

**EHPF  
EU  
HEALTH POLICY FORUM**

**Recommendations on  
Health Information**

Brussels  
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## Introduction

The EU Health Policy Forum is a multi-stakeholder group of health actors established by DG SANCO in November 2001. In December 2003, the Health Policy Forum decided to establish a working group on health information.

With the adoption of this paper the Forum notes that information is a vital part of our daily lives. We use it to make decisions ranging from the most important questions in life to mundane daily choices. Modern society functions on the provision and flow of information, directed through a huge array of channels and formats (the media, the Internet, personal interactions). All information, whether specifically health related or not will contribute to our perception and management of choices and risk and will influence our behaviour, which will in turn have an impact on our health.

## The Nature of Health Information

Health information covers an extensive range of issues, it comes from a wide range of providers – family, peers, professionals and industry, public bodies and authorities and includes information on products, services, treatments, and health promotion and prevention. Recognising the value of information to behavioural choice, health professionals, civil society organisations (including patient associations) public bodies and authorities and market actors have long sought to deliver sound and understandable information to individuals to help them make healthy choices.

It is well established that access to health information is of vital importance to citizens of all ages, patients and their carers, as well as to professionals, in the context of education and awareness. Clear objectives on health information will contribute to good governance and help bring institutional and governmental structures closer to the citizen.

It is however important to make a distinction between health information which is provided in order to inform in as unbiased way as possible and commercial communications which are designed to create demand for or promote the consumption of a product or service. The issues addressed in this paper encompass all types of information, from scientific publication to commercial advertising. In extending its comments to include commercial advertising the Forum is seeking to underline the role advertising can play in influencing health related choices. **Recognising the impact of such advertising the Forum argues that no relaxation of current EU legislation which prohibits the advertising of prescription only medicines should be envisaged.**

Recognising the value of health information necessitates also a recognition of the importance of health literacy which may be broadly defined as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”<sup>1</sup>. The concept holds that people need more than basic literacy (reading, writing and numeric skills) if they are to participate in modern society; they must develop a number of literacies (e.g. quantitative literacy, media literacy, computer literacy). Efforts must, in this context, also be made to develop people’s ‘health literacy’ so that they develop the competences to find, select and use the right information, and to navigate through the situation most of us face, of ‘information overload’.

**Furthermore, the Forum notes that health literacy issues are compounded by the significant use of eye-catching logos, slogans, endorsements and celebrity promotion which can produce misconceptions and misunderstanding of health enhancing properties of products and services.**

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<sup>1</sup> Nutbeam, D. (1998) Evaluating health promotion—progress, problems and solutions. *Health Promotion International*, 13, 27–43

## Quality of Health Information

Much has been written about the quality of health related information available to the public. In recent years, the emphasis has been on Internet based information, although it is well recognised that many channels can and should be used to deliver health information. Because of the diversity of information in terms of content, format, and nature and interest of provider and target audience, it is difficult to identify common themes. Nevertheless, it is universally true that **to be useful, information must be relevant, appropriate, timely, up-to-date, understandable and factually accurate**. It must also be tailored to the needs and abilities of specific target groups, and be accessible (easy to understand and to use/act upon.) In addition people must know where to go if they are trying to find good quality information and how to assess the reliability of the information they find.

It is also well accepted that the way in which information is developed, provided and consumed is necessarily influenced by its context. This context includes the organisational, financial, intellectual, educational and emotional circumstances of both the provider and consumer of the information. Our need for information, our efforts to find information and our motivation to use the information vary dramatically according to our given situation. **Information is consumed along the continuum of our lives and our information needs change according to our situation**. For example, when we are in good health our interest in health issues can be quite passive, guided by curiosity. In periods of crisis, when ill health affects our families or us, our need for information becomes acute, with little time to search and compare.

## Health Information and European Public Health Policy

In deciding to establish a working party on health information, the European Health Policy Forum recognises the role of information in meeting the aims and objectives of European public health policy. Based on the discussions of the working group and of the European Health Policy Forum as a whole, the Forum has put forward this paper on health information, with two specific aims:

- 1) To set out a baseline from which a Code of Good Practice could be developed after rigorous research and consultation. The role of such a code would be to set common standards by which providers should abide and of which consumers should be aware in order to achieve optimal provision, uptake and use of health information and to argue that health information should be integrated into national public health care services and recognised as a necessary part of medical care
- 2) To argue for a feasibility study to examine the potential for a dedicated Health Information Programme.

