

Im Blickpunkt

Does WIKIPEDIA provide evidence based health care information? A content analysis

Ingrid Mühlhauser*, Friederike Oser

Unit of Health Sciences and Education, University Hamburg, Germany

Summary

Patients and consumers are increasingly searching the Internet for medical and healthcare information. Using the criteria of evidence-based medicine the present study analyses the websites of Wikipedia and two major German statutory health insurances for content and presentation of patient information. 22 senior students of health sciences and education evaluated one topic each. In a first step, they identified the evidence for their specific question. Afterwards they used their results as reference for the evaluation of the three websites. Using a check list each student and a second researcher independently rated content and presentation of the information offered. All these websites failed to meet relevant criteria, and key information such as the presentation of probabilities of success on patient-

relevant outcomes, probabilities of unwanted effects, and unbiased risk communication was missing. On average items related to the objectives of interventions, the natural course of disease and treatment options were only rated as "partially fulfilled." Overall, there were only minor differences between the three providers, except for items related to the specific nature of the web sites such as disclosure of authorship, conflict of interest and support offers. In addition, the Wikipedia information tended to achieve lower comprehensibility. In conclusion, the quality of the healthcare information provided by Wikipedia and two major German statutory health insurances is comparable. They do not meet important criteria of evidence-based patient and consumer information though.

Key words: evidence-based medicine, health education, health insurance, Internet, risk communication, Wikipedia, encyclopaedias

Sind medizinische und Gesundheitsinformationen auf den Internetseiten von Wikipedia evidenzbasiert? – Eine Inhaltsanalyse

Zusammenfassung

Das Internet wird zunehmend zur Suche von medizinischen Informationen genutzt. In der vorliegenden Studie wurden die Internetseiten von Wikipedia und 2 großen deutschen gesetzlichen Krankenkassen nach Kriterien für evidenzbasierte Patienteninformationen in Bezug auf Inhalt und Präsentation analysiert. 22 Studierende der Gesundheitswissenschaften wählten je eine Fragestellung und erarbeiteten hierzu die wissenschaftliche Beweislage. Die Ergebnisse dienen als Referenz zur Bewertung der dazugehörigen Informationen auf den 3 Internetportalen. Die Bewertung

erfolgte anhand eines Kriterienkatalogs von dem oder der jeweiligen Studierenden und unabhängig davon von einer weiteren Wissenschaftlerin. Insgesamt wurden von allen 3 Anbietern wichtige Kriterien für evidenzbasierte Patienteninformationen nicht erfüllt, wie die Kommunikation von Wahrscheinlichkeiten für Erfolg, Misserfolg und Nebenwirkungen von Interventionen in Bezug auf patientenrelevante Ergebnisparameter sowie die Darstellung von Risiken. Angaben zum Ziel der Interventionen, dem natürlichen Verlauf der Erkrankung oder Interventionsmöglichkeiten

*There is also a German version of this paper. When citing this paper please refer to the German version: Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen 102 (2008) pp. 441–448, doi:10.1016/j.zefq.2008.06.019.

*Corresponding author: Univ.-Prof. Dr. med. Ingrid Mühlhauser, Universität Hamburg, MIN Fakultät, Gesundheitswissenschaften, Martin-Luther-King Platz 6, D-20146 Hamburg. Tel.: 0049 (0)40 42838 3988; fax: 0049 (0)40 42838 3732. <http://www.chemie.uni-hamburg.de/igtw/Gesundheit/gesundheit.htm>, <http://www.gesundheit.uni-hamburg.de/>
E-Mail: Ingrid_Muehlhauser@uni-hamburg.de (I. Mühlhauser).

wurden im Durchschnitt nur als teilweise erfüllt bewertet. Insgesamt waren die Qualitätsunterschiede zwischen den 3 Anbietern gering mit Ausnahme jener Aspekte, die auf die spezifische Charakteristik der Anbieter zurückzuführen ist, wie Autorennennung, Angaben zu Interessenkonflikten und Unterstützungsangeboten. Die Informationen in

Wikipedia wurden zudem in der Tendenz als weniger gut verständlich bewertet. Zusammenfassend ist die Qualität der Informationen zwischen Wikipedia und 2 großen deutschen Krankenkassen vergleichbar, wobei aber wichtige Kriterien für evidenzbasierte Patienteninformationen von keinem der Anbieter erfüllt werden.

