Three years later, the 'Pharmaceutical Forum': a new masquerade

In late 2005 the European Commission replaced the G10 by a new group called the 'Pharmaceutical Forum' ("*a high-level political platform*", no less…) in order to continue "*discussions*" on three themes of the ex-G10, including drug information for patients (**a**).

Secrecy. This 'forum', far larger than the ex-G10, includes two European commissioners (Enterprise and Industry, plus Health and Consumer Protection), as well as member state ministers, 3 representatives of the European Parliament, representatives of 5 European pharmaceutical industry federations, and representatives of healthcare professionals, patients, and health insurers.

However, the full list of participants in the 'Pharmaceutical Forum' has never been made public, nor have the selection criteria, the forum's working methods, nor the management of conflicts of interest. Reports made by several participants suggest that several dozen people travel to Brussels to participate in each of the three working groups, including the one on patient information. They also report that the working group's methods are poorly defined and its objectives unclear. Two flimsy reports released by the committee responsible for leading the "forum", as well as a very vague interim report, are available on the European Commission's website, but they contain little concrete information (8,9).

Untruths. On 29 September 2006, at the first meeting of the 'Pharmaceutical Forum' (convened after preliminary work), a speech by the European Enterprise Commissioner nevertheless clearly stated its objectives (10). According to the Commissioner, the status of health information in Europe is "*unsatisfactory, and even unacceptable*". He described access to information as inadequate for those with no internet access and for non-English speakers. Access to 'information' should therefore be improved, and efforts should be made to "*create confidence of citizens and health professionals in the quality of any information provided by industry*".

The Commissioner described the pharmaceutical industry as the source of 'information', having the "*knowledge, skills and resources* (…)" necessary to provide it (**b**) (10). The Commissioner responsible for Health and Consumer Protection declared that "*Industry can help to provide information that is trusted. It wants to be able to play a legitimate role in communication about its own products.*" (11).

The Commission regretted that its "*last attempt to modernise the legislation failed*" [referring to the massive rejection of its 2001 proposal], and announced that in 2007 it would present a report to the Council and to the European Parliament aimed at modifying the framework of patient information (10).

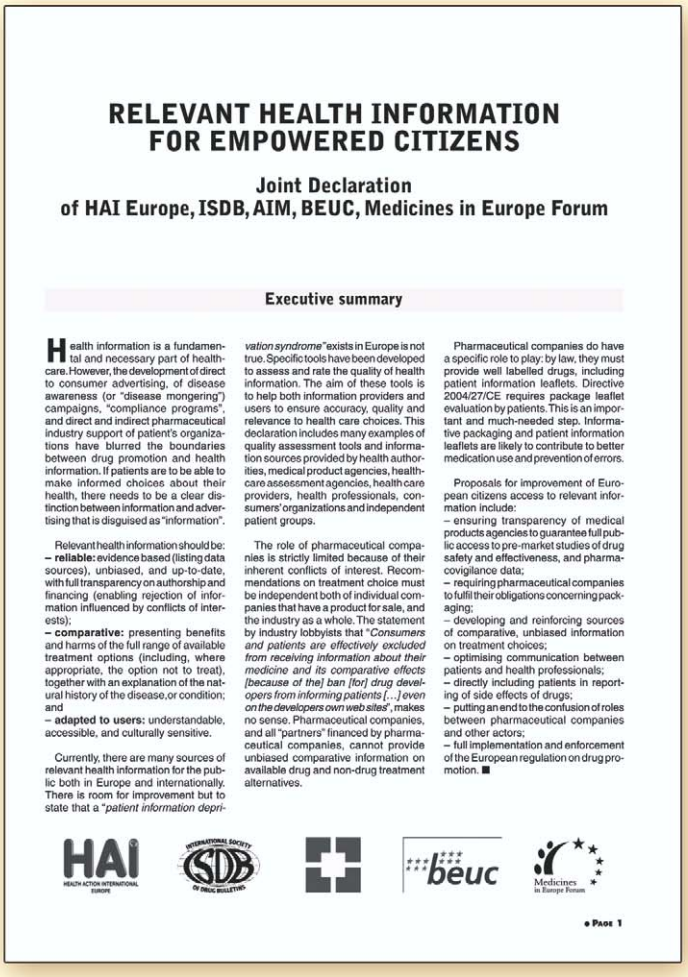
'Patient representatives' curiously in line with industry claims

According to the vague description of the 'Pharmaceutical Forum' posted on the European Commission's website, patients are represented by the 'European Patients' Forum'.

