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Abstract (for dissemination)	This report aims to describe and evaluate the content already provided by the medical partners of the project as well as relevant content of other providers throughout the world. Based on these findings it gives some recommendations on the type and quality of content that should be provided by the KOM2002 project.

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2. Executive summary

The present report, part of the first work package, will aim to evaluate existing content that has been developed either by the medical partners of the project or by external sources. The rationale behind this evaluation is based on the following:

- a) Content already developed by partners can be used directly for the project if it meets certain quality criteria,
- b) The evaluation of external content will help in identifying areas that have not been covered adequately or in high standards,
- c) External content of high quality might be available in the public domain and therefore it could be used for the purposes of KOM2002.

The summary conclusions and recommendations of the authors are the following:

- a) The medical partners have already developed content of accepted quality that can be used directly by the KOM2002 project in the original language.
- b) It is recommended that all medical partners collaborate to select their own content of the highest quality to translate into English, in order to be used by the main web site of the project. Since, some of the sites are focused in specific disorders, this procedure should be easy and should not create conflicts between medical partners.
- c) Evaluation of existing content and/or new content should be based in reliable instruments such as the Discern instrument.
- d) External content should be reviewed by medical partners and efforts should be made to select particular high quality leaflets that meet the criteria and interests of KOM2002. Permission to modify or use these texts might be preferred than writing our own texts. We should however write new text if the quality standards are not met or if material is copyrighted.

3. Introduction - Background

It has been estimated that a very large portion of those with access to Internet search regularly for health information on the World Wide Web. Given the phenomenal growth of Internet use, especially in European countries and the developed world, the Web has become an increasingly important source of health information. People of all ages search for information related to various health conditions, and children and adolescents, due to the easier adaptation to new technologies, are over-represented. As a result of this, issues of quality of the information provided begin to receive more attention and many rating instruments have been developed to help consumers evaluate the quality of information they read.

Problems of mental health (such as depression or anxiety) are very prevalent in the general population and several reports have shown that such problems are among the most popular subjects searched by users. It has been reported, for example, that more Internet users search the Web for information on depression than any other health condition. This is not surprising given the high level of disability associated with depression in the community and the fact that the Web provides a convenient, anonymous means of obtaining information about the problem. The stigma associated with mental illness creates barriers in seeking diagnosis and treatment and the provision of such information through the web might help some patients to get treatment. Web pages available for mental health problems are also very common. A search in the "google" (www.google.com), one of the most popular search engines, has shown that the term depression yields 5.160.000 different pages far more than other common conditions such as heart disease (2.910.000 pages) cholesterol (2.370.000 pages), headache (1.780.000) or influenza (870.000 pages).

Users are turning to the Internet partly because of a lack of information available from traditional sources. They demand this information in order to help them make informed decisions about their medical or alternative care. No longer dependent solely on their doctor's word on diagnoses and treatments, the Internet is enabling patients to uncover the information themselves. There are, however, risks in gaining health care information on line, as there are no guarantees that the information or advice is accurate. But even when information does come from the web site of a reputable source, patients often do not have the knowledge to judge whether it applies to their own situation. Patients, therefore, still need to talk to their doctor in order to best utilize the information they have received.

Taking into account these limitations, the KOM2002 project will aim to collect information of a high quality standard and provide this information to the European citizen. In particular we aim to produce information with the following characteristics:

- ❖ It will be accurate and evidence-based
- ❖ It will be easily accessible from citizens across Europe and in particular in several languages
- ❖ It will be easily searchable and relevant
- ❖ It will give the user the opportunity to interact with specialists at his or her own language

The present report, part of the first work package, will aim to evaluate existing content that has been developed either by the medical partners of the project or by external sources. The rationale behind this evaluation is based on the following:

1. Content already developed by partners can be used directly for the project if it meets certain quality criteria,

2. The evaluation of external content will help in identifying areas that have not been covered adequately or in high standards,
3. External content of high quality might be freely offered and therefore can and should be used for KOM2002

The outline of this report will be as follows: first, we review and evaluate the sites of the collaborating medical partners, second, we review and evaluate external sites, third based on these evaluations we make a synopsis and give some recommendations regarding the development of new content for KOM2002.

4. Evaluation of existing content of medical partner's sites

The task of evaluating existing content of different medical partners is made difficult by the fact that the sites are in several languages and therefore in this section only a crude evaluation will be made, mainly with descriptive data. This does not limit the conclusions of the evaluation, because most of the content that will be translated in English will be re-evaluated along with the new content. Since for practical reasons we had detailed data for the Greek site, we decided to select this site as a representative site across partners to evaluate in more detail with the use of the "Discern" quality instrument.

