EuroHealthNet

the European network for public health, health promotion and disease prevention

Health Literacy and Internet

Recommendations to promote Health Literacy by the means of the Internet

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CONTENTS

INTRODUCTION

Due to a changing pattern in disease burdens from infectious diseases to chronic diseases and the aging of the population in Europe health information becomes increasingly important for citizens to act in a healthy way. Terms like empowerment and informed-shared-decision-making describe a situation that citizens are encouraged to take an active part and accountable role in their own health.

What about citizens, who don't have the ability to be informed? How can an equal access and the ability to use health information in an effective way be assured? The concept of health literacy offers a new approach to health promotion work.

This paper will explore in which way the use of Internet can contribute to improve health literacy among European citizens, especially of those with low health status.

1. HEALTH LITERACY

Primarily used in the context of medical care to help patients understanding health care information, health literacy has recently become a topic in the field of health promotion.

Health literacy is based on improved access to information and knowledge, informed consent and negotiating skills and affects on health care utilization and the active participation in health promotion activities (Kickbush 2001). Health literacy is clearly dependant upon levels of fundamental literacy (Nutbeam 2000). While general literacy and education are important determinants of health and inadequate literacy is a risk factor for low health literacy, literate people are not consequently health literate (Kickbush 2001).

The potential of Health literacy lies in its holistic approach, which takes into consideration not only personal skills and environmental factors but requires tailored information to develop the social and cognitive skills fundamental to act on health determinants. Beside general strategies to promote literacy, stronger cooperation between the health and education sector will therefore be essential so that people are able to make healthy choices.

1.1 Definition of health literacy

The term health literacy is originally used in the United States and describes and explains the relationship between patient literacy levels and their ability to comply with prescribed therapeutic regimens (Ad Hoc Committee on Health Literacy 1999). This approach defines health literacy as "the ability to read, understand and act on health care information"(Center for Health Care Strategies 2000).

Most research and publications about health literacy concentrate on improving the ability to read consent forms and other written health care information, understand and act on written and oral information given by health care professionals (Kickbush 2001).

The US Healthy People 2010 objectives expand the patient-oriented approach of health literacy towards health promotion by defining health literacy as "the capacity to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health" (USDHHS 2000).

The broadest definition of health literacy is drawn by the World Health Organization (WHO). Nutbeam describes health literacy in the WHO health promotion glossary as follows: "Health literacy represents 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. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment."(Nutbeam 1998).

1.2 Consequences of low health literacy

Limited health literacy increases the disparity in health care access among exceptionally vulnerable groups (Partnership for Clear Health Communication 2003). Due to an unequal access to information technology, poor health literate people are less informed and often produce supplementary costs to the healthcare system because of inadequate or inappropriate use. Low health literacy is often linked to chronic health problems because patients know less about their conditions and how to handle symptoms.

According to the Center for Health Care Strategies, poor health literacy is disproportionately more likely among **older people, immigrants and those with low incomes** (CHCS 2003).

The health literacy of disadvantaged groups has therefore to be improved by supporting access to health information, providing special information for people with low health literacy skills and promoting their capacity to use information effectively.

According to Nutbeam, the outcomes of high levels of health literacy will lead to personal benefits, such as healthier lifestyle choices and effective use of the health services. Furthermore, the ability to use information effectively, can lead to social benefits, "e.g. by enabling effective community action for health" (Nutbeam 2000).

1.3 Levels of health literacy

Nutbeam classifies health literacy as a continuum with three levels: functional health literacy, interactive health literacy and critical health literacy. These levels reflect increasing degrees of autonomy and personal empowerment, dependant on cognitive development and exposure to different information (Nutbeam 2000).

Level 1: functional health literacy: Functional health literacy means the "ability to apply literacy skills to health related materials such as prescriptions, appointment cards, medicine labels" (Parker et al. 1995). By communication of factual information, education in this field tends to promote knowledge of health risks, health services and compliance with medical advice.

Examples of activities to improve functional health literacy: production of information leaflets, traditional patient education. (Nutbeam 2000).

Level 2: interactive health literacy: Interactive health literacy is characterized by personal skills like the capacity to act independently on knowledge as well as motivation and self-confidence to provide information and interact with social groups. Activities to improve interactive health literacy will result in individual benefit by focussing on personal and social skill development as well as behavioural outcomes

Examples of activities to improve interactive health literacy: school health education programmes, tailored health communication regarding specific needs of different groups (Nutbeam 2000).

