

The European Patients' Forum Position Statement on Information to Patients

THE FUNDAMENTAL RIGHT TO KNOW

EPF believes that ALL patients, no matter their condition, background or nationality, have a fundamental and legitimate human right of access to information about their health, medical conditions and the availability of treatments including knowledge of the best available management of their disease. They need to be able to understand their condition and to be able to receive information on genetic and hereditary factors where relevant and on all available treatments. It is a question of solidarity, equity and patients' rights.

A holistic approach

It cannot be stressed too strongly that the provision of information to patients is not purely about information on medicines, but rather an all-embracing approach to information including a variety of quality of life, prevention, lifestyle, treatment, therapies, disease management, social and peer support, patient education and reimbursement options.

Information to patients is part of a bigger picture: information to, education of, and knowledge management by patients themselves are all essential to ensure they are empowered and confident in dealing with their disease.

The optimum information model

EPF is of the view that any 'information to patients' model should include the following elements.

- Disease (symptoms, life-cycle/development of the disease, risk factors, health related quality of life)
- European treatment guidelines
- Prevention information (diet, exercise, environment and treatments)

- Diagnosis information (questions to ask your doctor)
- Treatment information (choices, risks, benefits, side-effects, cost, written self-management plan, follow up, emergencies and compliance information)
- Patient resources throughout the patient's journey (government, patient groups, services)

Universal principles and specificity

One size does not fit all. Whilst there are universal principles linked to information to patients, information also needs to be disease specific, sometimes age, gender group specific and accessible to the individual patient, in his or her cultural context.

Partnership

EPF firmly believes that partnership is key: Sustainable, effective approaches to information to all patients across Europe should involve **all stakeholders** including governments, medical professionals, industry, and of course representative patient organisations.

NO to Direct to Consumer Advertising

The line between provision of high quality information and Direct to Consumer Advertising, which patient groups in Europe clearly do not want, is becoming better defined; with the distinction between 'pull' mechanisms whereby the patient is actively seeking out information and needs to know where and how to access it , and push mechanisms where it is thrust indiscriminately upon the patient through media advertising.

A crucial concept is an independent governance system to ensure that the information patients will access from any sources on prescribed medicines meets rigorous quality standards, and sanctions are imposed when this is violated.

WHY IS INFORMATION TO PATIENTS SO IMPORTANT

Well-informed patients are empowered patients and are an asset to society. Higher awareness enables patients to take greater responsibility for their own health and medical treatment. The patients' themselves benefit, healthcare systems benefit and so do budgets through reduced wastage.

EPF believes that access to information enables patients throughout the European Union to:

- enhance the ability to make informed decisions about best disease management in full partnership with health care professionals;
- optimise health outcomes through improved treatment concordance based on our belief that the more informed patients are, the better they understand their

treatment and how medicines must be taken;

- make more effective and rational use of the therapies that are available and prescribed;
- increase awareness of risks and benefits of prescription medicines and the importance of reporting and managing possible side effects;
- improve patients' quality of life by adopting preventive measures, seeking earlier diagnosis, recovering faster from illness, avoiding hospitalisation and invasive surgery, and enabling them to continue our normal daily routines and participate effectively in work and society.

Though we recognise that governments fear increased pressure on health care budgets since informed patient *might* demand better and more effective drugs for his/her diseases, we argue that informed patients are more efficient and prudent users of health care resources. Often under-prescribing, non-compliance or irrational prescribing are a heavier overall financial burden for health care and social security budgets. Better information can increase the ability of patients to manage their condition effectively as well as improve their quality of life. Information should be seen as an enabling tool to improve health care for all EU citizens - not as a cost/control instrument for EU Member States.

INFORMATION TO PATIENTS' ORGANISATIONS

At macro level, information is key to the advocacy and campaign role of patients' organisations. To play our role as a partner around the decision-making table effectively we need timely, accurate and transparent information.

We need to be able to consult our members and contribute their expertise, knowledge and aspirations to the policy debate, and in turn to inform them of policy and programmatic developments that will affect their lives.

HEALTH LITERACY AND INFORMATION

Information to patients is part of a bigger picture: information to, education of, and knowledge management by patients themselves are all essential to ensure they are empowered and confident in dealing with their disease.

There is a distinction between health literacy (one's understanding of the information provided through education about diseases, their prevention, their diagnosis, their treatment and their management) and more specific information about the treatment options available once a patient has been diagnosed.

Health information + education = empowerment

Health information and education empower citizens to seek early diagnosis, better

understand and describe the symptoms, engage in a meaningful dialogue with their physician and be more concordant with the chosen treatment.

Disease Awareness Campaigns

Health education can be embodied by disease awareness campaigns for the public and health professionals, and include on-going training for the professionals and communication skills in the health professional's curriculum.

Tailored information

Health education and information must be tailored to the needs of very distinct audiences and their cultural context: the diagnosed person (patient), the carer and the citizen who is not a patient yet. Each audience will have different information needs: the diagnosed patient and the carer will want to know more about the treatment options (including side effects, treatment modalities) while the citizen not yet diagnosed will be more interested in learning about diseases and how to avoid them.

A gender-specific approach should be considered too as men and women are affected differently by diseases. In addition, health education is less likely to reach men.

It is extremely important to avoid information that only raises anxiety, promotes denial and hides the benefits provided by a given treatment

Professional education and communication training can be enhanced through discussions and effective communication between health-minded stakeholders.

Partnerships should ensure that, in the end, every citizen and patient must become inquiring, and thus knowledgeable, about his or her health.

Patients have a responsibility to use the healthcare services effectively and efficiently. Health literacy and information are tools to empower patients to take on this responsibility.

CONTACT DETAILS

For further background on EPF's work on 'information to patients', please contact info@eu-patient.eu

or visit our website
www.eu-patient.eu