4.1 Methodology of the evaluation

a) descriptive evaluation: domains that were evaluated included:

1. Source of the site: We looked whether each site displays the institution's or organization's name and logo as well as the name and the title of the authors of the material provided.

2. Purpose of the site: We looked whether the mission statement or purpose of the site has been displayed or clearly stated for users to understand how best to utilize the information.

3. Personnel involved in the development of the content: This refers to number of mental health professionals involved in the writing of relevant content.

4. Currency of the site: We looked whether the date of the original document and the date of content posting has been displayed so the user can judge the timeliness of the information.

5. Logical Organization and presentation of the site: We looked for simplicity of design and ease of returning to the homepage or to the top page of any specific section of the site as a key navigation criterion.

6. Presence of internal search engine: We looked whether there is any internal search engine capable of searching specified content by keyword or search string and retrieving only relevant materials

7. Interactivity of the site: Does the site give the opportunity to the user for feedback regarding the quality of information provided, any possible omissions or further questions to experts that can be answered in reasonable time?

8. Usage of the site: Statistics of the number of visits-hits per month

9. Accessibility of the site through the search engines: We used Google to see whether the partners' sites appear in high positions for the material they cover in their countries. We restricted our search only to URLs coming from the same country

10. Disclosure of Funding of the site: Is the site referring to all possible sources of funding?

11. Crude description of the content of the site

Most of these criteria have been selected by the well-known document developed by the Health Information Technology Institute of Mitretek Systems, a nonprofit organization

(<http://www.mitretek.org/hiti/showcase/documents/criteria.html>).

b) detailed evaluation of the Greek site:

We used the Discern instrument. The Discern project was funded by the British library and the NHS Research and Development program and aimed to develop an easy to use instrument that can be used by consumers to rate the quality of health related information published in a written form or through the internet. This

instrument has been used to rate the quality of information of various sites with health material in general and mental health material in particular. The full instrument is given in Appendix A.

As mentioned before we did not try to evaluate the scientific quality of the content according to the Evidence Based Medicine (EBM) criteria proposed for example by the Cochrane Collaboration. Although we believe that this information is crucial for the professional, it is not directed to the consumer. However, since the EBM approach is now spreading across the world, we will emphasize that production of new content should try when possible to meet the EBM criteria, without on the other hand become so technical that it is difficult for the public to judge for him or herself.

4.2 Description of the sites covered in this survey

We covered the following sites of the collaborating medical partners:

1. The site provided by the Greek medical partner, University of Ioannina with the URL: www.stress.gr
2. The site provided by the Italian medical partner, ABIT, with the URL: www.anoressia-bulimia.it
3. The site provided by the German medical partner, FH-NON, with the URL: www.adhs.ch/
4. The site provided by the Dutch medical partner, EMERGIS with the URL www.emergis.nl

4.3 Descriptive Evaluation

4.3.1 Domain: Source of the Site

Partner	Description
Greek Partner (www.stress.gr)	<p>It is very clear from the home page that Stress.gr is the collaborative effort of various nonprofit organizations across Greece to provide mental health information to the public.</p> <p>Authors appear at a special section of the site and doctors give brief details of their work both in private practice and public hospitals. However, not all articles state clearly the name of the principal author creating the impression that it is the collaborative result of all authors.</p> <p>Texts that have been translated by English sources usually state their original source and they all come from the public domain.</p>
Italian partner (www.anoressia-bulimia.it)	<p>It is very clear from the home page that the site has been developed by Drs Piccini and Bavestrello and their affiliations both with private and public institutions are given in the 'about' section.</p>
German Partner (www.adhs.ch)	<p>The first page of this site is more impersonal and is not easy to understand who developed the site. However, in the 'about' section it is very easy to understand that the site has been developed by one German psychiatrist working in a public institution (Dr Winkler) and a Swiss psychologist mainly working privately (Dr Rossi) who have a special scientific interest in ADHD.</p>
Dutch Partner (www.emergis.nl)	<p>It is very easy to understand from the home page that this the official site of EMERGIS organization which focuses on the diagnosis and treatment of mental disorders in the Netherlands.</p>

General comment: All partners appear to have a financial incentive in developing and maintaining their own site and none is being provided solely by public institutions.