## Towards a Baseline of Good Practice in Health Information Development

Health and well-being are at the centre of our lives, and always have been. However, recent changes in attitudes to health and healthcare have changed the perspective of many individuals. Our health is no longer something we entrust entirely into the hands of others. Individuals are stakeholders in their own health, taking an active role in preventative and curative healthcare in collaboration with health professionals.

A key feature of the new trend towards greater involvement by individuals in their own healthcare has been the increased availability of health related information, particularly through the Internet and the advocacy of citizens and patient groups.

Health information comes to us from a wide range of sources – friends and family, professionals and interest groups, public bodies and authorities, general and specialist print media, television and

radio, as well as the Internet. We are subject to ‘health information’ all of the time – some of which we absorb passively and some of which we actively seek out. A survey of American TV viewers by the American Center for Disease Control in 2000 indicated that 52 % of prime-time viewers reported picking up health information that they trusted from TV programmes; 26 % said that these popular programmes were among their top three sources of health information<sup>2</sup>. A snapshot of the numbers using the Internet to find answers to health related questions is seen in the recent nationwide American survey conducted between 9th and 16th February 2004 which found that 74% of Internet users, or 111 million people, in the United States (51% of all adults), had gone online in search of health information<sup>3</sup>. While a Eurobarometer survey of March 2003 found that 41% of the population of the EU 15 believed the Internet to be a good source of health related information<sup>4</sup>.

If then people look for and absorb health information so eagerly, it is extremely important that those who provide such information understand their responsibility and adopt a code of good practice. A number of members of the European Health Policy Forum have adopted guidelines on health information issues and the relevant links to these documents are annexed to this paper. It is also important to empower people to look critically at health information provided and should thus be encouraged to use health information websites that meet the quality criteria for health related websites laid out in the Commission communication (COM 667-2002). Notwithstanding that good information and advice is available via the internet, care providers and advisors should remind their target groups that websites on medicinal products and medical treatments should contain explicit advice to people to discuss the information, or any medication difficulties with healthcare professionals<sup>5</sup>.

A valid Code of Good Practice needs to be developed through rigorous research and in consultation with a wide range of stakeholders. The Forum notes that a number of its members have adopted policies and guidelines on good practice in information provision in their given areas of expertise. A range of these publications are noted in Annex 1 and should be consulted. The Forum does not seek to introduce one common Code of Good Practice, but argues instead that any such Code should be based on rigorous research which accepts and seeks to create a deeper understanding of the following issues:

### ***The role of health information***

- Information is an integral part of healthcare but does not replace supportive environments and healthcare delivery in partnership with the appropriate actors.
- The way in which information can be used is hugely influenced by the socio-economic status of the consumer; it may even compound and magnify socio-economic inequalities.
- Health information covers information on products, service providers, services and treatments, health promotion and prevention. It includes data collection and statistical analysis.
- Information flow should be a two-way process of exchange between the provider and the recipient. Consumers are not passive receivers of information, but themselves generate and synthesise their own information. Health information is part of the health policy dynamic – feeding upwards into policy and legislation to optimise health and downwards to individuals to make decisions in their lives.

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<sup>2</sup><http://www.cdc.gov/communication/surveys/surv2000.htm>

<sup>3</sup> Harris Interactive Health report April 2004

<sup>4</sup> EUROBAROMETER 58.0 European Union citizens and sources of information about health, March 2003

[http://europa.eu.int/comm/public\\_opinion/archives/ebs/ebs\\_179\\_en.pdf](http://europa.eu.int/comm/public_opinion/archives/ebs/ebs_179_en.pdf)

<sup>5</sup> As provided for by the Committee of the Regions opinion on the e-health communication (CDR 256-2004)

- Health information is generated and used at all levels, from the individual through to global organisations.

### ***The nature of the sources of health information***

- The impetus (push) to provide information will depend on the end objective and nature of the provider – efforts should be made to help consumers of health information understand the ‘push’ mechanism and to be discerning about the information they receive.
- Health information is not just about information given at the point of healthcare delivery. Some information that has an impact on our choices is health disinformation – for example misleading product claims.
- Health information could be analysed and filtered to help clarify the deluge of information into manageable and usable segments. Such filtering and analysis may be undertaken by healthcare professionals, self-support networks, health advocates and disease-specific interest or patient groups. By focussing on one issue or condition they can provide a channel of information that is specific and often enriched by personal experience. Filters can also play a role in overcoming distance and isolation, for example for rare diseases and conditions. This makes it critically important that the filters meet the highest ethical and quality standards such as full transparency about possible competing interests, such as sources of funding.
- Health information is also shaped by what is not included, notably information on alternative treatments and/or side effects.

