



Response to the High Level Pharmaceutical Forum consultation on Health-Related Information to Patients – May 2007

The European Men's Health Forum (EMHF) is the only European organisation dedicated to the improvement of men's health in all its aspects. EMHF is a coalition of organisations actively contributing to the improvement of men's health in Europe. Represented in 20 European countries, EMHF provides a stronger voice for men's health. It actively promotes collaboration with other international networks and institutions sharing the same goals.

This document presents a few points of EMHF's position on information to patients in relation to the High Level Pharmaceutical Forum's consultation on Health-Related Information to Patients. It comments on the principles for generating quality information, and addresses critical issues relating to delivery of such information to main population groups which may be 'hard to reach', such as men.

EMHF is pleased to contribute to the Commission's coordinated action at a European level and to its support for national, regional and local health information initiatives, by proposing the following comments and suggestions:

- Important additional factors should be explored in order to improve the basis from which to judge information quality. Further specification of the criteria for quality assessment, validation and monitoring processes leading to the selection of information would greatly enhance the perception of high standards.
- Concerns for appropriately delivering quality information, particularly to those who may need it most, should be integrated in the proposed principles:
 - Gender sensitivity is a most fundamental and important factor to be considered for the effective presentation and dissemination of health information. It must be included.
 - Specific dispositions regarding dissemination channels and settings must ensure that large 'hard to reach' population groups, such as men, can fully benefit from the proposed information resources.
- The development of provisions for supporting individual empowerment should form part of the Commission's recommendations to Member States. Addressing gaps in health literacy can help translate quality information into effective action and a better health for all.

EMHF will examine the issue of information to patients as part of the high level debate it will organise in June on men and long term conditions. EMHF also takes seriously the safety issues associated with counterfeit medicinal products and men's use of the internet to access health information.

A number of specific suggestions are made under sections 1 and 3 below in support of these arguments. We would be pleased to expand on this summary. Please contact (office@emhf.org) for further information.

1. Is a set of principles on good quality information on health related information and treatment for patients and citizens useful at EU level?

The Forum believes the development of key principles is a necessary condition to the development of good quality information, but not sufficient to guarantee usefulness for end-users.

Among challenges for health information, the Commission mentions that 'there are still differences between European countries and regions in terms of access and quality of information' and varying levels of health literacy. Yet gender is not mentioned as a fundamental and most important factor to consider in the presentation and dissemination of quality health information.

Recommendations from the Commission should include provisions for the effective diffusion of such information, including dissemination channels and settings most appropriate to the specific patterns of access and use of health information among main population groups. This is particularly important for groups which tend to be harder to reach such as menⁱ, migrants, the aged or the young.

With particular reference to men, EMHF refers to key research conducted in several European countries which lead to the following conclusions:

- Men and women access and use health information in different ways, yet most health information is often presented in a format that is most appropriate to women^{ii iii}.
- Men tend not to use clinical settings to seek health information. They are more likely to seek health information on the internet. The workplace is a particularly effective setting for the communication of health messages to men^{iv v vi}.
- Quoting the consultation document: 'Information... is an important decision aid to allow patients to make informed decision. This is particularly important in self-managing diseases'. This statement has strong implications for the health outcomes of male patients. Men tend to self care less than women.
- Health literacy and the propensity to effectively act upon health information are largely influenced by gender. By gender impact, EMHF means the effect of social constructs on men and women's health behaviours rather than the result of biological differences^{vii}.
- Considerations should be given to the production of similarly standardised but non-disease specific information, treatment options for other substantial causes of ill health such as smoking, alcohol abuse and drug addiction.
- Consequences of relatively poorer health information and literacy in men are likely to include higher rates of under-diagnosis (e.g. diabetes), repeated emergency hospital admissions, factor contributing to the spread of communicable diseases, particularly HIV^{viii ix}.