Level 3: critical health literacy: Critical health literacy empowers individuals and communities to critically analyse information and use it to exert greater control over life events and situations. By improving individual and community capacity to act on social, economic and environmental determinants of health, activities to promote critical health literacy will be beneficial for the individual and the community. Helping people to develop confidence to act on knowledge and the ability to work with and support others will best be achieved through community-based actions

Examples of activities to improve critical health literacy: Provision of technical advice to support community action (Nutbeam 2000).

Health literacy is therefore a useful concept, which differs from Health Promotion and Health Education approaches as it really focuses on communication and empowerment of people to act upon the information they receive.

2. INTERNET AND HEALTH COMMUNICATION

Internet proposes an easy-to-use, universal access to information and provides various possibilities to find the latest up-to-date, barrier free information that is independent of location and time. Interactive services like online self-help-groups, chats with experts and forums on special health topics can support active coping and social support in a virtual community by anonymous contact.

Due to a wide-spread pool of information, which can be personalised, Internet can enhance health literacy, health related knowledge and support people to become responsible for their own health.

The paper will now focus on the role of Internet in providing health information as well as the use of this media among vulnerable groups.

2.1 Internet and health information

Internet is increasingly becoming a key source of health information to most people (Kickbush 2001). A majority of the population of the EU-15 (41.5 %) believed that the Internet is a good source of health related information (European Opinion Research Group 2003). About half of the people seeking health information on the Internet believe that the Internet has a major impact on their understanding of health problems and on their interaction with their doctor (Wilson et al. 2004). The proportion of users drops with age and increases with educational level: 35.3 % in the 15-24 age group use Internet for health-related information, compared to 8.3 % in the older age group (55+). Only 5.8 % among people who left full-time education at the age of 15 use the Internet to get information about health.

Interestingly, health information is demanded both by Internet users and non-users of all age groups (European Opinion Research Group 2003).

As with other media, there is a danger that the information provided via Internet is false, of low quality or too complex for the average user. Information provided on Internet is unfiltered, in that it does not always disseminate between user groups (professionals, lay persons, etc.). The information could therefore generate emotional reactions, if, for example, it discusses survival rates for specific diseases. Users may not have adequate support to understand and process this information. Unequal access to the medium can also lead to a widening social gap (Schmidt-Kaehler 2003). Internet can be regarded as a pull-information[1] source rather than a push-

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[1] Pull-information require an actively search and selection process by the user to choose the information he needs among a huge pool of information.

information[2] source (Television and printed media). Users may be overwhelmed by the amount of information that they pull. Searching for "health" and "health information" on Google (http://www.google.com), for example, results in 321,000,000 hits and 3,330,000 hits respectively.

In order to use Internet effectively, therefore, the general public must know how and be supported in their efforts to manage this information. Health literacy is crucial to use the Internet in an effective way and being capable to assess the available health information.

2.2 Use of Internet among vulnerable groups

Internet is actually not very attractive and accessible to vulnerable groups. The working document "eInclusion revisited: The Local Dimension of the Information Society" from the European Commission (2005) emphasizes low Internet use among housepersons (especially women), older citizens, retired people and people living in rural areas. Education and income appear to be the most important variables to digital exclusion. According to Eurobarometer 58.0 the subjectively identified reasons for non-use of the Internet among European citizens are non availability of a PC at home (high cost of PC ownership and internet connection); lack of access at work or at Public Access Points, the complexity of technology and the lack of basic skills (EC 2005 a).

While young people as well as people with a higher educational level mention costs as main barrier for their non-use of the Internet, elderly (55+) and low educated (up to 15) see the lack of training as main barrier (figure 1).
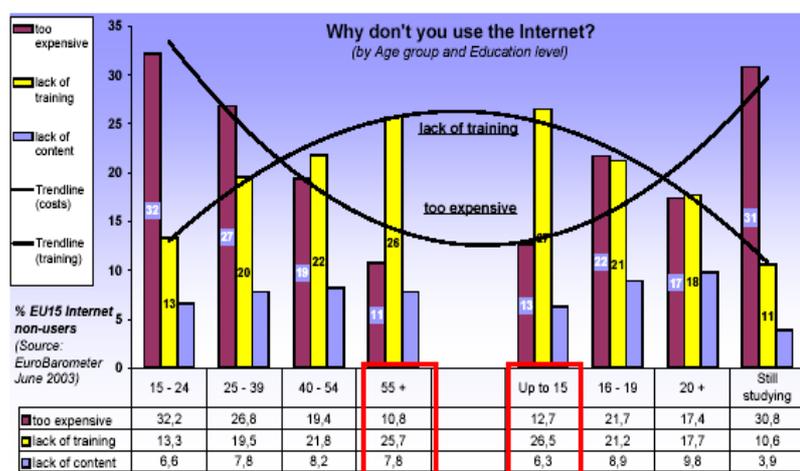