Schlüsselwörter: Evidenzbasierte Medizin, Patienteninformation, Internet, Krankenkassen, Risikokommunikation, Wikipedia

Introduction

Patients and consumers increasingly want to participate in medical decision making [1,2]. This requires unbiased, evidence-based, comprehensive and understandable information [3,4]. In Germany, patients still use physicians and statutory health care insurances as primary sources for medical information although the internet is becoming more and more popular.

Worldwide, one of the most frequently used Web sites is the freely accessible encyclopaedia Wikipedia which also contains health related information [5]. However, the quality of the medical information in Wikipedia could be questioned for various reasons. Anyone can edit articles in Wikipedia irrespective of professional expertise, authors remain unknown and contributions can be changed anonymously by any others. Thus, the information provided could be wrong, incomplete and biased.

Recently, experts rated 42 nature science contributions in Wikipedia and the Encyclopaedia Britanica. „On average, an article in Wikipedia had four inaccuracies and in the Britanica three,“ [6]. Overall, differences were minor. However, little is known about the quality of health information in Wikipedia according to criteria of evidence based medicine (EBM). EBM has become the standard procedure for the best use of available evidence in the care of individual patients and public health issues [7]. A search in the medical database PubMed in March 2008 identified only 74 articles related to Wikipedia and none that studied the quality of the medical information according to EBM.

We conducted a descriptive study to characterize the medical and health information on the Web sites of Wiki-

pedia and major German statutory health insurances according to criteria of evidence based medicine related to patient information.

Methods

Participants

Participants were 22 senior students of Health Sciences and Education at the University Hamburg, Germany. During the summer term 2007 they took part in a seminar led by the first author (I.M.) on the quality of information provided on Web sites of Wikipedia and health insurances. All participants had passed exams on basic statistics, the methodology of EBM, and were familiar with the concepts of evidence based patient and consumer information as well as informed and shared decision making [3,7].

The goal of the seminar was to evaluate the health care information offered on the Web sites of the German Wikipedia and three of the largest German statutory health insurances: 1) Allgemeine Ortskrankenkasse (AOK) with about 25 Mio. members [8] 2) Techniker Krankenkasse (TK) with about 6 Mio. members [9] 3) Betriebskrankenkassen (BKK) with about 14 Mio. members [10]. The German Wikipedia is the second largest section after the English version with about 700.000 articles in March 2008 [5].

Each seminar participant was asked to select one controversial topic of personal or professional interest. Following the methodology of EBM [7] they had to compile the evidence for their specific study question. This means to formulate a question that can be answered, to search databases for relevant publications such as Medline and Cochrane, to critically appraise the articles and to apply the information to

answer the question. Students presented their results stepwise during the seminar, procedures were critically discussed and results revised. Using this evidence as reference, each participant was asked to evaluate the information related to his or her personal question on the four Web sites using a check list. All relevant information was screened. In case no information was available for the specific question general information related to the topic was searched and analysed. For Wikipedia the German language version was evaluated except for one topic where an English language article was used since a German contribution could not be identified.

The check list

The check list reviewed the content and the presentation of the information as well as meta-information. The check list was based on a previous review of criteria for evidence based patient information [11]. Similar instruments or parts of it have been used previously on various health issues [12–17].

The underlying philosophy has initially been defined in 1998 by the British General Medical Council in the ‘Ethical Guidelines for Seeking Patients’ Consent’ [4] and has been extended and redefined following further evidence [11–17]. It constitutes that patients have the right to be fully informed before diagnostic, therapeutic, preventive and screening procedures to allow informed and shared decision making. This includes evidence-based and unbiased information about all options including to refrain from intervention. Information on patient oriented outcomes must be provided about probabilities of success, risk of failure, and risk of harm for the various options. In case of diagnostic interventions

information on the likelihood of false positive and negative test results has to be presented. In addition, medical, social and financial consequences, follow-up plans, counselling and support services should be discussed. The information must be understandable. Conflicts of interest by the health care providers should be stated. There should be sufficient time for decision making, and the information must not be withheld because of the possibility that the suggested intervention might be refused. This philosophy has been widely accepted. For example, the European guidelines for quality assurance in breast cancer screening and diagnosis, edited in 2006 by the European Commission, state the following: "Screening usually involves a healthy and asymptomatic population which requires adequate information presented in an appropriate and unbiased manner in order to allow a fully informed choice as to whether to attend. Information provided must be balanced, honest, adequate, truthful, evidence-based, accessible, respectful and tailored to individual needs where possible." [18].

