available at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejconline.com

Information about cancer clinical trials: An analysis of Internet resources

Craig P. Carden[a,*], *Michael Jefford*[b,c,d], *Mark A. Rosenthal*[a]

[a]*Department of Clinical Haematology and Medical Oncology, Royal Melbourne Hospital, Parkville, Victoria, Australia*
[b]*Department of Haematology and Medical Oncology, Peter MacCallum Cancer Centre, St Andrews Place, Melbourne, Australia*
[c]*Cancer Information and Support Service, The Cancer Council Victoria, Australia*
[d]*Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Australia*

ARTICLE INFO

Article history:
Received 28 March 2007
Accepted 12 April 2007
Available online 1 June 2007

Keywords:
Internet
Clinical trials
Patient
Information
Cancer

ABSTRACT

Purpose: Clinical trials are critical to improving patient outcomes, but participation in cancer clinical trials is low. Patient understanding of clinical trial process is also limited. Patients are increasingly using the Internet as a source of information. It is critical that such Internet-based information is relevant, current, balanced, and easy to access and navigate. We critically reviewed seven international online resources that provide information for patients/consumers regarding cancer clinical trials.

Methods: Seven international websites from North America, Europe and Australia were selected based on profile/usage. Sites were evaluated with respect to their content, readability and appropriateness using a suite of standard assessment tools.

Results: No sites performed well in terms of all assessment criteria. There was substantial variation between sites regarding information provided, content, design and readability. All sites required high literacy levels and assessment using the Standard Assessment of Means tool showed consistent deficiencies.

Conclusion: Although there are numerous websites providing information about cancer clinical trials to patients/consumers, all evaluated sites have several shortcomings. Attention to the content of information, its presentation and the design of Internet resources has an ethical imperative, and is likely to lead to improved patient satisfaction.

1. Introduction

Access to clinical trials is a crucial element of cancer patient care. As a corollary, patient access to information regarding clinical trials is essential. This information should inform the patient about the nature of clinical trials, ethical considerations, and should consider the potential risks and benefits of trial participation.[1,2]

Patients may have difficulty in understanding the process of clinical trials and may refuse to participate for a variety of reasons. Studies have identified lack of adequate understanding, concerns about randomisation, inconvenience, possible risks and lack of family support as contributing to refusal to participate.[3] Estimates of patient refusal to clinical trial participation range between 40% and 90%.[4,5] Participation in clinical trials is as low as 2% of all patients with cancer, with many patients unaware that participation in a clinical trial was an option.[4,5]

Patients seek information regarding clinical trials from a variety of sources including from medical and nursing staff, fellow patients and family. Increasingly, patients are using the Internet as a source of information.[6–8] The proportion

* *Corresponding author:* Tel.: +61 3 9342 7560; fax: + 61 3 9347 7508.
E-mail address: craig.carden@mh.org.au (C.P. Carden).
0959-8049/$ - see front matter
doi:10.1016/j.ejca.2007.04.016

of patients with cancer who use the Internet for information ranges from 9% to 50%, and appears to be related to education and location of residence/treatment.[8] There is also evidence that the proportion of non-university educated users accessing health information on the Internet is increasing.[9]

We were interested in examining information regarding clinical trials provided on a variety of prominent websites. In particular, we aimed to assess each of the websites according to prespecified criteria including information content, readability and form. This report summarises our findings.

2. Methods

2.1. Websites

We chose seven sites based on their prominent standing, representation from different countries and easy access from commonly used search engines.[10–16] We examined two Australian sites: The Cancer Council Victoria (CCV) and The Cancer Council New South Wales (CCNSW); two United States sites: American Cancer Society (ACS) and the National Cancer Institute (NCI); two European sites: the Cancer Research United Kingdom (CRUK) and the European Organisation for Research and Treatment of Cancer (EORTC); and one Canadian site: that of the Canadian Cancer Society (CCS).

2.2. Assessment

There are no validated tools designed specifically to assess patient information websites. Therefore, we used a variety of tools commonly used in related areas particularly in the evaluation of written information for patients. Assessment focussed on form and content. We defined form as the structure of the site and divided this further into general and web specific elements. We defined content as the subject covered by the sites.