% EU15 Internet non-users (Source: EuroBarometer June 2003)	15 - 24	25 - 39	40 - 54	55 +		Up to 15	16 - 19	20 +	Still studying
too expensive	32,2	26,8	19,4	10,8		12,7	21,7	17,4	30,8
lack of training	13,3	19,5	21,8	25,7		26,5	21,2	17,7	10,6
lack of content	6,6	7,8	8,2	7,8		6,3	8,9	9,8	3,9

fig. 2. Why don't you use the Internet ? (by Age group and Education level)

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[2] Push- information describes an information offer where media professionals have already selected available information so that their reception occurs in a passive way, independently of the recipients' special needs.

In general, the interest in Internet use among elderly and people of lower educational level is significantly lower than among the general public (European Opinion Research Group 2003). Regarding the results of the question "What would encourage NON-users to use the Internet?", the low response rate of 31.7 % of the elderly and 38.4% respectively of low-educated could suggest that there is an additional cause for the non-use, which is specific to vulnerable groups, that has not been identified.
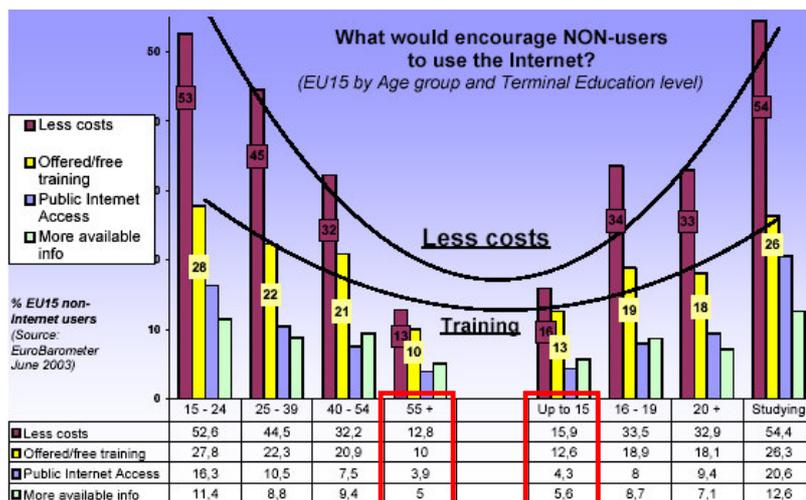

	15 - 24	25 - 39	40 - 54	55 +		Up to 15	16 - 19	20 +	Studying
■ Less costs	52,6	44,5	32,2	12,8		15,9	33,5	32,9	54,4
□ Offered/free training	27,8	22,3	20,9	10		12,6	18,9	18,1	26,3
□ Public Internet Access	16,3	10,5	7,5	3,9		4,3	8	9,4	20,6
□ More available info	11,4	8,8	9,4	5		5,6	8,7	7,1	12,6

fig. 2 What would encourage NON-users to use the Internet? (EU 15 by Age group and Terminal Educational Level)

That additional cause for the low rate might be the inadequate sensitivity of the value of Internet use in the life of disadvantaged populations as well as the mistrust in technology in general (Chang et al. 2004).

Chang et al. see the digital divide prior in content-related barriers, such as lack of local information, literacy barriers, language barriers and lack of cultural diversity. On the one hand, disadvantaged people believe that Internet is of no use to them and on the other hand they mention the high investment costs for hardware and connection as well as the lack of training as the greatest barrier to using the Internet. The underlying reason, however, could be that people don't use Internet because they are not interested in the information provided (EC 2005 a).

The Internet requires basic skills, such as literacy and much of its content is addressed to better educated people (EC 2005 a). On average, Internet health information requires a 10th grade (= age of 15) or higher reading level and only 10 of 1000 Web sites reviewed provided understandable content for low-literacy adults. Zarcadoolas et al. explains that complex web features, such as animated links, may be too complicated for low-literacy adults to identify and use. Concerning the use of search engines, searching strategies, such as generation of specific search terms,

differentiation between sponsored and non-sponsored sites and the correct spelling of the search terms were sub optimal (Birru et al. 2004).