With respect to risk information a large body of evidence is available to define criteria for understandable and unbiased presentation of medical outcomes [19,20]. This includes the use of natural frequencies rather than relative risk reductions and reference populations of comparable size [19,20].

The check list was slightly adapted and consented by all seminar participants. The final check list targeted 11 areas and consisted of 47 items. Ratings included 5 possible categories: 1) correct or criterion fulfilled; 2) wrong or criterion not fulfilled; 3) incomplete or criterion partially fulfilled; 4) missing; 5) not relevant.

Analysis

Each student provided a written document on his or her specific topic. At the end of the seminar one of the students and co-author of this manuscript (F.O.) independently re-evaluated and updated all Web sites on all topics in November/December 2007. In case of

disagreement with the original ratings consensus was sought together with the student who had originally worked on the respective topic. Only descriptive data are presented.

Results

The 22 questions were related to the following medical or health issues: Achilles tendon rupture, depression, endometriosis, first trimester screening, therapeutic fasting, hallux valgus, heroin substitution, HIV-structured treatment interruption (HIV-STI), testicular cancer, hearing loss, hypoplastic left heart syndrome, headache, myopia, malaria, food allergy, neurodermitis, Parkinson, PSA screening, motion sickness, sudden infant death syndrome (SIDS), leg varicose, preventive extraction of third molars. Table 1 displays the 22 topics with the related individual questions and results on whether information was found on the 4 Web sites. Specific information was provided for 10 (AOK), 14 (TK) and 19 (WIKI) of the 22 topics, and general information was identified for 9 (AOK), 7 (TK), and 2 (WIKI) of the remaining topics, respectively. The BKK did not offer any medical information for patients on their freely accessible main Web site and is therefore excluded from further reporting.

Table 2 provides detailed information on ratings of the quality criteria for all individual topics and Web sites. Only exceptionally was the provided information rated as wrong. However, information was lacking for many important aspects or important criteria were not fulfilled. This is particularly true for the key elements of evidence based patient information such as the communication of probabilities of success and of unwanted effects, evidence based risk communication on patient relevant outcomes, and statements of conflicts of interest. Partly fulfilled were criteria on the goal of interventions, options, the natural course of the disease and the provision of links or further information sources. Overall differences between the 3 providers were minor except for items that related to the specific and unique nature of the Web

sites such as authorship, statements about conflicts of interest, and offers for counselling and support for decision making. In addition, information on Wikipedia tended to be more frequently rated as of low comprehensibility (Table 2). Table 3 summarizes ratings across topics and criteria categories.

Discussion

This is the first study that reports on the quality of health information provided by Wikipedia according to evidence based medicine. The study shows that the quality of information is comparable between Wikipedia and two major statutory health insurances. However, all three providers do not fulfill important criteria for evidence based patient information.

Analysis targeted both, content and presentation of the information. Best available evidence was used as reference. Only in few cases was the information rated to be wrong. However, important information was missing. In this respect, most relevant quality criteria of evidence based medicine and evidence based patient information are disregarded.

The lack of high quality patient and consumer information is a well recognized general problem [13–17,19,20]. It is not restricted to Wikipedia or health insurances. Patient information is often paternalistic, persuasive, incomplete, misleading and biased if provided by medical associations or health insurances [13–17,19,20]. Only few institutions develop and provide evidence based patient information such as the German Institute for Quality and Efficiency in Health Care [21]. User tools for the evaluation of health information on the Internet such as HON or DISCERN do not even consider rating of the evidence of the medical content or criteria for the presentation of risk information [22].

The study has some limitations: 1) Although students had been trained in EBM and results were critically appraised and revised during the seminar minor errors in the work-up of the 22 medical topics cannot be excluded.

Table 1. Individual questions, related health topics, and availability of information on the websites of three health insurances and Wikipedia.