2.3. Form (general)

The assessment of the general form of the websites used tools commonly used to assess other media. These were primarily readability formulae and the Standard Assessment of Materials.[17]

There are numerous readability formulae. The 'Simple Measure of Gobbledegook' (SMOG) readability formula assesses readability based on the total number of polysyllabic words.[18] This formula is commonly used and has been extensively validated.[19]

The Flesh Reading Ease (FRE) Scale is based on the number of syllables per 100 words and the number of words per sentence, and leads to a score between 0 and 100, where 100 indicates that the material is very easy to read, and 0 indicates that the material is unreadable.[20] The Flesh–Kincaid (F–K) formula is a modified version of the FRE, which generates a reading grade level. The FRE and F–K formulae can be calculated by computer programs, with the provisos that abbreviations, numbers with decimals and bullets may lower the reading grade level and underestimate text difficulty.

We assessed each site for their reading level by the online SMOG calculation at the National Literacy Trust website (http://www.literacytrust.org.uk-/campaign/SMOG.html), and calculated the Flesch–Kincaid (F–K) scores and the Flesch Reading Ease scores, using the grammar function of Microsoft Word 2003 (Microsoft Corporation, Redmond, WA).

Readability scores do not take into account legibility, ease of navigation, layout, length of lines, font size, diagrams, graphs and interactivity, as well as a host of other factors that impact upon ease of use and understanding.[17,19] Thus, we also used the Standard Assessment of Materials (SAM), to assess written materials by criteria of content, literacy demand, graphics, layout and typography, learning stimulation and cultural appropriateness.[17] The SAM is a 22 item written checklist assessing content, literacy requirement, graphics, layout, learning stimulation, and cultural appropriateness. It has been validated with 172 heath care providers.[21] The SAM has been used in other assessments of online cancer information.[22–24]

2.4. Form (Internet specific)

There are no widely used validated tools to assess Internet health sites despite at least 50 tools becoming available since 1998.[25–27] Therefore, we elected to evaluate the Internet form of the sites using the United States Department of Health and Human Services tool: usability.gov.[28] The usability.gov site and recommendations have been developed by an independent government body to rate the importance of, and evidence for, different criteria in designing and assessing patient information websites. Assessment of the strength of the evidence for each recommendation is provided (ranked 1–5), based on predefined criteria, as well as the relative importance of the recommendation (ranked 1–5). The tool is not designed to provide numerical ratings of sites, and has not been used in assessing online cancer websites. However, it specifically addresses the technical aspects of web design from a patient information perspective, and is built upon a strong evidence foundation.

The usability.gov guidelines are divided into categories, and some of these, dealing for example with site design process and data input, are not relevant to the present inquiry. These guidelines were discarded and the remaining guidelines used to assess the sites.

Because the information available on the EORTC site is only available in PDF format, it was not assessed according to the usability.com recommendations as these are only relevant to web based formats. We also assessed whether patient pre-testing of the websites was performed.

2.5. Content

There is no standard list of content factors that document what should be covered by a clinical trials patient information site. We approached compiling a list of information that should be covered by Internet site in two ways. We examined the National Cancer Institute consent form template and extracted different elements from it, with the rationale that this document draws from federal regulations and is widely accepted, and because elements of informed

consent and trials information overlap.[2] We also prospectively compiled a list of items the investigators believed should be included in a cancer clinical trials information site. This list included such basic information as: what is a clinical trial, phases of a clinical trial and the nature of randomisation. Each site was individually assessed for the information it contained, against these predetermined criteria.

Although the DISCERN instrument is used primarily for information regarding treatment decisions, it is a validated tool that has potentially useful application to the presentation of cancer clinical trials information.[29,30] It has 16 questions and assesses the reliability, sources, range of choices, potential bias, specialist knowledge and quality of information or written materials.