The literacy level needed to read health information on the Internet appears to inhibit information-seeking efforts of low-literacy adults (Birru et al. 2004). Birru also reports that low-literacy adults who participated in a computer skill workshop felt positive about continuing their online experiences and all expressed enthusiasm to improve their skills (Birru et al. 2004).

These results show that a combined strategy of designing websites providing easy-to-read health information, improving Computer- and Internet-skills and promoting Computer and Internet access is necessary to improve health literacy among vulnerable groups and to encourage them to use the Internet.

3. INITIATIVES OF THE EUROPEAN COMMISSION TOWARDS HEALTH INFORMATION ON THE INTERNET

The European Commission, DG Information Society, declared E-Health as a priority target in 2002. Since the inauguration of the eEurope action plan in 2002 by DG INFO, the importance of Health Information is mentioned in various communications of DG SANCO and "improving health information and knowledge" is the first strand of the EC's current Public Health programme (2000-2006).
What is the role of online health information for the general public in the current public health work programme as well as the eEurope 2005 Action Plan?

The Commissions' communications often refer to the need for quality-proofed and accessible health information. In 2004, the EC mentioned that a "growing number of people are looking proactively for information (..) and want to be actively involved in decisions related to their own health"[3]. But how can the provision and accessibility of this information for everyone be assured?
The "Health Information" strand deals with a wide range of issues such as development of health indicators, analysis and reporting on health or dissemination of health information, mostly focusing on health information for public health professionals. Even in the area of E-health, the EC attaches only a little importance to online health information for the general public. Previous activities of the European Commission, like the establishment of standards for "Accessibility of Public Web

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[3] EC 2004 a, p.7

Sites and their Content"[4] and "Quality criteria for Health related Websites"[5], concentrate on establishing formal criteria for barrier-free access instead of ensuring the provision of "barrier-free content". For example, the quality criteria for Health related Websites (see Annex I) contains an entire paragraph on transparency and regularity of updating the information, whereas important factors regarding the content, such as usability and readability, are only enumerated under the point "Accessibility".

The priorities of the EC in the area of e-Health, such as the published quality criteria, are necessary but not sufficient to provide better health information to everyone, including low health literate people. Proposed education campaigns to inform the general public about the existence of quality codes and to educate site developers about minimum quality standards as well as monitoring the member states actions to make health information as accessible as possible to citizens, are useless if the provided information (content) is neither understandable nor designed to answer the information needs of the specific user.

In the context of its Public Health Programme the EC is preparing to establish a European Union-wide public health portal with information "relevant to European citizens"[6], to be launched by the end of 2005. This Portal would be structured thematically, mainly addressed to the general public, with a special section for professionals. Concrete details about for example, what will be included in the "citizens' section" or if the portal pays attention to the specific information needs of different population groups (such as youth, elderly or men, women), have not yet been communicated.

A paper produced in the context of the European Health Policy Forum (EHPF 2005), a multi-stakeholder group of health actors, initiated by the Commission in 2001, points out the importance of health information for the empowerment of citizens. In their latest position paper of 9th march 2005 "Recommendation Paper on Health Information"), the working group on health information encourage the Commission to develop a more coherent and comprehensive approach to health information provided in the EU. For this purpose, the EHPF proposes a policy mapping exercise to identify all EU initiatives and policies addressing health information, as well as a consultation with key stakeholders (providers and user of health information).
This initiative, which takes the various aspects of health communication into consideration and requires the improvement of general health literacy, could

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[4] EC 2001, http://europa.eu.int/eur-lex/en/com/cnc/2001/com2001_0529en01.pdf
[5] EC 2002 a, http://europa.eu.int/eur-lex/en/com/cnc/2002/com2002_0667en01.pdf
[6] EC 2004 a, p.20.

contribute to the development of a user-relevant EU public health portal, also accessible to low-health literate citizens.

4. RECOMMENDATIONS TO PROMOTE HEALTH LITERACY BY INTERNET

To achieve functional health literacy, general literacy has to be improved to ensure the ability to read and understand health materials. Existing initiatives in the health care sector to promote functional health literacy among patients should be extended to the general public.

An analysis of the level of comprehension of written health materials (SMOG-readability formula) revealed that only 3% of the available information is suitable for people with a low educational level (Dierks et al. 2000).

The Internet is a developing and interactive media and has great potential to provide understandable and useful health information, especially to people with low literacy skills. New information technologies might address health information in a more visual and interactive manner to make the information more accessible to those having lower reading skills. Interactive tools like video streams and possibilities to use technologies for disabled people like software that read Website content aloud, could contribute to reduce the digital divide. New initiatives should be taken to promote interactive and critical health literacy among vulnerable groups.