Individual question	Health topic	Information available for the specific question				Only general information available on related health topic				No information on study question or related health topic available			
		AOK	BKK	TK	WIKI	AOK	BKK	TK	WIKI	AOK	BKK	TK	WIKI
What is the better treatment for rupture of the Achilles tendon – surgical or conservative – with respect to long-term success and side effects?	Achilles tendon rupture			x	x					x	x		
Does initiation of treatment with a serotonin-reuptake-inhibitor in a depressive phase increase the risk of suicide in depressive patients older than 20 years?	Depression	x		x	x						x		
Does treatment with Gestagens compared to GnRH-analogs in patients with endometriosis improve quality of life?	Endometriosis	x		x	x						x		
How accurate are first trimester screening tests for Down syndrome in women between 10th and 14th gestational weeks?	First trimester screening			x	x	x					x		
Does therapeutic fasting reduce joint swelling in patients with rheumatoid arthritis?	Therapeutic fasting				x	x		x			x		
Does surgery prevent further deterioration and reduce pain in patients who severely suffer from Hallux valgus?	Hallux valgus	x		x	x						x		
Is substitution with heroin superior to substitution with methadone with respect to mortality and health status in heroin dependent patients?	Heroin -substitution				x	x		x			x		
Is early initiation of antiretroviral therapy (ART) combined with structured treatment interruptions superior to continuous treatment with respect to side effects and duration of effectiveness?	HIV- structured treatment interruption (HIV-STI)				x	x		x			x		
What is the prognosis of watchful waiting for stage 1 carcinoma of the testis compared to chemotherapy or radiotherapy?	Testicular cancer				x	x		x			x		
Is cortisone therapy in acute hearing loss evidence based standard therapy?	Hearing loss	x		x	x						x		
Does improvement of surgical procedures for newborns suffering from hypoplastic left heart syndrome justify general recommendation of this surgical intervention?	Hypoplastic left heart syndrome (HLHS)				x					x	x	x	
Does a self-administered diagnostic headache test as offered at the websites of two German health insurances allow a valid diagnosis of headache?	Headache diagnostic test				x					x	x		x
Does laser therapy in patients with myopia (LASIK) compared to no surgical intervention render correction of visual sight by glasses or contact lenses unnecessary?	Laser therapy for Myopia	x		x	x						x		
What interventions work to prevent Malaria in non-immune travellers to Africa?	Malaria	x		x	x						x		
Does breast feeding prevent neurodermitis in infants?	Brest feeding and neurodermitis	x		x					x		x		
Does feeding of newborns with increased risk of atopia with hydrolysed food compared to usual nutrition (cow milk) prevent food allergy?	Food allergy			x	x	x					x		
How effective is monotherapy with transdermal Rotigotin in persons with idiopathic early stage Parkinson disease in reducing the leading symptoms and maintaining autonomy and activities of daily living?	Parkinson				x	x		x			x		
Does PSA screening in men aged 50 years or older, with genetic disposition reduce prostate cancer mortality?	PSA screening	x		x	x						x		
Can self-administered acupressure prevent motion sickness?	Motion sickness					x		x	x		x		
Does bed sharing (parents sleep together with newborns in one bed) increase the risk of sudden infant death?	Sudden infant death syndrome (SIDS)				x	x		x			x	x	
Is risk of recurrence higher after vein stripping compared to cauterisation in patients with primary varicose?	Leg varicose	x		x	x						x		
What is the risk of extracting healthy third molars?	Third molars	x		x	x						x		
Total	22 topics	10	0	14	19	9	0	7	2	3	22	1	1

AOK, BKK, TK health insurances; WIKI Wikipedia.

Table 2. Ratings of the quality of medical information of 22 health topics on websites of health insurances (AOK, TKK) and Wikipedia.

