

Core quality principles for patient information on diseases and treatment options

High quality information must meet the criteria set out in these principles and should also have a clear process for compliance/certification. Information provided by a Member State and/or the European Commission should be done without restricting or replacing other sources.

Objective and unbiased

Information is objective when it is based on facts and not influenced by prejudices or personal perceptions. Information is unbiased when it is impartial, non-directive and balanced. These two definitions do not relate to the source of information which is a separate issue (see the 'Transparent' principle).

Patient-oriented

Information provided should be patient-centred taking into account patients' needs and expectations in order to empower patients. Patients should be involved in the production and dissemination of information on diseases and treatment options wherever possible.

Evidence-based

The evidence base for any information resource needs to be clearly stated, including making clear the level of evidence. Information should be verifiable, based on comparisons and backed up by scientific peer review where possible.

Up-to-date

Information should be kept up-to-date and the date of publication should be included.

Reliable

Information needs to be factually correct and not misleading. Information should be scientifically valid and reflect latest knowledge.

Understandable

Information provided should be comprehensible for a patient/citizen.

Accessible

Information should be easily accessible via different mechanisms for example, through written documents, websites of certified official bodies etc. Information should also be accessible to people with disabilities.

Transparent

Informed choice requires transparency. That entails transparency of what is known as well as what is not known. Funding, sources of information, evidence for that source and transparency when there is known controversy about a particular treatment, for example, all need to be made clear.

Relevant

Information should include issues of relevance and importance to patients' decision-making e.g. including adverse effects. Impact on quality of life and the consequences of the disease on

contribution of the patient to society/the work place are important elements of information on disease.

Consistent with Statutory Information

Information not regulated by statute should, nevertheless, be consistent with the legal requirements of European law (e.g. must not be designed to promote a prescription only medicine, reflecting the prohibition of direct to consumer advertising of prescription only medicines, must not be misleading etc.) and should refer, where appropriate, to statutory information approved through the process of regulation.