4.1 Target Groups:

• Elderly
• Immigrants
• families in poverty (esp. focus on house-hold women, youth)

4.2 Possible set of recommendations:

1. Improve Internet access for vulnerable groups

2. Ensure specific and high quality online health information, which is understandable and relevant to the target group.

3. Provide skill training to develop the capacity of Computer/Internet-use among vulnerable groups.

4. Implementation of a broad communication strategy to promote the general concept of health literacy among public, health professionals and politicians at national level as well as specific projects among vulnerable groups at local level.

5. Further Research/Analysis on how to support vulnerable groups in the use of computers/internet

4.3 Detailed Recommendations to promote health literacy by the means of the Internet (personal and community empowerment)

4.3.1 *Improve Access to the Internet for vulnerable groups (Public Internet Access Points)*

All citizens should have easy access to Public Internet Access Points, which could be offered in two locations: Those that are highly frequented by the general population on a daily basis (supermarkets, fast-food restaurants, phone-shops and libraries) and social/health centres .The access points should provide long opening hours to ensure accessibility after work and during the weekend and should integrated in existing infrastructure.

Providing Public Internet Points in highly frequented central locations means that people don't have to change their daily routine to get Internet Access.

Health centres offer a fixed location, additional information as well as assistance by professional staff, but have the disadvantage of requiring a high budget for human resources and office costs.

Developing collaboration with the private sector could promote the objective of improving overall accessibility by contributing computers, and reduced or free connection to Internet, as well as broadband access to poorer regions.

4.3.2 *Development of a Regional/Local Health Portal, which offers information appropriate to age, culture and language.*

Regional/local authorities should develop health portals that are accessible through a well-known site. The portal ensures quality information of regional relevance that is written at a level that is easy to understand. Content is kept up-to-date by a network of health professionals, social workers, communication and education specialists and supervised by a independent team. This could stimulate multidisciplinary collaboration between the different professions.

A barrier free and easy to handle health portal encourages person with low Internet experience to start using this media. The most important barriers like having to use search queries and search engines and to differentiate between good quality and sponsored sites or incorrect information will be reduced by providing information on a quality-proofed Portal. With growing media competence, people can leave the easy-to-use and quality-assured area of the central portal.

The regional focus means that users can access relevant information about resources available to them in their community. The aim is to foster social contacts between citizens as well as professionals in the community and to improve knowledge about available health information and services in the area.

The Health Portal should be based on 3 strands:

- **Health information** (tailored and at a basic literacy level; nontextual messages like video streams, graphics and audio should be developed to respond to different learning styles (visual or audio learners)

- **Practical information about the Health System** (regional Infrastructure +. a interactive community map to see where the next doctor, hospital, self-help-group, health promoting activities (nutrition course, walking group, etc.,) is located.

- **Interactive part** (forum, thematically chat rooms, mail to experts, FAQ to share the knowledge of the target group, possibility to valuate offers in the community)

To ensure useful and targetted information, health information needs of vulnerable groups in the community "XY" should be examined through a social assessment. This social assessment should take place in locations frequented by the specific target group, such as schools for children of disadvantaged families, social welfare offices (migrants) as well as hospitals, pharmacies or doctors offices (elderly people).

To guarantee a Health Portal which is oriented to the needs and interests of the target groups[7], representatives of the target group should be actively involved in the designing process. It is strongly recommended that he portal be pre-tested among individuals of the target group.

The Portal should be based on a set of new Guidelines, based on existing quality instruments, such as the quality criteria of health-related websites (EC), afgis[8], HON-Code of Conduct[9] or HIDDEL-vocabulary[10]. In order to ensure that the portal meets the needs of low health literate people, the Guidelines should take into consideration the content of the site, and ensure that the particular needs and abilities of specific usergroups.

Main priorities could be a detailed description on important factors like "Usability" (of the Site[11], as well as the content[12]) as well as "Understandability"(didactics) of the information provided for all citizens.

Additionally, a quality assessment tool (e.g. a short checklist) could be developed to offer all citizens, especially members of the target group a easy-to-use tool to critically use information.

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[7] .e.g. Elderly: The design of the information offered has to be adapted to their characteristics (decreased attention span, simple and clear web pages, large buttons, large font sizes (14 points or more), high contrast, no sound effects.