Quality criteria	Ratings														
	AOK (19 topics)					TK (21 topics)					Wikipedia (21 topics)				
	A	B	C	D	E	A	B	C	D	E	A	B	C	D	E
Criteria group I: Content of information															
Goal of intervention	10	1	2	6	0	14	1	1	5	0	14	0	5	2	0
Prognosis without intervention	6	0	6	7	0	7	0	5	9	0	5	0	4	12	0
Options including not to intervene with data on patient relevant outcomes	4	0	9	5	1	6	0	10	4	1	5	0	10	5	1
Probabilities of success, failure, side effects (therapeutic, preventive, screening interventions)	0	0	6	13	0	1	0	11	9	0	1	1	6	13	0
Probabilities of false positive and false negative results (diagnostic interventions)	0	0	2	2	15	0	0	2	3	16	0	1	1	2	17
Consequences of intervention (medical, psychosocial or financial)	2	0	3	14	0	1	0	6	14	0	2	1	4	14	0
Follow-up plans	1	0	3	15	0	3	0	2	16	0	2	1	0	18	0
Counselling and support for decision making ^{a,b}	0	0	19	0	0	21	0	0	0	0	5	0	3	13	0
Comprehensibility	14	5	0	0	0	18	3	0	0	0	10	11	0	0	0
Controversy	1	1	1	16	0	1	0	2	18	0	4	0	5	12	0
Metainformation															
Authorship	0	0	19	0	0	15	0	1	5	0	0	0	21	0	0
Sponsorship ^c	0	0	0	19	0	21	0	0	0	0	0	0	0	21	0
Financial disclosures ^d	0	0	0	19	0	21	0	0	0	0	0	0	0	21	0
Sources, references	7	0	7	5	0	11	0	5	5	0	7	1	11	2	0
Up-to-datedness	2	12	0	5	0	7	6	1	7	0	6	11	4	0	0
Links, further information sources	6	0	4	9	0	1	0	0	20	0	10	0	7	4	0
Additional support, self-help groups	19	0	0	0	0	2	0	0	19	0	6	0	2	13	0
Criteria group II: Reporting the strength of evidence															
Patient relevant outcomes															
– Mortality	0	0	0	9	10	0	0	1	8	12	0	0	1	9	11
– Morbidity	0	0	1	17	1	0	0	1	19	1	0	0	1	19	1
– Quality of life	0	0	3	16	0	0	0	5	16	0	0	0	3	18	0
– Effects	2	0	3	14	0	2	0	6	13	0	1	0	7	13	0
– Side effects	4	0	2	13	0	1	0	8	12	0	2	1	6	12	0
– Side effects	1	1	1	16	0	2	0	1	18	0	3	1	1	16	0
Criteria group III: Reporting lack of evidence															
Criteria group IV: Presentation of results															
General aspects															
– Natural frequencies	1	0	1	17	0	1	0	1	19	0	0	0	2	19	0
– Comparability of proportions	1	0	0	18	0	1	0	0	20	0	0	0	0	21	0
– Use of reference populations	3	0	1	15	0	2	0	1	18	0	1	0	1	19	0
Risks															
– Lifetime risk	2	2	2	13	0	1	0	4	16	0	0	2	3	13	3
– Risk according to age groups	0	0	4	15	0	0	0	6	15	0	1	1	5	11	3
– Persons without events	0	0	0	18	1	0	0	1	19	1	0	0	1	17	3
– Risks compared to other risks	0	0	0	19	0	0	0	0	21	0	0	0	0	19	2
Effects															
– Absolute risk reduction (ARR)	0	0	0	19	0	0	0	0	21	0	0	0	0	21	0
– Relative risk reduction (RRR)	0	0	0	19	0	0	0	0	21	0	0	0	0	21	0
– Number needed to treat (NNT)	0	0	0	19	0	0	0	0	21	0	0	0	0	21	0
– Number needed to harm (NNH)	0	0	0	19	0	0	0	0	21	0	0	0	0	21	0
– Uncertainty of effects	1	0	0	18	0	0	0	0	21	0	2	0	0	19	0
– Lack of benefit	1	0	1	17	0	2	0	2	17	0	1	0	4	16	0
– Change in proportion of subjects without event	0	0	0	19	0	0	0	0	21	0	0	0	1	20	0
– Average change in life expectancy	0	0	0	7	12	0	0	0	7	14	0	0	1	7	13
– Average change in life expectancy	0	0	0	19	0	0	0	0	21	0	0	0	0	21	0
Criterion V: numerical and graphical presentation of outcomes	0	0	0	19	0	0	0	0	21	0	0	0	0	21	0
Criterion VI: in addition to text also pictures or graphs	0	0	0	19	0	0	0	0	21	0	0	0	0	21	0
Criterion VII: comparative presentation of benefit and risks	0	0	0	19	0	0	0	0	21	0	0	0	0	21	0
Criterion VIII: consideration of cultural aspects															
– Various languages ^e	19	0	0	0	0	0	0	0	21	0	18	0	0	3	0
Criterion IX: Layout															
Clarity															
– Table of contents	3	0	0	16	0	11	0	1	9	0	19	0	0	2	0
– Headings, subheadings	19	0	0	0	0	21	0	0	0	0	21	0	0	0	0
– Legends to pictures and graphs	0	0	0	0	19	1	0	0	0	20	4	0	7	2	8
Criterion X: Language															
Non-paternalistic language supportive of informed and shared decision making	3	0	10	6	0	4	0	3	14	0	3	0	10	8	0
Criterion XI: Involvement of patients															
Feedback possible	19	0	0	0	0	21	0	0	0	0	21	0	0	0	0

A = Correct or criterion fulfilled; B = Wrong or criterion not fulfilled; C = Incomplete or criterion partially fulfilled; D = Missing; E = Not applicable.

