

A/7423
Patient organisation

Public consultation on Legal Proposal on Information to Patients

The Public and Patient Involvement (PPI) Forum for primary health care is part of a national network which focuses on patients' interests. This particular Forum, which involves patients in Craven, Harrogate and rural areas, is situated in a rural part of North Yorkshire. It is independent and does not rely – as do some patients' associations – on pharmaceutical companies for funding. The PPI Forum has a strong interest in achieving readable, understandable and reliable information for all patients irrespective of their educational standards. And it believes in involving patients themselves in assessment of information. It has carried out a survey among women's organisations into Patient Information Leaflets (PILs) provided by drug companies, and in spite of recent EU improvements, has found a substantial number of shortcomings. (This survey was forwarded and appreciated by DG SANCO, and is now enclosed with this submission.)

General points

The PPI Forum is glad that the Commission has produced this public consultation and hopes that contributions will reflect a true evaluation of patients' needs. It feels that the nature of respondents may produce biased results and therefore trusts the Commission to publish classified details of contributors.

It stresses the need for the interests of patients to be put first, and for healthcare professionals to remain the primary source of health information. It is concerned that if pharmaceutical companies provide information on prescription drugs, the focus will be on branded products and not on generic medicines. It appears to be British national policy for generics to be promoted wherever possible (e.g. statins) in the interests of efficiency and economy. There could therefore be a conflict in future between the promotion and prescription of brands and generics. The Forum is concerned about the maintenance of a reasonable balance between the two.

It also urges the Commission to focus on the need for objective, factual information that is essentially readable by the vast majority of patients.

Information is the key to making informed decisions about the most suitable healthcare, with patients increasingly being involved in partnership with professionals. It is essential for patients to be aware of the pros and cons of particular treatments. The PPI Forum is therefore concerned that pharmaceutical companies will select only the good features of their products, relying on Patient Information Leaflets (PILs) as a primary source, and that adverse side effects will not be mentioned.

Specific comments.

(The paragraph numbers are those in the Commission's text)

3.2. The Forum remains concerned that if pharmaceutical companies rely on the content of PILs for potential information, they will pick out only the best features relating to their own products. No unbiased comparisons of a range of other possible treatments are possible under these circumstances. The Forum remains uneasy about PILs being one of the proposed sources of information unless careful monitoring by dispassionate regulatory bodies can maintain balanced, accurate and fair communication.

3.3.1. The Forum is concerned, not so much about information supplied by pharmaceutical companies and used by health professionals as *support*, but about information which patients receive on their own, unaided by professional help. Therefore the Forum is appalled at idea of any TV or radio communication inevitably unsupported by this help. Patients are unduly influenced by TV as a medium of communication and tend to believe unquestioningly all that they see. The fact that they are in their own homes and not in a clinical or hospital surrounding contributes to the indiscriminating acceptability of the message.

3.3.2. The Forum points to the need for much more rigorous control of internet websites. It accepts that it is impossible to control US websites, but EU controls need to be much stronger. Patients are becoming more active and involved, wanting to participate in their own healthcare, which is a step forward; but they can fall victim to internet communications. Once again these are viewed alone without support to help in evaluation. And there can be the additional inducement of the opportunity to buy prescription drugs, maybe even counterfeit drugs, which have not been prescribed to them by a professional.

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