2. Do these principles provide a clear basis on which to judge the quality of information at a European level?

The principles reflect the intent to establish processes for the collection and presentation of health information. Until more is known and understood of such processes, particularly in the way they can be assessed, validated and monitored, judging the quality of information at European level still remains an aspiration.

3. Should these principles be revised and if so, how? Are there important principles missing?

The proposed principles were: Objective (Unbiased/Neutral), Evidence-based, Up-to-date, Reliable, Understandable, Accessible, Transparent, Relevant (and appropriate), Consistent with Statutory information. Of these, EMHF has selected the following for comments:

Objectivity:

- EMHF welcomes the attempt made to clarify the objective information, yet there needs to be an explanation about what a clear process for compliance and certification means.
- This section seems to indicate that only a Member State or the Commission should provide high quality information at a European level. Guaranteeing the effective involvement of other stakeholders, including representatives of patient groups, may help enhance the level of objectivity.

Reliability:

- Consistency in methodology and presentation of information is crucial to ensure reliability. It also contributes to a better understanding of information.

Ability to be easily understood:

- EMHF deplores the proposed summary description of this principle, when it is probably the most important quality of health information. This principle should reflect that the value of health information is largely a function of the level of health education and general health literacy among end-users.
- The need for validation processes should be clearly specified, particularly with population groups that are traditionally hard to reach.
- The section should detail the need for translation in all European languages, and not assume that all citizens understand one of the main European languages.

Accessibility:

- Equal opportunity of access to information is essential. EMHF welcomes the document's acknowledgement that a multiplicity of media is required to ensure effective dissemination of health information. Access to health information should naturally be free of charge.
- Accessibility is however an insufficient sufficient condition to guarantee effective use.

Usability (suggestion for additional principle)

- Equal opportunity to use health information should be made as high a priority as equal opportunity of access. Key factors to realise this condition include knowledge of the existence

of required information, appropriate settings for delivery, and adequate levels of health literacy among individuals in target groups to understand and effectively act upon it.

Key population groups such as men or migrants are traditionally hard to reach with health information as their patterns of access and usage of information then to be specific. It is now well documented that men do not use the clinical setting nearly as often as women, and that other environment such as the workplace may be a more opportune.

Relevance:

- The involvement of patient groups, and groups representing gender concerns should no doubt be required to define what constitutes relevant and important information.
- Among issues of relevance, gender differences ought to be mentioned one of the fundamental and most important aspects of relevance to patients.

ⁱ Macdougall J, 1999, Community access to health information in Ireland, Health Libraries Review 16 (2), 89–96

ⁱⁱ EUROBAROMETER 58.0 European Union citizens and sources of information about health, The European Opinion Research Group (EORG), for Directorate-General SANCO, March 2003

ⁱⁱⁱ Kickbusch I, Wait S, Maag D, 2006, Navigating Health – the role of health literacy, published for the European Health Forum Gastein 2005. http://www.emhf.org/resource_images/NavigatingHealth_FINAL.pdf

^{iv} Workplace education can increase prostate awareness,
http://www.menshealthforum.org.uk/userpage1.cfm?item_id=924#pr

^v Work Fit proves a hit, Issue 9, January 2006 Men's Health Forum Magazine
http://www.menshealthforum.org.uk/uploaded_files/MHFmag9.pdf

^{vi} EUROBAROMETER 58.0 European Union citizens and sources of information about health, The European Opinion Research Group (EORG), for Directorate-General SANCO, March 2003

^{vii} Wilkins D, Baker P. 2004, Getting it sorted: a Policy Programme for Men's Health, London
http://dev.menshealthforum.co.uk/uploaded_files/gettingsorted2004.pdf

^{viii} Ilic D ; Risbridger G P, Green S. 2005, The informed man : Attitudes and information needs on prostate cancer screening, The Journal of men's health & gender, vol. 2,n°4,pp.414-420

^{ix} Hamers FF, Downs AM. 2004, The changing face of the HIV epidemic in western Europe: What are the implications for public health policies? Lancet; 364: 83-94.