^aFor AOK rated as partially fulfilled for all topics as there is free telephone hotline counselling for all AOK members.

^bFor TK rated as fulfilled for all topics as there is free telephone counselling for members and non-members.

^cFor TK rated as fulfilled (For further information: http://www.tk-online.de/centaurus/generator/tk-online.de/s10_nutzungsbedingungen/nutzungs_teilnahme_bedingungen/01_nutzungsbedingungen/06_medizinische_inhalte/medizinische_inhalte.html, accessed on 10.12.2007).

^dFor AOK rated as fulfilled (For further information: http://www.aok.de/bund/tools/ges_wissen/verbraucherschutz/selbsthilfe.php (accessed on 25.11.2007).

^eFor AOK rated as fulfilled as all information is available in German and English.

Table 3. Ratings of criteria for evidence based patient information of 22 health topics of two health insurances (AOK, TKK) and Wikipedia.

Ratings of quality criteria	AOK (19 topics, 893 items)*	TK (21 topics, 987 items)*	Wikipedia (21 topics, 987 items)*
Correct/fulfilled	151 (17%)	220 (22%)	174 (18%)
Wrong/not fulfilled	21 (2%)	10 (1%)	32 (3%)
Incomplete/partially fulfilled	110 (12%)	89 (9%)	137 (14%)
Missing	552 (62%)	605 (62%)	582 (59%)
Not applicable	59 (7%)	63 (6%)	62 (6%)

*47 items per health topic.

2) Since each participant was free to choose one topic it cannot be excluded that students screened Web sites before they decided on a particular study question. Hence we refrained from quantitative comparisons between Wikipedia and health insurances. 3) Although 22 topics have been analysed this is still a small number and may not be sufficiently representative for the overall quality of information offered by the investigated providers. 4) Since an update was performed some months after the initial evaluation calculation of kappa statistics for ratings was not performed. 5) With the exception of one topic only the German Wikipedia was evaluated. It may be that the English or other language versions are of higher quality. 6) Direct comparison of the 3 providers is limited by partly differing topics evaluated.

Further limitations relate to the check list: 1) Although most criteria are supported by evidence [11,12] and some by strong evidence such as the use of natural frequencies instead of relative risk reductions [19,20] some remain controversial such as grading of the evidence [23] or the need for the presentation of links or further information sources [12]. Although similar criteria have been used previously by others [12–17] further validation of the check list is necessary. 2) Some items might have been rated too high such as the comprehensibility of the text as university students evaluated the information, and consideration of cultural aspects is clearly not restricted to the offer of translations. 3) Assessment of Web sites by study participants was not blinded.

Conclusions

Neither Wikipedia nor major statutory health insurances provide medical information that sufficiently fulfils internationally agreed criteria for evidence based patient or consumer information. However, the quality of information was comparable between Wikipedia and health insurances. Differences were mainly due to the specific policy of the providers such as unknown authorship in Wikipedia.

Providers of medical or health related information for patients or the public are urgently asked to follow internationally agreed standards of evidence based medicine for the development and communication of information.

Acknowledgements

We thank all students for participation: Kathie Brügge, Kathrin Dehning, Melanie Filz, Petra Gutzeit, Adriane Hollenbeck, Andreas Kolbinger, Kay Krause, Melanie Marek, Nina Marx, Kathrin Pröpsting, Katrin Reckhaus, Nicole Reil, Charlotte Richter, Maren Schade, Susanne Schubert, Nina Strelow, Sandra Thieme, Sandra Trapp, Annika Vorwig, Maike Wegner, Christina Wiegand.

Financial support: none

Interest of conflict: none

References

[1] Hamann J, Neuner B, Kasper J, et al. Participation preferences of patients with acute and chronic conditions. *Health Expectations* 2007;10:358–63.