[8] The Health Information System Action Forum (afgis) provides criteria for the quality assurance of health information in the new media like transparency, usability, accessibility. www.afgis.de

[9] The Health on the Net Foundation sets an ethical standard for online health information. Provider, commiting to these principles are allowed to put the HON-logo on their Website. www.hon.ch

[10]The Health Information Description, Disclosure and Evaluation Language (HIDDEL) enables the Labeling of Websites based on the use of specific vocabulary to describe the information offer. www.medcircle.org

[11] is the navigation structure intuitive, does the site take into account the site specific needs of the target group? e.g. elderly need simple pages, whereas young people are attracted by interactive tools)

[12] is the provided information relevant to the specific target group

4.3.3   Strengthen individual competence

ICT- skills are nowadays an essential to individual development in our knowledge-based society. It is therefore of great importance that vulnerable groups, especially immigrants and young people, develop these skills, in order to gain professional qualifications and employment opportunities. The community-based trainings can contribute to the building of a social network by learning together.

Modular trainings, focussing on problem-based learning, should therefore be provided to improve the Computer/Internet-skills of vulnerable groups. To overcome mental barriers such as mistrust of new technologies and the lack of useful content, a focus of the training should be on revealing the use amongst specific target group by indicating how it can help facilitate interests or issues that are of real concern to the participants (e.g. how they can use it to find out what specific health promotion courses are offered in their community).

The trainings should be provided in different settings according to the specific target group and preferably by a community member, who takes the role of a peer ("peer to peer teaching"). Offering skill training in less formal circumstances by an instructor from the same culture tends to be more motivating, especially for immigrants and women.

The training programme should contain the following contents:

a) Providing computer and Internet- skills (how to use a computer/ what is the Internet?)
b) How to manage the information overload (Pull-information) (Finding information: How to use search engines (e.g. Google) and define search strategies)
c) Critical reception of information provided (Communication of existing quality criteria, development of a easy to use- tool specific to the needs of the target group to judge the quality of information, exchange about the search results in small groups).

- Additionally, the development of media-competence (in particular PC + Internet) in school curricula should be strongly encouraged.

4.3.4 *Communication Strategy*

Promoting the strategies by a social marketing concept targeted at vulnerable groups, which focuses on concrete values of the Internet use in their every-day-lives. The communication strategy must address thus group's mistrust of technology in general. The communication strategy should take into account the low use of Internet among vulnerable groups by making use of non-digital communication to deliver the message.

The Guidelines should be promoted among producers of health information to ensure high quality information that is understandable to the whole European Population, especially people with low health literacy skills. In addition, a universal tool to facilitate the valuation of information should be promoted among the general public through the use of different media.

5. ANNEX

5.1 Quality Criteria for Health Related Websites (EC 2002).

Quality Criteria for Health Related Websites

Developed in widespread consultation with representatives of private and public eHealth websites and information providers, other industrial representatives, public officials, and representatives of government departments, international organisations, and non-governmental organisations.

These criteria should be applied in addition to relevant Community law

Transparency and Honesty

- Transparency of provider of site – *including* name, physical address and electronic address of the person or organisation responsible for the site (see Article 5 and 6 Directive 2000/31/EC on Electronic Commerce).

- Transparency of purpose and objective of the site

- Target audience clearly defined (further detail on purpose, multiple audience could be defined at different levels).

- Transparency of all sources of *funding* for site (grants, sponsors, advertisers, non-profit, voluntary assistance).

Authority

- Clear statement of sources for all information provided and date of publication of source.

- Name and *credentials* of all human/institutional providers of information put up on the site, including dates at which credentials were received.

Privacy and data protection

- Privacy and data protection policy and system for the processing of personal data, including processing invisible to users, to be clearly defined in accordance with community Data Protection legislation (Directives 95/46/EC and 2002/58/EC).

Updating of information

- Clear and regular updating of the site, with date of up-date clearly displayed for each page and/or item as relevant. Regular checking of relevance of information.

Accountability

- *Accountability* - user feedback, and appropriate oversight responsibility (such as a named quality compliance officer for each site).

- Responsible partnering - all efforts should be made to ensure that partnering or linking to other websites is undertaken only with trustworthy individuals and organisations who themselves comply with relevant codes of good practice.

- Editorial policy - clear statement describing what procedure was used for selection of content.

Accessibility

- *Accessibility* - attention to guidelines on physical accessibility as well as general findability, searchability, readability, usability, etc.

Relevant Community Law is listed in footnote 3. Terms *in italics* are further discussed in the Glossary of Terms

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