4.3.2 Domain: Purpose of the Site

Partner	Description
Greek Partner (www.stress.gr)	Mission of the site in the home page and in more detail in the 'about' section.
Italian partner (www.anoressia-bulimia.it)	Mission is included in the home page.
German Partner (www.adhs.ch)	Mission is included in the home page.
Dutch Partner (www.emergis.nl)	Mission is included in the home page.

4.3.3 Domain: Mental Health or medical personnel Involved:

Partner	Description
Greek Partner (www.stress.gr)	Two psychiatrists, two general practitioners, one psychologist.
Italian partner (www.anoressia-bulimia.it)	Two psychologists.
German Partner (www.adhs.ch)	Two psychiatrists.
Dutch Partner (www.emergis.nl)	Collaborative effort of the whole organization.

4.3.4 Domain: Currency of the site

Partner	Description
Greek Partner (www.stress.gr)	No date shown in educational material. Dates shown for answers to users' questions.
Italian partner (www.anoressia-bulimia.it)	No dates shown for educational material.
German Partner (www.adhs.ch)	Dates of last revision shown for educational material.
Dutch Partner (www.emergis.nl)	No dates shown for educational material.

4.3.5 Domain: Logical Organization and presentation:

Partner	Description
Greek Partner (www.stress.gr)	Simple but effective format. Easy navigation through pages.
Italian partner (www.anoressia-bulimia.it)	Very attractive and easy presentation. Nice use of relaxed colors.
German Partner (www.adhs.ch)	Simple and easy navigation.
Dutch Partner (www.emergis.nl)	Looks professional but requires latest updates of browser, sometimes it gets stuck with older versions.

4.3.6 Domain: Internal Search Engine

Partner	Description
Greek Partner (www.stress.gr)	No internal search engine – no site map.
Italian partner (www.anoressia-bulimia.it)	Internal search engine and site map.
German Partner (www.adhs.ch)	Internal search engine.
Dutch Partner (www.emergis.nl)	Site map.

4.3.7 Domain: Interactivity of the site

Partner	Description
Greek Partner (www.stress.gr)	“Ask the experts section”. Promises to answer all e-mails within 48 hours.
Italian partner (www.anoressia-bulimia.it)	Presence of forums and online chats.
German Partner (www.adhs.ch)	Feedback form. Limited availability of “Ask the Experts” section
Dutch Partner (www.emergis.nl)	Feedback form.

4.3.8 Domain: Usage and external accessibility (Search in www.google.com*)

Partner	Description
Greek Partner (www.stress.gr)	Rank for depression: 2 nd Rank for OCD: 1 st Rank for Schizophrenia: 1 st Rank for Agoraphobia: 1 st Rank for Obesity: 1 st
Italian partner (www.anoressia-bulimia.it)	Rank for Anorexia nervosa: 1 st Rank for Bulimia: 5 th
German Partner (www.adhs.ch)	Rank for ADHD: 11 th
Dutch Partner (www.emergis.nl)	Rank for bipolar disorder: 22 nd Rank for depression >100

*Note: We searched for these terms in the local language in www.google.com and we report the rank of the partner's site for this specific term. For example we searched "katathlipsi" or "depressie" for depression in Greek or Dutch respectively.

4.3.9 Domain: Disclosure of funding

Partner	Description
Greek Partner (www.stress.gr)	Site refers to the sources of funding (a pharmaceutical company has funded the hosting of the site).
Italian partner (www.anoressia-bulimia.it)	Not mentioned.
German Partner (www.adhs.ch)	The site mentions that it is not related to any pharmaceutical companies.
Dutch Partner (www.emergis.nl)	Not mentioned.

4.3.10 Domain: Description of the content

Partner	Description
Greek Partner (www.stress.gr)	The site offers educational material for all the common mental disorders in simple language for the general public. Most of the material has been written either by the psychiatrists of the site or they have been translated from English. Although the authors do not state that their aim is to offer evidence-based material, the material is compatible with current evidence due to the main author's interests. The site offers also some introduction to psychotherapy with a particular focus on cognitive-behavioral methods. One of the most developed areas is the 'ask the expert section' with more than 150 e-mails indexed in the database of questions and answers that can be browsed.
Italian partner (www.anoressia-bulimia.it)	The site has a focus on eating disorders and offers good information on various aspects for diagnosis and treatment for the general public . It also gives the opportunity to the user to participate in online forums or chats with other users or experts.
German Partner (www.adhs.ch)	The site has a focus on ADHD and covers comprehensively various aspects of diagnosis and treatment. It does not offer an ask the expert section.
Dutch Partner (www.emergis.nl)	The site gives very basic descriptions of various mental disorders.