- [2] Sawicki PT. Qualität der Gesundheitsversorgung in Deutschland – Ein randomisierter Sechs-Länder-Vergleich aus Patientensicht. *Med Klin* 2005;100(11):755–68.
- [3] Entwistle VA, Sheldon TA, Sowden AJ, Watt IS. Supporting consumer involvement in decision making: what constitutes quality in consumer health information? *Internat J Quality in Health Care* 1996;8:425–37.
- [4] General Medical Council: Protecting patients, guiding doctors. Seeking patients' consent: the ethical considerations. 1998. <http://www.gmc-uk.org/guidance/current/library/consent>; accessed on 12.02.2008.
- [5] Wikipedia: <http://de.wikipedia.org/wiki/Wikipedia>; accessed on 12.02.2008.
- [6] Giles J. Internet encyclopaedias go head to head. *Nature* 2005;438:900–1.
- [7] Straus SE, Richardson WS, Glasziou P, Haynes RB. Evidence-based medicine: how to practice and teach EBM. 3rd ed. Elsevier Churchill Livingstone: 2005.
- [8] Bundesverband der Allgemeinen Ortskrankenkasse. <http://www.aok.de/bundesweit/>; accessed 09.02.2008.
- [9] Technikerkrankenkasse. <http://www.tk-online.de>; accessed 12.02.2008.
- [10] Bundesverband der Betriebskrankenkassen. <http://www.bkk.de/> accessed 09.02.2008.
- [11] Steckelberg A, Berger B, Köpke S, Heesen C, Mühlhauser I. Kriterien für evidenzbasierte Patienteninformationen. [Criteria for evidence-based patient information]. *Z Arztl Fortbild Qualitätssich* 2005;99:343–51.
- [12] Trevena LJ, Davey HM, Barratt A, Butow P, Caldwell P. A systematic review on communicating with patients about evidence. *J Eval Clin Pract* 2006;12(1):13–23.
- [13] Steckelberg A, Balgenorth A, Mühlhauser I. Analyse von deutschsprachigen Verbraucher-Informationsbroschüren zum Screening auf kolorektales Karzinom [Analysis of German consumer information brochures about screening of colorectal cancer]. *Z Arztl Fortbild Qualitätssich* 2001;95:535–8.
- [14] Jorgensen KJ, Gotzsche PC. Presentation on websites of possible benefits and harms from screening for breast cancer: cross

- sectional study. *BMJ* 2004;328:148 (online version).
- [15] Coulter A, Ellins J, Swain D, Clarke A, Heron P, Rasul F, et al. Assessing the quality of information to support people in making decisions about their health and healthcare. Picker Institute Europe; Oxford: 2006.
- [16] Feldman-Stewart D, Brennenstuhl S, McIsaac K, Austoker J, Charvet A, Hewitson P, et al. A systematic review of information in decision aids. *Health Expectations* 2006; 10:46–51.
- [17] Meyer G, Steckelberg A, Mühlhauser I. Analysis of consumer information brochures on osteoporosis prevention and treatment. *GMS Ger Med Sci* 2007;5:9 pages (online).
- [18] European guidelines for quality assurance in breast cancer screening and diagnosis. Fourth Edition, European Communities, 2006.
- [19] Edwards A, Elwyn G, Covey J, Matthews E, Pill R. Presenting risk information – a review of the effects of “framing” and other manipulation on patient outcomes. *J Health Commun* 2001;6:61–82.
- [20] Hoffrage U, Lindsey S, Hertwig R, Gigerenzer G. Communicating statistical information. *Science* 2000;290:2261–2.
- [21] Institute for Quality Assurance and Efficiency in Health Care. www.iqwig.de; accessed 30.03.08.
- [22] Köpke S, Berger B, Steckelberg A, Meyer G. In Deutschland gebräuchliche Bewertungsinstrumente für Patienteninformatio- nen – eine kritische Analyse [Evaluation tools for patient information commonly used in Germany – A critical analysis]. *Z Arztl Fortbild Qualitatssich* 2005;99:353–7.
- [23] Schünemann HJ, Best D, Vist GE, Oxman AD. Letters, numbers, symbols and words: How to communicate grades of evidence and recommendations. *CMAJ* 2003; 169(7):677–80.