Public consultation on Health-related information to patients

The Danish Medical Association (DMA) has the following comments to the High Level Pharmaceutical Forum’s hearing on Health-related information to patients.

General comments

The DMA finds that correct and well-formulated written information on diseases and treatment may support the possibilities of a good and coherent patient course of treatment. The basis is, and should be a good patient/doctor relationship, where the doctor as an impartial expert guides and advises the patient, and together they make decisions about which treatment to choose, including decision on which drugs to choose. Correct written patient information may in this connection support the patient’s chosen course of treatment. The doctor may either hand out the material or refer to it, as well as the material may be a good entrance for the patient to a dialogue with the doctor, which may lead to a decision about the patient’s course of treatment. This context should be considered when preparing written information material for patients.

Furthermore, the DMA understands that the High Level Pharmaceutical Forum’s initiatives will be carried out within the existing framework of the EU-directives, and that there hasn’t been opened up for further possibility of commercial companies for direct patient information. This development is not acceptable in the opinion of the DMA.

Comments to the present proposal

Issue 1: Diabetes Information package

The DMA finds that, if information is to have a general value for the citizens and patients in the EU-countries, it is essential that the information is available in all languages represented in the EU. In Denmark, for example, the information must be written in Danish and include the correct professional terminology and also information about the structure of the Danish Healthcare sector. Furthermore, there should be a possibility of attaching comments on explicit conditions for Danish patients. At the same time, it would be appropriate to adjust the information to the already available public health information, which, in Denmark, is collected on the website: www.sundhed.dk.
If the patient information is to have an impact, a thorough translation work on a medical professional qualified level has to be done in each country.

**Issue 2: Quality Principles**

It is of great importance for the credibility of the patient information that it is built on an acknowledged set of principles.

The DMA finds that the presented principles are good and essential.

The DMA points out 2 additional principles:

- **Reference to the author and assessor.** A significant element in relation to the mentioned principle on transparency is also to refer to the author of the patient information and who has assessed the text. For example this doesn’t appear from the existing patient information on diabetes. The author and assessor must be independent of special interests of the information area.

- **Independency.** Patient information must be independent of advertising income and other irrelevant interests to ensure the validity and credibility of the information. Therefore, such patient information should be public financed or financed by neutral non-commercial partners.

The DMA has noted that funding is emphasised in connection with the principle on transparency. The DMA finds that cf. the principle on independency funding can only be taken care of by public authorities or neutral non-commercial partners. Private companies as for example the pharmaceutical industry, which has a special interest in the character of the information – must not have the possibility of financing the patient information. Beside the question on the credibility of the information if it is company financed, it might also imply that the patient information is prepared from a company point of view and not a patient point of view, which also include information to the small patient groups with special diseases.

Finally, the DMA acknowledges that for example pharmaceutical companies might have a specific knowledge and relevant information on drugs and the use of drugs in certain areas. The DMA finds, that this regard is considered by the obligation of the authors to make the information evidence based and up to date and thereby also – in a professional evaluation – an obligation to include relevant knowledge from these companies in connection with preparation of the patient information.

Yours sincerely,

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