Big pharma spokespeople. This organisation, created in 2003, is referred to in the report of a survey published in July 2005 by Health Action International, as "*a model of secrecy and conflict of interest*" (12). The evidence is overwhelming: this organisation's activities are funded by drug companies; events are held jointly with organisations representing drug companies; and when the European Patients' Forum represented patients on the Board of the European Medicines Agency (EMEA), sources of funding were not disclosed (**c**). Yet the European Commission chooses to give this organisation a central role each time patients' inter-

Read and pass along the joint declaration

The joint declaration by Health Action International (HAI) Europe, the International Society of Drug Bulletins (ISDB), the *Association Internationale de la Mutualité* (AIM), the European consumers' organisation (BEUC) and the Medicines in Europe Forum, published on 3 October 2006, is available in French at www.prescrire.org (9 pages) and in English at www.isdbweb.org (8 pages). It was also included with the December 2006 issue of *Prescrire International*.



RELEVANT HEALTH INFORMATION FOR EMPOWERED CITIZENS

Joint Declaration of HAI Europe, ISDB, AIM, BEUC, Medicines in Europe Forum

Executive summary

Health information is a fundamental and necessary part of healthcare. However, the development of direct to consumer advertising, of disease awareness (or "disease mongering") campaigns, "compliance programs", and direct and indirect pharmaceutical industry support of patient's organizations have blurred the boundaries between drug promotion and health information. If patients are to be able to make informed choices about their health, there needs to be a clear distinction between information and advertising that is disguised as "information".

Relevant health information should be:
– **reliable:** evidence based (listing data sources), unbiased, and up-to-date, with full transparency on authorship and financing (enabling rejection of information influenced by conflicts of interests);
– **comparative:** presenting benefits and harms of the full range of available treatment options (including, where appropriate, the option not to treat), together with an explanation of the natural history of the disease, or condition; and
– **adapted to users:** understandable, accessible, and culturally sensitive.

Currently, there are many sources of relevant health information for the public both in Europe and internationally. There is room for improvement but to state that a "*patient information deprivation syndrome*" exists in Europe is not true. Specific tools have been developed to assess and rate the quality of health information. The aim of these tools is to help both information providers and users to ensure accuracy, quality and relevance to health care choices. This declaration includes many examples of quality assessment tools and information sources provided by health authorities, medical product agencies, healthcare assessment agencies, health care providers, health professionals, consumers' organizations and independent patient groups.

The role of pharmaceutical companies is strictly limited because of their inherent conflicts of interest. Recommendations on treatment choice must be independent both of individual companies that have a product for sale, and the industry as a whole. The statement by industry lobbyists that "*Consumers and patients are effectively excluded from receiving information about their medicine and its comparative effects [because of the] ban [for] drug developers from informing patients [...] even on the developers own web sites*", makes no sense. Pharmaceutical companies, and all "partners" financed by pharmaceutical companies, cannot provide unbiased comparative information on available drug and non-drug treatment alternatives.

Pharmaceutical companies do have a specific role to play: by law, they must provide well labelled drugs, including patient information leaflets. Directive 2004/27/CE requires package leaflet evaluation by patients. This is an important and much-needed step. Informative packaging and patient information leaflets are likely to contribute to better medication use and prevention of errors.

Proposals for improvement of European citizens access to relevant information include:
– ensuring transparency of medical products agencies to guarantee full public access to pre-market studies of drug safety and effectiveness, and pharmacovigilance data;
– requiring pharmaceutical companies to fulfil their obligations concerning packaging;
– developing and reinforcing sources of comparative, unbiased information on treatment choices;
– optimising communication between patients and health professionals;
– directly including patients in reporting of side effects of drugs;
– putting an end to the confusion of roles between pharmaceutical companies and other actors;
– full implementation and enforcement of the European regulation on drug promotion. ■

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