

National Prostate Cancer Website

Resource Rating Scheme

Report to Steering Committee, 11th April 2005

This document contains a brief overview of our thinking around how to rate the quality of resources included in the Website and a summary of our literature review in this area.

Summary:

- Any quality criteria must be achievable, measurable, observable, understandable and reasonable¹
- As previously noted, we favour addressing three broad aspects of quality:
 1. Accessibility (Can users get access to the information when they need it?)
 2. Usability (Can users find what they need from the resource?)
 3. Reliability (Is the information provided of good quality)
- There are many, many instruments for assessing the quality of health information.
 - Ours must at least address ownership of the site, conflicts of interest, design, purpose, currency and editorial policy (including linking, citations, review and content development).²
- Most of them haven't been properly validated
 - Of those that have, most of them are unreliable³
 - The DISCERN instrument⁴ has been subject to the most rigorous evaluation of all the existing instruments, including several studies in cancer and one in prostate cancer.
 - However, DISCERN does not address usability nor accessibility.
- Key stages in the "patient journey" which can assist in interface design are:⁵
 - When worried about symptoms
 - During investigations
 - After the diagnosis
 - When choosing treatments
 - Before treatment
 - Short term follow up
 - Long term follow up

Recommendations

- We will develop augmented criteria which incorporate Accessibility and Usability. These will may include:
 - Conformance to W3C Accessibility criteria, browser compatibility and coding best practice;
 - Requirements for registration or payment for information;
 - Clarity, Consistency and Functionality of a site design
- These criteria will be subject to validation exercises throughout the lifetime of the project.

Summary of literature search

For a detailed account of our search methodology, see the Search Narrative in this section.

This document reports the “bottom line” extracted from each study found. We were not able to assess the quality of most of these studies as yet and our interim conclusions (above) placed greater emphasis on those studies which were high quality. Some of the studies were opinion pieces.

Sections:

- General Health Information Quality
- Accessibility and Usability
- Cancer Information
- CAMs (Complementary and Alternative Medicines)
- Criteria for Evaluating Information Quality
- Evidence Appraisal and Guidelines Schemes
- Bibliometric Approaches
- Kitemarking

General Health Information Quality

4.5% of internet searches are health-related⁶

- In 2002, 60% of US households used the internet for accessing health information⁷
- A survey of colorectal cancer surgical patients found that 45% had internet access at home, 88% wanted more information about their condition; 8% had used the internet to look for information but 57% would use a web site if recommended⁸; similar results in lung cancer (16%/60%)⁹

Health web information is mostly accurate^{10;11} but often (20%) isn't¹²

- It seems to have improved in recent years¹³
- Non-commercial web sites were found to be of better quality than commercial¹⁴
- No evidence that web information is any worse than non-internet information¹⁵
- There have been instances reported of harm caused by internet health information^{16;17}; drug safety information was often inadequate, especially when the author or source of the information was unclear¹⁸
- Online information about men's health was of a poor standard^{19;20}
- The vast majority of French language web sites don't provide information about methodological quality of their sources²¹

Answers are incomplete^{10;11}

It is hard to understand¹⁰

- Readability levels correspond to 13-yr-old²²
- Users don't remember where they got information from²³

Search engines are inefficient¹⁰

- Users will look at a few sites even if they find an answer on the first one¹²

Users are concerned about quality but don't know how to evaluate it⁶

- Professionals should recommend sites, promote more effective search and evaluation techniques, involved in developing and promoting uniform standards for health and mental health sites; it may affect patients' use of medicines.²⁴
- Different things matter to different demographic groups: e.g. older patients are less likely to believe doctors²⁵
- People look for: source, professional design, scientific or official look, usability²³ but they may mix intuitive and rational approaches in evaluating the information they see²⁶
- Four dimensions for users: content, usage, authorship, and publication²⁷
- There is a confusing plethora of quality schemes²⁸

It's better to educate the producers than regulate them²⁹

Accessibility and Usability

Web sites must be accessible to disabled users³⁰

The most usable health web sites were also the most popular ones³¹

- Enhance scanning by providing clear links, headings, short phrases and sentences, and short paragraphs³²
- Web site usability means:³³
 - Speak the users' language. Use words, phrases, and concepts familiar to the user. Present information in a natural and logical order.
 - Be Consistent. Indicate similar concepts through identical terminology and graphics. Adhere to uniform conventions for layout, formatting, typefaces, labelling, etc.
 - Minimize the users' memory load. Take advantage of recognition rather than recall. Do not force users to remember key information across documents.
 - Build flexible and efficient systems. Accommodate a range of user sophistication and diverse user goals. Provide instructions where useful. Lay out screens so that frequently accessed information is easily found.
 - Design aesthetic and minimalist systems. Create visually pleasing displays. Eliminate information which is irrelevant or distracting.
 - Use chunking. Write material so that documents are short and contain exactly one topic. Do not force the user to access multiple documents to complete a single thought.
 - Provide progressive levels of detail. Organize information hierarchically, with more general information appearing before more specific detail. Encourage the user to delve as deeply as needed, but to stop whenever sufficient information has been received.
 - Give navigational feedback. Facilitate jumping between related topics. Allow the user to determine her/his current position in the document structure. Make it easy to return to an initial state.
 - Don't lie to the user. Eliminate erroneous or misleading links. Do not refer to missing information.