3. Results

3.1. Form (general)

The seven sites were presented in a combination of multipage hypertext markup language (html) and portable document formats (PDF) and ranged in page numbers from 5 to 45 pages. Table 1 documents the characteristics, apparent review dates and readability of the sites. The UK cancer research site and the CCV sites had the lowest readability scores (easier to read), while the NCI and the CCS sites had the highest readability scores.

Table 2 details the Standard Assessment of Materials. Six sites achieved total SAM scores equivalent to 'adequate material'. These scores ranged between 47% and 63%. The ACS site achieved a total score of 34%. This is considered 'not suitable' in terms of content. The ACS site performed poorly primarily because of its layout and high reading level. Sites rarely presented the context or background to information. As well as deficiencies in readability, the SAM analysis points to consistent deficiencies in writing style, active voice and vocabulary. There were general deficiencies in graphics, with sparse illustrations in all sites. There was little in the way of 'learning stimulation' factors – i.e. interaction, modelling of specific behaviours, and motivational strategies. All sites were lacking in a specific cultural focus, perhaps as expected for general sites with broad exposures.

3.2. Form (Internet specific)

Analysis of the sites based on the usability.gov criteria for all components is shown in the online only content. There were a large number of basic web design factors that were fulfilled by all of the sites. However, there were several deficiencies with respect to Internet specific form. These included layout issues, difficult navigation, inconsistent links, difficult printing options, misleading cues to click upon an icon or link, lack of indication that links had been previously used, lack of cues to internal versus external links, and the lack of colour and images to enhance learning. All sites were deficient with respect to several layout issues, including appropriate page length, off set main items and long line lengths. Assistance to users was minimal in all sites. In addition, there was a noticeable lack of resources for patients from non-English speaking backgrounds, with only the Canadian and the NCI sites having options for French and Spanish speakers, respectively. Accessibility for disabled users was generally not well addressed.

3.3. Content

Table 3 documents 44 information items variably covered by the seven sites. Most sites covered the nature, rationale for considering, ethical bases, phases, and types of clinical trials, the randomisation process, questions to ask your doctor, informed consent and side effects. However, there was significant variance in the offering of information on such practical questions as: the role of supportive care, right to withdraw from trial, examples of useful trials, eligibility, confidentiality, what happens on disease progression or at the end of study, the role of primary health care providers, and what happens if the patient decides not to enrol. Twenty-four information items were covered by fewer than three sites.

Analysis by the DISCERN tool reveals a range of scores (Table 4). Most sites failed to identify sources, did not state aims, did not address quality of life issues (a common and important component of clinical trials), or omitted the procedure followed if not on trial. Sites scored well for discussing how trials work, how they benefit patients and the potential risks, and they seemed to support shared decision making. None of the sites gave evidence of having pre-tested with patients.

Table 1 – Patient information on cancer clinical trials: cancer resources assessed

Institution	Format/number of pages	Size (kb)	Date of last review[a]	SMOG grade	Flesh-Reading ease	Flesh–Kincaid grade
Cancer Council Victoria	Multipage-4	57.3	February, 2002	9.62	67.3	7.4
Cancer Council New South Wales	PDF 45 pages	353	September, 2004	11.84	61.1	7.8
American Cancer Society	Multipage-13	90.1	March, 2006	11.37	57.4	9.9
National Cancer Institute-US	Multipage-5	72.0	December, 2003	12.23	49.3	10.8
Cancer Research UK	Multipage-20	254	Not clear	10.07	70.0	6.4
EORTC (Adapted from NCI)	PDF 14 pages	353	Not clear	11.73	55.7	6.9
Canadian Cancer Society	Multipage-15	125	April, 2006	11.89	43.2	12.0

SMOG, Flesch Reading Ease and Flesch–Kincaid Grade are readability tools described in the text. SMOG and Flesh–Kincaid give US Reading Grade Equivalents, and the Flesch Reading Ease is a 0–100 scale where 0 is very easy and 100 is unreadable.
a All sites were evaluated in June, July 2006.