### ***The phases of need for health information***

- Health information is produced and absorbed along the continuum of our lives, by way of multiple media and interactions. It is important that consumers of information are as aware as possible of their own particular situation and its potential impact on their perception of information (e.g. accepting that a point of crisis is not always the best time to make decisions). There are three broad situational contexts for health information:
- Non-critical, non time-urgent – on an individual level this may relate to some aspiration or be driven by curiosity and is the type of change that they might like to consider for the future, e.g. a change in diet, starting exercise, travelling abroad, sexual health and family planning. For policy makers, this is about setting overall health targets and goals that they want to achieve. (PLANNING)
- Urgent, time critical – for the individual this is driven by worry about a specific illness/condition. For healthcare planners and providers this means responding to emerging problems and threats, the need to make contingency plans. (CRISIS)
- Time and goal specific – this is a period of active change in lifestyle or policy. For example for individuals this could be stopping smoking or following a treatment regime. For policy-makers this might involve a re-organisation of services, deployment of staff etc. (CHANGE)

Information tends to be sought and used most by people who are already in good health, accordingly it is of great importance for those in a position of providing health information to target

those with poor access to health information who might be in greatest need of finding such information and guidance.

Given these potential phases of need for health information, it should be recognised that use of health information is influenced by attitudes, community or cultural norms and individual levels of self esteem.

### ***The channels of delivery of health information***

- Informal channels of delivery are central to health information dissemination – in particular, interactions with friends, peers and family.
- More formalised information channels are provided through educational, professional and patient organisations and in healthcare settings.
- The prevalence of mass communication channels is important; the media, TV and Internet being the most obvious and predominant sources of information for citizens. Much of this information is commercial, designed to influence our purchasing and consumption behaviour.

### ***The ethics of health information provision***

The European Commission has established a baseline standard (COM(2002)667) for quality criteria for health information provided on websites. The following five general points may be extrapolated from that Communication:

- **TRANSPARENCY:** health information providers should build trust by providing verifiable, credible information, the source of information and of funding, and their motivations for providing that information. Health information providers should also include references to persons or organisations that users can contact if they have additional questions and require further information. Information users should be wary of the information when these facts cannot easily be discerned from either the published material or the interaction.
- **OBJECTIVITY:** information providers need to make clear the context within which they operate and make every effort to ensure that the information provided is complete and balanced especially where commercial interests are involved. Information users should be aware that information that is left out of a communication may also be important.
- **TIMELINESS:** health information providers should regularly update and review information. Information users should be vigilant to check that information is current. Information should be available at the time of need.
- **RELEVANCE:** health information providers should do their utmost to ensure that information is understandable, relevant and in an appropriate format for the target group and that it does not conflict with cultural and religious traditions.
- **CONFIDENTIALITY:** information provision often develops into a two-way exchange of information. Full disclosure of how any data collected during such an interaction will be used must be made available to all parties concerned. Full consent to the collection, storage and use of such data must be obtained.

## **Towards a dedicated European Health Information Programme**

The current Public Health Programme contains one strand on Information. This strand deals with a wide number of issues and gives only limited emphasis to provision and accessibility of health

information to the general public, whether citizens or patients. In this context, the long-awaited EU Health Portal is expected to be launched in summer 2005. Furthermore, responsibility for health information at EU level is currently very fragmented. Several Commission Directorate-Generals have responsibilities that include health information e.g. DGs Public Health & Consumer Protection, Information Society, Research, Environment, Enterprise and Employment. Responsibility is also divided among the EU Agencies, such as the European Medicines Agency (EMA), European Food Safety Authority (EFSA), European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), European Centre for Disease Prevention and Control (ECDC) and the European Agency for Health and Safety at Work (EU-OSHA).

Moreover, different aspects of health information are addressed in a range of programmes and policy areas. For example, DG Information Society has drawn up quality guidelines for health-related websites. DG Enterprise has been charged with devising a new framework for patient information on medicines as part of the review of pharmaceutical legislation. Articles designed to clarify individuals' rights to accessing treatment in another Member State are included in the draft Directive on Services in the Internal Market. The protection of personal data, as well as the labelling of tobacco, alcohol and food products are also regulated by various EU legal instruments.

