

Right to information

Supporting the EC's initiative to provide reliable data to empower patients is crucial

In Europe, advertising prescription medicines to the general public is prohibited. The doctor-patient relationship continues to be the bedrock on which European healthcare systems are founded and no one questions this. However, the current EU system should not be fixed rigidly, as it does not allow patients to access reliable sources of information. Everyone agrees that patients need to be empowered and better informed. The average consultation time with a doctor is 10 minutes throughout Europe and this is constantly decreasing.

Therefore, the question the EU is currently struggling with is whether it can develop a model which allows patients to access reliable information from a source other than advertising.

What is interesting is that the European Commission's proposal on information to patients has proved to be highly controversial, although a large consensus exists among key stakeholders, including EU institutions, member states, the pharmaceutical industry, plus doctor and patient organisations, on the need for better information and the rejection of the US direct-to-consumer (DTC) advertising model. At this stage, it does not have sufficient support to be taken further in the European Parliament.

Most of the member states have given a definite rejection, the European Parliament is divided and the new Health and Consumer Commissioner, John Dalli, mentioned, during his January hearing before MEPs, that this proposal needed to be "reassessed" and injected with a stronger patient perspective.

On the member states' side, despite the fact that the EU's role in health is still being questioned, the main argument seems to be that providing reliable information to patients, which implies putting monitoring systems in place, will be too costly.

Although a few countries have proved to be more open-minded, the belief of the majority is ingrained and, I believe, represents a short-sighted approach.



Evidence shows that keeping people well for longer will actually allow health systems to save money in the long term. A huge amount of money is being wasted through non-compliance and if patients' knowledge of the medical consequences of this were improved, society as a whole would benefit.

On the consumer and patient side, in the past, a lot of criticism was linked to the fact that the Directorate-General (DG) for Enterprise and Industry, which was in charge of this dossier previously, only embraced the industry's perspective. It makes sense for DG Health and Consumers (DG SANCO) to have this remit now. The move should help the development of a more constructive dialogue with consumer and patients' associations.

Most health NGOs have bluntly rejected the European Commission's proposal, basing their arguments on the fact that it represents a step towards US-type direct-to-consumer advertising. This has led to many inconclusive discussions

on how to define the distinction between information and promotion/advertising. In this context, the European Association of Communications Agencies Health Communications Council (EACA HCC), representing the experts on healthcare communications in Europe, has a significant role to play in working with all parties, both on definition and the practicalities of how to implement any acceptable patient information programmes.

The discussions on this proposal are not straightforward because we are facing a huge challenge. The current regulation is obsolete and does not take into account the internet revolution. The internet is a frightening beast, as it is borderless and difficult to control. The amount of unreliable information available on it is a major concern. For example, in a search for 'cancer cure' on Google, the third link is to a site selling a "new herbal cancer cure with tree leaves from the Amazon rainforest", which is claimed to work based on the

assumption that “the Protestant bible says that all the leaves of the tree are for the healing of the nations”.

I believe good information will chase bad information. In addition, clarity is needed on push versus pull information. The idea is not to bombard patients with further data, but to allow them to find reliable, appropriate and validated information when they seek it.

Most lacking is the sense of trust among all stakeholders. DG SANCO has shown itself to be very successful in building trust over the last few years, through the Platform on Diet, Physical Activity and Health and the Alcohol and Health Forum. It has demonstrated that dialogue can be created between conflicting stakeholders. I hope it will achieve the same confidence within the EU healthcare ecosystem.

In the past, the pharmaceutical industry has not always been clear about its intentions with regard to the information-to-patients debate in Europe. At one stage, there may have been a desire to import the US model, but this situation has changed now. Recently, several leading industry figures have questioned publicly the role of the current US model, and there is evidence

that the US is, indeed, looking to Europe for ideas on what changes are needed.

“FASS ... gives patients reliable, unbiased and understandable information”

The Swedish medicines information engine, FASS, has proved that solutions can be reached and that the pharmaceutical industry can provide, and be seen as, a reliable source of information. FASS is funded by the industry, relies on a strong self-regulatory system and gives patients reliable, unbiased and understandable information.

The European Commission’s proposal should not be buried, but it does need to be improved. Although the aim to provide reliable and high quality information to patients throughout Europe is a straightforward one, the Commission may need to give more consideration

to how this new system could work, and the monitoring system necessary to support it. Lack of clarity can fuel fear and result in a chaotic situation at a time when patients need more guidance on which information they should believe.

Regarding the ongoing debate on information versus advertising, rather than trying to find the perfect way of distinguishing information from advertising, the proposal should concentrate on defining what information actually consists of and then set a gold pan-European standard for it.

New regulation is needed to encompass the modern patient’s mindset. Patients are more and more interested in their own health and in finding relevant treatment. This proposal also represents an opportunity to invent a whole new model and I hope that all parties, including the members of the EACA Health Communications Council, can contribute to its creation.

The Author

Max Jackson is the chairman of the EACA Health Communications Council. He is CEO for the EMEA and APAC regions with Sudler & Hennessey.

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