commission and the European Parliament, suggesting that if a conflict exists, it should be spotted by the Brussels officials that review the candidates: "They send us approved people and we have to take them."

He added that patient groups at the national level depend for the bulk of the funding on the money people leave in their wills, often people who have been afflicted by the given illness.

"But at the European level, no one wants to leave an EU patient group money. There's no emotional connection, there's no link with your family," he said. "So if they don't take money from industry, where will they take it from?"

The EMA accepts that patient groups take money from pharmaceutical companies, "but we mitigate this by requiring that they be scrupulously transparent and that the funding comes from a diversity of sources."

He also said that the individuals concerned by the report were "hard-working volunteers who commit an awful lot of time to these causes and were quite shocked by the accusations."

EU health commissioner John Dalli in his hearing in the European Parliament before being confirmed promised to reconsider the issue of the funding of patient groups to prevent conflict of interest.

Mr Harvey said that in the absence of money from big pharma, the only way to completely avoid conflict of interest was to have European patient groups publicly funded.

"Although then you have the situation of the EU paying patient groups to lobby itself."

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