On the basis of such a diversity of programmes, initiatives and actors, a study could be undertaken to establish if a single coherent programme or other integrated initiatives might better meet the health information needs of Europe. Such a study would map current activities and include a consultation of key stakeholders.

### **Policy mapping**

A comprehensive mapping exercise is needed to identify all initiatives and policies addressing the different aspects of health information as part of current EU activities.

To cover the range of issues and activities effectively, such a mapping exercise should use a series of approaches which might include:

Institutional analysis to identify the different EU programmes and initiatives that cover health information issues;

National, regional and collaborative analysis to identify relevant activities and structures at national level in the Member States. In addition, the review could extend to cross-border and international initiatives;

Legal analysis to clarify the range of EU Directives and Regulations that cover the different aspects of health information. A comprehensive inventory of current legislative provisions, including the jurisprudence of the European Court of Justice (ECJ) on health information issues, should be assembled and analysed to review the rights of citizens and economic actors;

Literature review to identify relevant studies on sources and channels of health information and how such information is used by professionals, patients and individuals. This work could be based on Eurobarometer surveys, reports and studies from think-tanks, as well as commissioned studies or *grey literature*<sup>6</sup> evaluating existing information-provision initiatives in the Member States;

Evaluation of previous and current EU programmes (including the mid-term review of the Public Health Programme), feedback from and lessons learnt in developing the EU Health Portal. An analysis should look at overall policy coherence and highlight the synergies and gaps.

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<sup>6</sup> *Grey literature* refers to publications issued by government agencies, professional organisations, research centres, universities, public institutions, special interest groups, and associations and societies whose goal is to disseminate current information to a wide audience. These publications are not controlled by commercial publishing interests, and publishing is not the primary business activity of the organisation. (<http://library.brooklyn.cuny.edu/access/greyliter.htm>)

## Stakeholder consultation

On the basis of the outlined mapping exercise, the Commission should initiate a stakeholder consultation to include the range of providers and users of health information, for example:

- *International organizations*, in particular the WHO and OECD, which use health related data for epidemiological studies, analysis of health trends and projections, collation of evidence of effectiveness, defining standards and guidelines and exchange of best practice;
- *National governments*, which need information for developing and monitoring legislation, authorising products and services, policy-making and resource allocation, epidemiological surveillance and health reporting;
- *Health-sector enterprises*, which use information in developing new products, predicting market trends, advertising and promotional campaigns, meeting legislative requirements;
- *Local and regional authorities*, which use data for planning social and healthcare service delivery, urban planning, health monitoring and reporting, health promotion and improvement activities;
- *Healthcare professionals*, who use information for continuing professional development (CPD) in order to guarantee the highest quality care delivery and patient safety. Healthcare professionals provide information to patients and individuals to enable them to decide, in true partnership between professional and individual, the best personalised options for treatment and well-being;
- *NGOs, disease-specific organisations and patient groups*, which are both users and providers of health information. As users, they need access to high quality validated information. As providers of information to patients, health professionals, relevant authorities, media and society as a whole, they offer unique health information based on the experience of the patients' community living with the disease;
- *Formal and informal carers*, who need medical and social information in order to help them make treatment and care decisions with or for those in their care.
- *Individuals and family members*, who need information to help them consider, change and adapt their behaviour, make purchasing and consumption choices, become more involved in decisions about their own health, to better comply with or be involved in treatment options, and to improve their general health literacy.

If the conclusion of the mapping and consultation exercises outlined above is that a dedicated Health Information Programme would indeed be appropriate, plans for such a programme should be drawn up and presented to the Member States in the context of the next round of multi-annual programme planning. Should such a programme be initiated then a first priority should be to develop a Code of Good Conduct in Health Information built upon the concepts raised in this paper and duly adopted by the European Health Policy Forum.