Some pointers for the design process:

- In designing web resources for older adults: Start by defining objectives and tasks, Assess users' special needs and goals, Build a prototype, Assess and revise its usability.³⁴
- Key mistakes include using frames, too much scrolling, unnecessary animations and technology, poor navigation and out of date content^{35;36}
- Users often misspell and mistype words in search engines³⁷

CAMs

Most online CAM information is poor quality and potentially harmful if acted upon^{38 39}, especially the commercial sites⁴⁰

- Technical quality is not related to quality of information³⁸
- BIOME uses an additional checklist for CAMs. Note that RCTs are automatically included (even if they are poor quality RCTs)^{41;42}

Cancer information

Electronic information resources in cancer can be useful for patients and for professionals⁷

- Particularly in maintaining activities and checking up on treatment decisions⁵

Different people ask the same questions over and over (37 cancer terms represented 204,165 different queries on Ask Jeeves for June-August 2001)³⁷

- The most common categories of cancer question were: General Information, Symptoms, Diagnosis and Testing, Treatment, Statistics, Definition, and Cause/Risk/Link³⁷

Quality of cancer information:

- By adapting the Discern instrument, colorectal cancer information sites were classified as excellent 18 (15.3%), very good 19 (16.1%), good 28 (23.7%), fair 8 (6.8%) and poor 45 (38.1%). The Internet provides a wealth of information on colorectal cancer but the best sites are difficult for patients to distinguish from the thousands of sites returned by search engines.⁴³
- In a review of cancer sites, the majority were found to be written at "college level": sites must consider literacy levels more carefully or risk being inaccessible to readers with lower literacy^{44;45}
- Bladder cancer information was accurate but incomplete. Inaccuracies were usually due to being out of date.⁴⁶

Low use of the internet; age and other demographic patterns in information use; need for better information for cancer patients⁴⁷

- In an analysis of online behaviour, prostate cancer patients were found to be more focused on information (rather than support) than breast cancer patients.⁴⁸
- In Swedish, no breast cancer sites met EU guidelines; only 7 out of 29 sites were considered suitable for patients; accuracy and currency were highly variable⁴⁹

Criteria for Evaluating Information Quality

Findings from Reviews

- Any criterion must be achievable, measurable, observable, understandable and reasonable¹
- Poor inter-rater reliability is common with information quality assessment guidelines³
- DISCERN had good inter-rater reliability in the assessment of prostate cancer web sites.⁵⁰
 - A small scale study of 22 web sites found that DISCERN, IQT and QS were consistent between raters and agreed with each other implying external validity⁵¹
- Providing clear definitions and training to assessors is necessary for reliable quality assessments of web sites⁵²
- 165 criteria can be grouped into: content, design and aesthetics of site, disclosure of authors, sponsors, or developers, currency of information (includes frequency of update, freshness, maintenance of site), authority of source, ease of use, and accessibility and availability⁵³
- Health Improvement Institute:²
 - Top ten most-cited criteria for web information quality:

Criteria Description	Number	Percent
Does the site say who owns or pays for or created it?	17	77%
Conflict of interest, bias, disclosure of sponsorship, funding sources	14	64%
Navigability, logical organization	13	59%
Does the site indicate when it was last updated?	13	59%
Purpose/Mission/Scope: Does site state its purpose?	12	55%
Audience: Does the site state its intended audience?	12	55%
Author's credentials	12	55%
For reports of facts does site give source of specific information?	12	55%
Editorial policy, site evaluation process, peer review process	10	46%
Does the site link to other sites as sources of health information?	10	46%
Disclaimers, privacy policy, sponsorship, advertising policy	10	46%

- Of 273 tools for assessing the quality of health websites, only one was publicly available, had 10 or fewer elements, could be evaluated objectively and had shown good inter-rater agreement⁵⁴
- IN 1998, none of 47 instruments provided information on their reliability; in 2002, five out of 51 new instruments since 1998 provided such information^{55;56}
- Over 80% of HON-code materials were found to be too difficult to read for the average adult population⁵⁷
- Can be characterised as codes of conduct, quality labels, user guides, filter and third party certificates⁵⁸

Individual tools and criteria sets

BIOME/OMNI Evaluation guidelines⁴¹

- Contextual Factors:
 - scope and intended audience;
 - authority and reputation; and
 - how the resource compares to others.
- The content of the source:
 - coverage;
 - accuracy; and
 - currency.