Summarizing, most of the sites cover common conditions, offer basic information on various aspects of diagnosis and treatment and are accessible through the general search engines, with some being at the top five of their area in their country. It is expected that people from these countries that use internet for health information will browse through the content offered or ask the experts for their problems.

4.4 Detailed Evaluation of the Greek site

We used the Discern criteria to evaluate in more detail the Greek Site. The full instrument is given at the Appendix. For the purposes of this evaluation we printed out a copy of the leaflet for depression without reference of the source and we gave this to one external reviewer to review it.

Discern Criteria	Score (1=lowest, 5=highest quality)
1. Have explicit aims	4
2. Achieve its aims	5
3. Be relevant to consumers	5
4. Make sources of information explicit	1
5. Make date of information explicit	1
6. Be balanced and unbiased	3
7. List additional sources of information	1
8. Refer to areas of uncertainty	4
9. Describe how treatment works	5
10. Describe the benefits of treatment	5
11. Describe the risks of treatment	2
12. Describe what would happen without treatment	5
13. Describe the effects of treatment	4

choices on overall quality of life	
14. Make it clear there may be more than one possible treatment choice	5
15. Provide support for shared decision-making	5
16. Overall quality of publication about treatment choices	3 (moderate quality)

Comment: The reviewer thought the leaflet was of good quality and he would recommend it to his patients because it was simple, comprehensive and accurate. However, he thought that the text should refer more explicitly to the sources (i.e. be more evidence-based) and also less biased towards some particular forms of psychotherapy. However, he was very happy to see that the text referred to many alternative treatment options, including the no-treatment option. He also commented on the lack of date of development or revision of the text, although he recognized that the text was still current.

5. Evaluation of external content

5.1 Methodology

With so many sites for mental health problems it would be impossible to evaluate and rate all the sites with relevant content. For this reason, we searched several web sites which aim to collect links of mental health content (“metasites”). These include lists of yahoo and other similar organizations. We then manually evaluated the sites included there. We classified this information according to the disorder covered. We rated the information on a very simple 5 point scale of overall quality. We present here only the sites with the very highest quality, i.e. those with ratings of 4 or 5. Only sites in English were evaluated.

5.2 Results

We visited more than 500 sites dealing with mental health problems and listed in metasites. Some of the sites with high quality are mentioned below:

5.2.1 Addiction Sites

- ❖ <http://www.well.com/user/woa/> : A site dedicated to addictions with very good coverage of all addictions.
- ❖ <http://www.habitsmart.com/> : An alternative to the AA step program with use of cognitive – behavioral techniques and much information on alcohol and addictions.
- ❖ <http://www.nida.nih.gov/> : The web site of the US National Institute of Drug Abuse

- ❖ <http://www.dare.uk.com> : The Drug Abuse Resistance Education (D.A.R.E.) UK. A Charity established to reduce drug, solvent and alcohol abuse and violence by teaching children the consequences and resistance skills.

5.2.2. Anxiety Disorders

- ❖ <http://www.algy.com/anxiety/> : The anxiety panic internet resource (tapir) : A comprehensive overview of anxiety and panic with lots of humor.
- ❖ <http://www.paems.com.au/> : Australian site with many awards.
- ❖ <http://www.ocfoundation.org/ocf1030a.htm> : Specifically for OCD
- ❖ <http://www.socialphobia.org/> : Specifically for Social phobia

5.2.3 Attention Deficit Hyperactivity Disorder

- ❖ <http://www.add.org> :The US national association for ADHD

5.2.4 Child development and parenting

- ❖ <http://www.abcparenting.com/> : Comprehensive Source for Great Parenting, Pregnancy and Childcare.
- ❖ <http://npin.org/> : The parent information network

5.2.5 Dementia / Alzheimer's Disease

- ❖ <http://www.alz.org> : The site of the US Alzheimer's Association
- ❖ <http://www.acsu.buffalo.edu/~drstall/hndbk0.html> : A comprehensive handbook for caregivers
- ❖ <http://www.alzheimers.org.uk/> : The Alzheimer's Society is the UK's leading care and research charity for people with any form of dementia and their carers.

5.2.6 Eating Disorders

- ❖ <http://www.anred.com/> : Dedicated to anorexia nervosa and related eating disorders.
- ❖ <http://www.nationaleatingdisorders.org/> : The home page of the US National Eating Disorders Association.
- ❖ <http://www.edauk.com/> : The UK eating disorders association.