## **EHPF ORGANISATIONS ENDORSING THIS DOCUMENT**

The following members of the EU Health Policy Forum endorse this document and its recommendations:

1. AER (Association of European Regions)
2. AESGP (Association Européenne des Spécialités pharmaceutiques Grand Public)
3. AGE (European Older People's Platform)
4. ASPHER (Association of Schools of Public Health in the European Region)
5. BEUC (Bureau Européen des Unions de Consommateurs)
6. CHANGE (Coalition of HIV and AIDS Non Governmental organisations in Europe)
7. CPME (Standing Committee of European Doctors)
8. EAGS (European Alliance of Patients Support Groups for Genetics services)
9. EATG (European Aids Treatment Group)
10. EBU (European Blind Union)
11. ECH (European Committee for Homeopathy)
12. ECL (The Association of European Cancer Leagues)
13. EDF (European Disability Forum)
14. EFA (European Federation of Allergy and Airways Disease Patients)
15. EGA (European Generic medicines Association)
16. EHMA (European Health Management Association)
17. EHN (European Heart Network)
18. EHTEL Association (European Health Telematics)
19. EMA (European Midwives Organisation)
20. ENHPA (European Network of Health Promotion Agencies)
21. ENSP (European network for Smoking Prevention)
22. EPHA (European Public Health Alliance)
23. EPSU (European Federation of Public Service Unions)
24. ESIP (European Social Insurance Platform)
25. ESMHD (European Society for Mental Health & Deafness)
26. EUCOMED Medical Technology
27. EUPHA (European Public Health Association)
28. EUROCARE (Advocacy for the prevention of Alcohol Related Harm in Europe)
29. EUROPA DONNA (The European Breast Cancer Coalition)
30. EURORDIS (European Organisation for Rare Disorders)
31. GAMIAN-EUROPE (Global Alliance of Mental Illness Advocacy Networks)
32. GIRP (Groupement International de la Répartition Pharmaceutique)
33. HAI (Health Action International)
34. HOPE (Standing Committee of the Hospitals of the EU)
35. IAPO (International Alliance of Patients' Organisations)
36. IPPFEN (International Planned Parenthood Federation – European Network)
37. IUHPE (International Union for Health Promotion and Education)
38. MHE-SME (Mental Health Europe – Santé Mentale Europe)
39. PCN (standing Committee of Nurses)
40. PGEU (Pharmaceutical Group of the European Union)
41. Red Cross / EU – Bureau Croix-Rouge / UE
42. UEHP / CEHP (Union Européenne de l'Hospitalisation Privée)
43. UEMS (European Union of Medical Specialists)
44. Youth Forum Jeunesse

## **ANNEX 1**

The following websites have been suggested as providing further insight on health information. Please note that these links are external and that the associations listed above as endorsing the paper and its recommendations cannot be held responsible for the content of the sites.

**European Commission** overview of activities in the Health Information strand of the Public Health Programme

[http://europa.eu.int/comm/health/ph\\_programme/howtoapply/infoday\\_2005/ev\\_20050203\\_co03\\_en.pdf](http://europa.eu.int/comm/health/ph_programme/howtoapply/infoday_2005/ev_20050203_co03_en.pdf)

**EURORDIS** Guidelines for providing information on Rare Diseases

[http://www.eurordis.org/IMG/pdf/pard3\\_guidelines\\_leaflet.pdf](http://www.eurordis.org/IMG/pdf/pard3_guidelines_leaflet.pdf)

**EFPIA** policy memorandum on Enhancing the Provision of Health Information to Patients in Europe

[http://www.efpia.org/4\\_pos/informedpatient/policymemo0604.pdf](http://www.efpia.org/4_pos/informedpatient/policymemo0604.pdf)

## **CPME**

Information to Patients and Patients Empowerment

[http://213.177.130.12:591/adopted/CPME\\_AD\\_Brd\\_110904\\_080\\_EN.pdf](http://213.177.130.12:591/adopted/CPME_AD_Brd_110904_080_EN.pdf)

European patients demand access to information for ALL disease areas

[http://213.177.130.12:591/adopted/CPME\\_AD\\_Brd\\_300803\\_4\\_EN.pdf](http://213.177.130.12:591/adopted/CPME_AD_Brd_300803_4_EN.pdf)

Care and consent of the elderly

[http://213.177.130.12:591/adopted/CPME\\_AD\\_Brd\\_270304\\_111\\_EN-fr.pdf](http://213.177.130.12:591/adopted/CPME_AD_Brd_270304_111_EN-fr.pdf)

Informed consent

<http://213.177.130.12:591/adopted/CP%202001-045%20Final%20EN.pdf>

**Eurohealthnet** Recommendations to promote health literacy by means of the internet

<http://www.eurohealthnet.org/Eurohealthnet/documents/healthliteracy-final.pdf>

**HAI** : Bending the rules: medicines' promotion and the distortion of information

<http://www.haiweb.org/pdf/Bending%20the%20rules%20final.pdf>