- The format of the source:
 - accessibility;
 - design and layout; and
 - ease of use.

Centre for Health Information Quality⁵⁹

- Patient information should be evidence-based, clearly communicated and involve patients.
 - With contact details for provider, individual contributions stated, sources of further information, providing mechanisms for feedback.
 - accessibility (the information is in an appropriate format for the target audience);
 - accuracy (the information is based on the best available evidence);
 - appropriateness (the information communicates relevant messages);
 - availability (the information is available to the widest possible audience);
 - currency (the information is up-to-date);
 - legibility (written information is clearly presented);
 - originality (information has not already been produced for the same audience and in the same format);
 - patient involvement (the information is specifically designed to meet the needs of the patient);
 - readability (words and sentences are kept short where possible and jargon is minimized);
 - reliability (the information addresses all essential issues).
- Note: CHIQ has recently been wound up
- For consumers: QUICK guidelines⁶⁰
 - Is it clear who has written the information? Who is the author? Is it an organization or an individual person? Is there a way to contact them? An e-mail address on its own is not a proof that the author is a genuine expert on a subject or even who they claim to be as anyone can get an e-mail address especially with free services like Hotmail.
 - Are the aims of the site clear? What are the aims of the site? What is it for? Who is it for?
 - Does the site achieve its aims? Does the site do what it says it will?
 - Is the site relevant to me?
 - Can the information be checked? Is the author qualified to write the site? Has anyone else said the same things anywhere else? Is there any way of checking this out? If the information is new, is there any proof?
 - When was the site produced? Is it up to date? Can you check to see if the information is up to date and not just the site?
 - Is the information biased in any way? Has the site got a particular reason for wanting you to think in a particular way? Is it a balanced view or does it only give one opinion?
 - Does the site tell you about choices open to you? Does the site give you advice? Does it tell you about other ideas?

Cornell University (Review):⁶¹

- Berkeley:
 - What can the URL tell you?
 - Who wrote the page? Is he, she, or the authoring institution a qualified authority?
 - Is it dated? Current, timely?
 - Is information cited authentic?
 - Does the page have overall integrity and reliability as a source?
 - What's the bias?
 - Could the page or site be ironic, like a satire or a spoof?
 - If you have questions or reservations, how can you satisfy them?
- Johns Hopkins:
 - Authorship
 - Publishing body
 - Point of view or bias
 - Referral to other sources
 - Verifiability
 - Currency
 - How to distinguish propaganda, misinformation and disinformation
 - The mechanics of determining authorship, publishing body, and currency on the Internet
- Cornell:
 - Accuracy
 - Authority
 - Objectivity
 - Currency
 - Coverage

DISCERN⁴

- Are the aims clear?
- Does it achieve its aims?
- Is it relevant?
- Is it clear what sources were used (other than the author or producer)?
- Is it clear when the information was produced?
- Is it balanced or unbiased?
- Does it provide additional sources of support and information?
- Does it refer to areas of uncertainty?
- Supplementary treatment choice questions:
 - Does it describe how each treatment works?
 - Does it describe the benefits of each treatment?
 - Does it describe the risks of each treatment?
 - Does it describe what would happen if no treatment is used?
 - Does it describe how the treatment choices affect overall quality of life?
 - Is it clear there may be more than one possible treatment choice?
 - Does it provide support for shared decision making?
- Based on the above, rate the overall quality of the publication.

EQUIP⁶²

- Appropriateness - content should be suitable for the audience
- Design and navigability - ease of use, speed and appropriate use of graphics is assessed
- Authorship - authors and those who were involved in creation (i.e.: if patients were involved) and level of expertise of authors and reputation of the organisation should be identified. Contact details should be available.
- Sponsorship - sponsors should be clearly stated and suitable
- Readability - appropriate level of language for audience
- Currency - date of update should be clear and content still valid
- Legibility - sites ideally should adhere to RNIB (Royal National Institute for the Blind) guidelines etc.
- Accessibility - there should be no registration, cost or special software required to enter the site and sites should be viewable in Netscape and Internet Explorer and ideally fully accessible to those with a visual impairment
- Copyright - the information should be in the public domain

eEurope 2002 Quality Criteria for Health Related Web Sites⁶³

- Transparency and Honesty,
- Authority,
- Privacy and data protection,
- Updating of information,
- Accountability,
- Responsible partnering,
- