

# Health-related information for patients: how much input should industry have?

A draft report from the European Commission, recently closed for consultation, discusses the role of the pharmaceutical industry in the provision of information about medicines to the public. Some consumer groups have questioned how much input the industry should have and are concerned that the EC is looking to reopen the debate on direct-to-consumer advertising of prescription medicines. **Matthew Wright** reports

The pharmaceutical industry has the potential to be an important source of information to respond to the growing demand for more and better information by patients. This is the spirit of a European Commission consultation document "Current practice with regard to provision of information to patients on medicinal products".

Ostensibly the document sets out how the public is currently accessing information about medicines in different European member states and the role the internet plays.

However it is produced by the EC's Directorate-General for Enterprise and Industry — which looks after the interests of the business world — rather than by the Directorate-General for Health and Consumer Protection, known as DG SANCO. So some stakeholders, consumer groups in particular, are questioning the agenda of such a report.

"Patients have become more empowered and proactive users of healthcare, increasingly seeking information about their illnesses and treatment options including medicines from an ever growing and diverse range of sources," the document says. It argues that pharmaceutical companies want to be able to produce non-promotional information for patients about diseases and their own medicines, and make this information available to the public.

## Consumer response

Consumer organisation Which? points out that the EC report does not consider the information needs of consumers, how these needs are currently being met and where improvements are needed. "Instead," the group says in its response to the report, "we are repeatedly told that industry may have information that legislation prevents them from giving to patients, and that this may contribute to better health if it was made available, despite the fact there is 'insufficient' evidence to support this assertion."

Don Redding, head of policy and communications at the Picker Institute (a charity that champions patient choice in health care), says that the development of education materials for patients through so-called public-private partnerships needs to involve a wide range of interested parties. He also questions the current lack of engagement from DG SANCO.

In its response to the EC report, the Picker Institute calls into question "the report's assumption that the answer to patients' information needs lies with industry, and its

conclusion that the pharmaceutical industry should be allowed a greater role in the provision of information to patients".

Mr Redding elaborates: "We [the Picker Institute] do not have our own evidence on the degree to which patients find pharmaceutical industry information reliable. But consumer groups will say that the evidence shows patients do not find that information reliable."

## The Pharmaceutical Forum

The EC document also highlights the work of the high level Pharmaceutical Forum, set up by the EC two years ago to look at challenges faced by the industry. Its working group on information to patients — which recently reported to the Pharmaceutical Forum's annual meeting in Brussels — has the objective to "develop proposals for improving the quality and accessibility of information to patients on medicines and health issues".

However, the working group's contributions to the issue are under attack. The European Public Health Alliance believes that the Pharmaceutical Forum cannot be considered a legitimate body as it lacks transparency, and is not representative of the breadth of organisations working on information to patients. It notes that membership of the forum is mostly held by the industry, with the involvement of only one patient group. Academic and research institutions, consumer groups and public health organisations are absent.

Which? is concerned that the needs of consumers will not be met from the work of the Pharmaceutical Forum because of the lack of any consumer representation on it. "When this exclusion is considered alongside the over-representation of pharmaceutical industry interests on the steering group of the forum, it calls into question the aims and objectives for the forum's work in this area," Which? adds.

In an open letter to members of the European Parliament and the media, the Medicines in Europe Forum, Health Action International and the International Society of Drug Bulletins say that the EC report's conclusions "are exclusively biased in favour of allowing drug companies to communicate directly with the public", which, they say, undermines the EC's credibility.

"Comparative information, which is indeed crucial for informed decisions, cannot be provided by pharmaceutical companies because of inherent conflicts of interest," the

letter states. "What company could possibly recommend a competitor's product over its own, or recommend discontinuing treatment with its own product?"

## Information or advertising?

Changes addressing improved access and readability of product-related information, as well as measures for greater transparency, have been incorporated into legislation from 2001. However, the DG Enterprise and Industry document states: "More far reaching mechanisms to improve and harmonise the access of patients to information have been rejected in the legislative process with reference to the bureaucratic burden caused by enforcement mechanisms and the lack of a clear distinction between advertisement and information."

It seems unsurprising that many believe the Pharmaceutical Forum, with backing from DG Enterprise and Industry, is driven towards a lift on consumer advertising of pharmaceuticals.

The Royal Pharmaceutical Society acknowledges this link in its own response to the EC report: "The Society makes a distinction between advertising and information on medicines," it says. "The demand for information about prescribed medicines from patients and the public is likely to increase, but [direct-to-consumer advertising] is unlikely to be the best way of providing it because the aim of advertising is to persuade, not to give balanced information about benefits and risks."

The Society also says that lifting the ban on direct-to-consumer advertising could adversely affect doctor-patient relationships, distort public health priorities and disrupt cost controls operated by the NHS.

Mr Redding adds: "We [at the Picker Institute] restate to the EC our opposition to any relaxation in the rules on direct-to-consumer advertising of prescription pharmaceutical products." He questions what the current EC action does to add value, suggesting that the EC could be supporting the types of information that enable patients to be in a better position to make choices.

"A good decision aid," he explains, "will provide information about all the available treatment options, their benefits and harms, the unknowns. This will aim not just to convey that information, but to encourage the patient to consider their own position, values and preferences, and for them to make judgements about what treatment options might be appropriate for them."