Table 2 – Standard assessment of materials

Criterion	NSWCC	CCV	ACS	NCI	CRUK	EORTC	CCC
Content							
Purpose	1	2	2	2	2	2	2
Content about behaviours	1	2	2	2	1	1	1
Scope is limited	2	1	1	1	1	1	2
Summary included	1	0	0	0	1	0	1
Literacy demand							
Reading grade level	0	1	0	0	0	0	0
Writing style, active voice	2	2	1	1	1	1	1
Vocabulary – common words	2	2	1	1	1	1	2
Context given first	1	1	1	1	1	1	1
Learning aids via 'road signs'	2	1	0	1	2	1	1
Graphics							
Cover graphic shows purpose	1	1	–	–	–	–	0
Type of graphics	–	–	–	–	–	–	–
Relevance of illustrations	–	–	–	–	–	–	–
Lists, tables, etc. explained	1	–	–	–	–	–	–
Captions used for graphics	–	–	–	–	–	–	–
Layout and typography							
Layout factors	1	1	0	1	2	1	2
Typography	2	1	0	1	2	1	1
Subheads ('chunking') used	2	2	0	2	2	1	1
Learning stimulation, motivation							
Interaction used	0	1	1	1	1	1	1
Behaviours are modelled and specific	1	1	1	1	1	1	1
Motivation – self efficacy	1	1	0	1	1	1	1
Cultural appropriateness							
Match in logic, language, experience	1	1	1	1	1	1	1
Cultural image and examples	–	–	–	–	–	–	–
Total SAM score	22	21	11	17	20	15	19
Total possible score	36	34	32	34	34	32	30
Percent score (%)	61	62	34	50	59	47	63

Scale: 2, optimal; 1, adequate; 0, inadequate; –, not assessable; SAM, Standard assessment of materials.

4. Discussion

Clinical trials are a cornerstone of cancer management. They provide patients with opportunity, good clinical practice and, for some, a sense of altruism.[31] That information on cancer clinical trials be accurate, available and appropriate has a strong ethical basis.[1]

Increasingly, patients and their families are seeking information from the Internet.[6] The content and form of information available to patients is critical. Information must be readable, provide essential detail, be understandable and able to be accessed easily. A survey under the auspices of Health On the Internet (HON), an independent entity which provides a code of conduct for health information on the Internet, showed that users of the Internet rate availability of information, ease of finding information, trustworthiness/credibility and accuracy of information as the most important indicators of quality and usefulness of a website.[32]

This study accessed seven cancer information sites and reviewed information on clinical trials. Our study is the first to undertake such an examination and highlights at least five areas of concern. First, there is considerable variability between the form and content of the seven sites providing information on cancer clinical trials. Second, in general, the sites require an unacceptably high level of literacy. Third, in general, the sites omit items that might be considered critical information regarding clinical trials. Fourth, the sites are not well designed. Fifth, there is little if any allowance for non-English speakers or awareness of cultural appropriateness.

In this study, the SMOG grade was significantly higher in all of the sites than would be advised, representative of high school or higher education, meaning that a significant proportion of users would be unlikely to have sufficient understanding of the information presented. Twenty-five percent of patients on the USA and Canada are functionally illiterate, with a reading age of less than grade 5.[20] The International Adult Literacy Study found that the average reading level of the population in the United States, Canada, the UK and Australia is Grade level 8–9.[33] The elderly make up more than 50% of people with literacy problems. Low literacy is related to poor health outcomes and more anxiety with regard to cancer diagnosis.[34]

Previous research has demonstrated that consumer health information is frequently written at the level of senior high school or college levels, and is difficult to understand.[20] Readability levels in cancer patient information resources have been assessed in numerous studies and found to be consistently high.[35] Furthermore, two studies examining the read-

