CPME
COMITÉ PERMANENT DES MÉDECINS EUROPÉENS
STANDING COMMITTEE OF EUROPEAN DOCTORS

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At its Board meeting, Brussels, 11 September, 2004, the CPME adopted the following policy : On Information to Patients and Patient Empowerment (CPME 2004/080 Final EN/fr)

19/7/2004

On Information to Patients and Patient Empowerment

In order to achieve optimal results from treatment, a good patient-doctor relationship is essential. One of the prerogatives is patient empowerment and this requires an informed patient. But information as such is not enough to achieve an informed patient. Also communication must be established/secured. The patient is the key stakeholder. Accurate information must be based upon international medical science. It is the patient’s right to decide among suggested and proven therapies including medication. Many stakeholders are involved in this process of provision.

The principal route to an informed patient is the patient-doctor meeting (the clinical consultation). This leads to a joint decision on the individual patient’s health care. Doctors are obliged to follow professional ethical codes and to safeguard that all treatment is in accordance with international medical science. Medicine is not and should not be treated as a commercial market where one can shop for different therapies.

Basics

All information must be relevant and validated from the patient’s viewpoint. The information must be medically correct and understandable for the patient.

Verbal and written information must be seen as two sides of the same coin. Both must be aviable. Communication means that it must be possible to ask questions. And to get a professional advice.

In those situations where an interpreter is needed during a patient-doctor consultation a qualified interpreter is preferred over a family member so as not to put patient confidentiality at risk.

Written patient information is important. The quality of translation must be addressed thru quality criteria.

Many patients have impaired abilities that also must be taken into consideration (blind, deaf, mental, social).

Often time for reflection is needed after a patient doctor consultation. A patient might want to collect more information from different sources. It is important to secure this possibility before a decision on therapy is made.

Information on the Internet or printed information can never replace information and communication in a clinical consultation. It must be seen as complementary to direct communication between the patient and the doctor.

CPME position on information to patients:

- The patient is the key stakeholder and accurate evidence based information must be the basis for the patient's right to decide among suggested and proven therapies including medication.
- The patient-doctor meeting (the clinical consultation) must always be seen as the principal route to an informed patient.
- Qualified interpreters should be used when needed.
- Written patient information is important to achieve an informed patient.
- Communication skills for health care professionals should be promoted both as part of the pre-registration period and as part of continuous professional development (CPD).

Stakeholders and their role in information to patients

The patient is the key stakeholder. All information must safeguard the patient's right to self-determination as an empowered patient.

Patient organisations are important stakeholders representing different patient groups and their interests. They have an important role as partners in validating patient information.

Doctors are the key supplier of information to patients. It is also an ethical obligation to secure communication in order to achieve a joint patient-doctor decision on treatment.

Organisations of both health professionals and industry have a responsibility to set up quality criteria on patient information and as stakeholders to uphold professional standards on patient information.

Pharmacists are experts on medicines and have an important role to advice the patient on his/her medication. Furthermore, some patients seek health care information at the pharmacies and also advice about treatment. It is very important that the collaboration between the doctors and pharmacists is well established in order to secure accurate information about medicines in relation to diagnosis and treatment.

Pharmaceutical industry has its prime role in securing medicines to cure diseases. Also, industry has a responsibility in search for new knowledge and to find new medicines. On information to patient it is important to remember that the goal of the industry is to make a profit. It means that all information to patients must be validated as information and not marketing. More and more it is obvious that the pharmaceutical industry focus on health information to promote their drugs. Direct to patient information from the industry must therefore be seen as primarily marketing, whether or not a specific treatment is mentioned.

National Health Agencies have a responsibility to evaluate information to patients. Also they play a key role in informing health care professionals in the member states in established treatment of diseases. It is very important that their work is of the highest standards.

EMEA´s role is still unclear. Primarily they should act as a centre of expertises in relation to the national agencies and have a responsibility to involve all stakeholders on a European level to set up standards for patient information. Health care as such, including information to patients still remains the responsibility of each member state

Politicians as representatives of the population elected through democratic procedures have a key role in setting out standards on information to patient and to set out responsibilities regulated by law.

All providers of health care (including physicians, hospitals and insurers) have a paramount responsibility to inform patient on a broad set of issues like results, quality assurance systems including patient safety, accessibility of care etc.

WHO is at present the key global organisation in public health and patient empowerment. It has taken the lead to secure health care on a global level through intergovernmental cooperation.

CPME position on stakeholders:

- Professional organisations have an obligation to set up quality criteria on patient information and to uphold professional standards on patient information.
- The pharmaceutical industry has a key role on information on medicines for health professionals. It is important that the industry take responsibility to secure accurate and up to date information on drugs, also on the Internet.
- National Health Agencies have a responsibility to evaluate information to patients.
- A network should be established supported by the EU involving all relevant stakeholders on information to patient.

Information and marketing/advertising

It is the responsibility of the pharmaceutical industry to inform doctors and other health care professionals about their products. The information must be accurate and cover all aspects of the drugs.

Information to patients about medicines is important to patient empowerment. However, it is not a primary responsibility of the industry to inform patients about health. Furthermore, any information about health from the industry must be seen in the light of its primary goal, to make a profit.

There is an obvious need to clearly define information in contrast to marketing. A European network involving all relevant stakeholders at the European level should be identified and invited to define and promote clear rules about information to patients from the pharmaceutical industry in relation to health and medicines. Only thru such a system approved information should be accepted as information and not marketing. Direct information to patients on medication must be under strict national/European supervision and not include prescription-only drugs.

CPME position on information:

- Information must be differentiated from marketing
- Informing patients about medicines is important to patient empowerment.
- Direct information to patients on medication must be under strict supervision and under no conditions include prescription-only drugs.
- A European network involving all relevant stakeholders at the European level should be identified and invited to define and promote clear rules about information to patients from the pharmaceutical industry in relation to health and medicines.

E-health

E-health must be seen as complimentary to an established patient-doctor relationship and improve patient information. Information to individual patients only thru e-communication is not in accordance with professional ethics. It is important to take into account personal- and patient data protection in connection with teleconsultation and e-prescription. Many member states have established secured Internet connection between health care deliverers, also involving pharmacies.

CPME position on E-health:

- E-health must be seen as complimentary to an established patient-doctor relationship.
- Secure and interoperable data networks dedicated to health services should be developed across the EU.
- A reliable method enabling doctors and patients to identify each other over the net should be developed.

Validation of Information

It is important to remember that the best way of information is a personal meeting. Still, there is a need for further fact finding to obtain patient empowerment. Today the Internet plays an important role thru public health information sites. There is an obvious need to establish an international quality approved system. Quality criteria for health information web sites were set up 2002 by the commission. National agencies have the responsibility to disseminate these criteria and to secure the quality on the national net sites.

The pharmaceutical industry provides information on non-prescription drugs and life style drugs. This information needs to be comprehensive and include all data required to make an informed decision. It should also take into account that the drug may be non-prescription in one member state and Rx in another.

CPME position on validation of information:

- CPME supports the creation of a EU health portal for validated health information web sites.
- National agencies have the responsibility to disseminate the quality criteria set up by the commission on health information web sites.