5.2.7 Mood Disorders

- ❖ <http://www.wingofmadness.com/> : Comprehensive Depression Guide
- ❖ <http://www.depressionalliance.org/> : Comprehensive depression guide
- ❖ <http://www.psycom.net/depression.central.html> : Idiosyncratic but plenty of information for all mood disorders
- ❖ <http://www.frii.com/~parrot/bip.html> : A sufferer's excellent page on bipolar disorder
- ❖ <http://www.pendulum.org/index.html> : Comprehensive coverage of bipolar disorder
- ❖ <http://www.metanoia.org/suicide/index.html> : if you are thinking of suicide...read this first

5.2.8 Schizophrenia

- ❖ <http://www.schizophrenia.com/> : Comprehensive web page.
- ❖ <http://www.nsf.org.uk/> : The UK national schizophrenia fellowship.
- ❖ <http://www.mentalhealth.com/book/p40-sc01.html> : From Internet Mental Health a handbook for families.

- ❖ <http://www.openthedoors.com/> : The Open the Doors projects of the WHO in several languages.

5.2.9 Sexuality / Sexual Disorders

- ❖ <http://www.priory.com/sex.htm> : A brief description of Sexual disorders.
- ❖ <http://www.puberty101.com/> : Excellent site on puberty and sexuality.

5.2.10. Stress Management

- ❖ <http://www.guidetopsychology.com/pmr.htm> : Progressive Muscle Relaxation, a brief guide.

5.2.11 Marriage – Divorce

- ❖ <http://www.positive-way.com/relation.htm> : For couples that want to improve their relationships.
- ❖ <http://www.divorcesupport.com/> : Comprehensive information for divorce on the internet.
- ❖ <http://muextension.missouri.edu/explorepdf/hesguide/humanrel/gh6600.pdf> : Helping children understand divorce.

5.2.12 Metasites

Lists of Mental Health Resources

- ❖ <http://www.dr-bob.org/mental.html> : Mental Health Links by Dr Bob, the first and still the best.
- ❖ <http://www.mentalhealth.com/> : Another comprehensive metasite of mental health links.

❖ <http://psychcentral.com/> : From 1992.

5.2.13 Two general sites for high quality leaflets on all mental health problems

❖ <http://www.rcpsych.ac.uk/info/index.htm> : The leaflets offered by the Royal College of Psychiatrists in the UK.

❖ <http://www.nimh.nih.gov/publicat/index.cfm> : The leaflets offered by the US National Institute of Mental Health

6. Conclusions and Recommendations

6.1 The medical partners have already developed content of accepted quality that can be used directly by the KOM2002 project in the original language.

6.2 It is recommended that all medical partners collaborate to select their own content of the highest quality to translate to English, in order to be used by the main web site of the project. Since, some of the sites are focused in specific disorders, this procedure should be easy and should not create conflicts between medical partners.

6.3 Evaluation of existing content and/or new content should be based in reliable instruments such as the Discern instrument.

6.4 External content should be reviewed by medical partners and efforts should be made to select particular high quality leaflets that meet the criteria and interests of KOM2002. Permission to modify or use these texts might be preferred than writing our own texts. We should however write new text if the quality standards are not met or if material is copyrighted.

6.5 It is recommended that a systematic review of the content provided on the web for various common mental disorders could be valuable and could support the aims of the project. Although this is not a requirement from the contract, we suggest that this review would facilitate our own work. The possibility that the partners could jointly fund such a review should be discussed during the next meeting in January 2003.

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APPENDIX

The discern Instrument (www.discern.org.uk)

All questions are rated on a five point scale from 1 indicating low quality to 5 indicating high quality

SECTION 1. Is the publication reliable?

1. Are the aims clear?
2. Does it achieve its aims?
3. Is it relevant?
4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?
5. Is it clear when the information used or reported in the publication was produced?
6. Is it balanced and unbiased?
7. Does it provide details of additional sources of support and information?
8. Does it refer to areas of uncertainty?

SECTION 2. How good is the quality of information on treatment choices?

9. Does it describe how each treatment works?
10. Does it describe the benefits of each treatment?
11. Does it describe the risks of each treatment?
12. Does it describe what would happen if no treatment is used?

13. Does it describe how the treatment choices affect overall quality of life?

14. Is it clear that there may be more than one possible treatment choice?

15. Does it provide support for shared decision-making?

SECTION 3. Overall Rating of the Publication

16. Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices

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