Table 3 – Frequency with which information items are covered

Items covered	Number of sites covering item (%)
Phases I–V Informed consent Risks/side-effects Questions to ask	7 (100%)
Randomisation	6 (86%)
Other types of trials Why might you consider joining a CT Placebo How to find a CT Ethical issues Right to withdraw Protocol Funding	5 (71%)
Ethics committee Eligibility	4 (57%)
What clinical trials have found High quality care on a CT How to join a CT Further information Confidentiality	3 (43%)
Quality of life Percent patients on trials Standard care Glossary Available supports	2 (29%)
Supportive care How trials change treatment Carers information Personal insights Summary boxes Role of comorbidities Pharmacogenetic studies Stopping treatment early Blinding How to make decision Insurance How results are expressed OR, PFS, etc. Governmental agencies Definition Performance status What will happen if not eligible Example of patient scenarios Expanded access program	1 (14%)

CT, clinical trial; OS; overall survival, PFS, progression free survival.

ing and navigational strategies of web users with lower literacy skills found that users tend to read every word, tend to focus on a narrow field of view, skip large amounts of text, particularly long paragraphs, long pages, numbers and long difficult words.[22,36]

In a study by Kaphingst, redesigning a website to avoid the above faults improved time on a task by 134%, success rate of task completion by 77% (from 46% to 82%) and mean satisfaction by 24%.[22] Interestingly, users with high literacy also had improved speed, success and satisfaction with a site that was designed to be easier to use.

Navigability is also a critical issue. Many of the sites assessed had inconsistent clues to mouse click on links or text, and inconsistent clues to navigate. With regard to accessibility (access of users, able-bodied or disabled), there are few guides to users in these sites, and few directions to other sources of information, and few graphics.

Although there is not necessarily the same requirement for completeness in a cancer information site compared to a consent form, cancer sites nonetheless would seemingly have similar ethical responsibilities, and therefore ought to include information on such areas as consent, voluntary nature of trials, blinding, ethics committees, eligibility, quality of life, the publication of results, and the alternatives to participation, all of which were not found on some sites. Cancer clinical trials sites need to maintain the same neutral and balanced tone that participant information and consent forms are required to present.

With advances in trial design, such as the randomised discontinuation design, with new therapies such as biological agents, and with advances in Internet design and health informatics, clinical trials sites have a responsibility to be up to date, and to give evidence of the date of last review of the site. Two sites gave no such information; of the five sites that did, three had review dates from over two years ago. In addition, none of the sites gave evidence of pre-testing with patients and consumers; a phenomenon out of keeping with current design recommendations and recommendations for the development of patient information materials in general. Similarly, website layout, text size and appearance have well documented design imperatives.[28,37]

The specific information listed varied between the seven sites. At least 24 items that might be considered important were found in less than three of the seven sites. While one might debate the need for any particular item, the variability is of concern. Indeed, a number of specific items were not recorded by any of the seven sites including information on contemporaneous prescription and non-prescription drugs, possible effects on pregnancy, the effect of the trial on future treatment options, the availability of trial medication drug after trial completion, and the role of family members and the local doctor in ongoing management.

For the SAM assessment, of a potential 44 items, only 30–36 were assessed. The elements of graphics, and cultural appropriateness were not assessed because of the lack of significant graphic component in all of the sites, and the lack of cultural specificity that one would expect to find in sites that address a wide audience. Both of these facts could be construed to be a fault in the sites, rather than simply being not assessed, as the tool demands.

The SAM approaches information provision with the assumption that basic arrangement, form and interactivity are important in maximal understanding and learning. The predominance of low scores in areas which reflect this, such as lack of summary, context being provided first, learning aids, specific modelled behaviours and motivational factors, reflects that the sites do not generally appear to be optimally tailored to optimal health informatics principles. The CCV, CCNSW, CRUK and CCC sites, which prompted questions, or included patient stories or flow charts, were more engaging.

Additional resources, as opposed to information, were provided on some sites including glossary, further information/

Table 4 – DISCERN

Criteria	CCV	NSW CC	ACS	NCI	CRUK	EORTC	CCC
Clear aims	1	4	3	4	3	4	2
Aims achieved	3	4	4	4	4	4	3
Relevant	3	4	4	4	4	4	4
Clear sources	1	3	4	2	1	1	1
Dates	1	3	4	4	2	1	4
Unbiased	4	3	3	3	4	3	4
Further resources	5	4	3	1	2	3	1
Uncertain areas	4	4	4	3	4	3	3
How trial arms work	4	4	4	4	4	4	4
Benefits of trial	4	4	4	4	4	4	4
Risks of trial	2	4	4	3	4	4	3
If not on trial	3	1	5	1	4	1	1
QOL addressed	1	3	2	1	5	1	3
Option of not being on trial	3	3	4	3	4	2	3
Shared decision making	3	5	4	5	5	5	5
Overall	3	4	4	3.5	4	3	3.5
Percent	55	71	75	57	72	59	60

Out of a possible 5 for each category; overall = global impression of assessor, percent excludes overall impression.

links/support, personal insights, information on how to make the decision to join, links to other trial information sites, trial checklist, summary pages and the 'what is best for you' section in the CCC site.

There are a number of potential limitations of our study. Most critically, there are no validated tools to evaluate the content and form of Internet information. This study used a number of instruments that have been validated in related areas. We made a pragmatic decision to use these instruments in the absence of more suitable tools, and previous research into cancer information has used these measures.[35]

Secondly, one may argue that the best persons to assess patient information are the patients themselves rather than an investigator. It would be of interest to examine patient's understanding and recall of information provided by these websites. It is interesting to note that none of the websites indicated that patients, carers or consumers were involved in the website development.

In conclusion, we have examined the clinical trial information presented on the websites of seven leading cancer organisations. We paid particular regard to form, content and variability across the sites. We have shown that these sites require an inappropriately high literacy level, are not easy to navigate and vary considerably in the information provided. The challenge for organisations that provide such material is to ensure that their websites provide patients with appropriate information in the most appropriate manner.

Conflict of interest statement

Michael Jefford is a Clinical Consultant with The Cancer Council of Victoria, one of the bodies that provides an Internet information page on clinical trials.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.ejca.2007.04.016.

REFERENCES

1. National commission for the Protection of Human Subjects of Biomedical and Behavioural Research: The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research, April 18, 1979, online at <http:// ohsr.od.nih. gov/guidelines/belmont.html> (accessed 11.11.2006).
2. <http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfCFR/CFRSearch.cfm?CFRPart=50&showFR=1&subpartNode=21:1.0.1.1.19.2> (accessed 11.11.2006).
3. Simon MS, Du W, Flaherty L, et al. Factors associated with breast cancer clinical trials participation and enrolment at a large Academic Medical Center. *J Clin Oncol* 2004;**22**:2046–52.
4. Lara Jr PN, Higdon R, Lim N, et al. Prospective evaluation of cancer clinical trial accrual patterns: identifying potential barriers to enrolment. *J Clin Oncol* 2001;**19**(6):1728–33.
5. Harris interactive. Misconceptions and lack of awareness greatly reduce recruitment for cancer clinical trials. Healthcare News at <http://www.harrisinteractive.com/about/vert_healthcare> (accessed 11.11.2006).
6. Helft PR, Eckles RE, Johnson-Calley CS. Use of the internet to obtain cancer information among cancer patients at an urban county hospital. *J Clin Oncol* 2005;**23**:4954–62.
7. Dickerson S, Reinhart AM, Feeley TH, et al. Patient internet use for health information at three urban primary care clinics. *J Am Med Inform Assoc* 2004;**11**:499–504.
8. Avis S et al. *Factors associated with participation in Breast Cancer Treatment Clinical Trials* 2006;**24**(12):1860–7.
9. <http://www.hon. survey/survey2005/res.html> (accessed 6.08.2006).
10. <http://www.cancervic.org.au/cancer1/patients/clinicaltrials/clinicaltrials.htm> (accessed (06.08.2006).
11. <http://www.nswcc.org.au/editorial.asp?pageid=526> (accessed 06.08.2006).
12. <http://www.cancer.org/docroot/ETO/content/ETO_6_3_Clinical_Trials_-_Patient_Participation.asp> (accessed 06.08.2006).
13. <http://cancernet.nci.nih.gov/clinicaltrials/learning/what-is-a-clinical-trial> (accessed 06.08.2006).
14. <http://www.cancerhelp.org.uk/help/default.asp?page=52> (accessed 06.08.2006).

15. <http://www.eortc.be/About/PatientsBrochure/EORTC_E.pdf> (accessed 06.08.2006).
16. <http://www.cancer.ca/ccs/Internet/standard/0,3182,3172_367616_275645_langId-en,00.html> (accessed 06.08.2006).
17. Doak CC, Doak LG, Root JH. *Teaching patients with low literacy skills*. 2nd ed. Philadelphia, PA: Lippincott; 1996. p. 49.
18. McLaughlin GH. SMOG grading: a new readability formula. *J Reading* 1969;**12**(8):639–46.
19. Bailin A, Grafstein A. The linguistic assumptions underlying readability formulae: a critique. *Language Commun* 2001;**21**:285–301.
20. Friedman DB, Hoffman-Goetz L, Arocha JF. Health literacy and the World Wide Web: comparing the readability of leading incident cancers on the internet. *Med Info Internet Med* 2006;**31**(1):67–87.
21. Doak C, Doak L, Miller K. Suitablility Assessment of Materials (SAM), In: Presentation at American Public Health Association annual meeting, Washington (DC); 1994.
22. Kaphingst KA, Zanfini CJ, Emmons KM. Accessibility of web sites containing colorectal cancer information to adults with limited literacy. *Cancer Causes Contr* 2006;**17**(2):147–51.
23. Weintraub D, Maliske SL, Fink A, Choe S, Litwin MS. Suitability of prostate cancer education materials: applying a standardized assessment tool to currently available materials. *Patient Educ Couns* 2004;**55**(2):275–80.
24. Rees CE, Ford JE, Sheard CE. Patient information leaflets for prostate cancer: which leaflets should healthcare professionals recommend? *Patinet Educ Couns* 2003;**49**(3):263–72.
25. Gagliardi A, Jadad A. Examination of instruments used to rate quality of health information on the internet: chronicle of a voyage with an unclear destination. *BMJ* 2002;**324**: 569–73.
26. Kim P, Eng TR, Deering MJ, Maxfield A. Published criteria for evaluating health related web sites: review. *BMJ* 1999;**318**:647–9.
27. Eysenbach G, Powell J, Kuss O, Sa E. Empirical studies assessing the Quality of Health Information on the world wide web. *JAMA* 2002;**287**:2691–700.
28. United States Department of Health and Human Services, available at: <www.usability.gov> (accessed 18.08.2006).
29. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: and instument for judging the quality of written consumer health information on treatment choices. *J Epidem Comm Health* 1999;**53**(2):105–11.
30. Rees CE, Ford JE, Sheard CE. Evaluating the reliability of DISCERN: a tool for assessing the quality of written patient information on treatment choices. *Pat Educ Couns* 2002;**47**(3):273–5.
31. Joffe S, Cook EF, Clark JW. Altruism among patients in cancer clinical trials. *Proc Am Soc Clinic Oncol 22 abstr.* 2003:2103.
32. <http://www.hon.ch/survey/survey2005/res.html> (accessed 12.12.2006).
33. Centre for Literacy of Quebec. Background document of Literacy and Health. Available at: <http://www.nald.ca/PROVINCE/QUE/litcent/health.finalsum.bd.bd3-sec1.html> (accessed 23.08.2006).
34. Friedman DB, Hoffman-Goetz L, Arocha JF. A systemic review of readability and comprehension instruments used for print and web-based cancer information. *Health Educ Behav* 2006;**33**(3):352–73.
35. John AK. A critical appraisal of internet resources on colorectal cancer. *Colorectal Dis* 2005;**8**:217–23.
36. Birru MS, Monaco VM, Charles L. Internet usage by low-literacy adults seeking health information: an observational analysis. *J Med Internet Res* 2006;**6**(3):e25.
37. Chernecky C, Macklin D, Waller J. Internet design preferences of patients with cancer. *Oncol Nurs Forum* 2006;**33**(4):787–92.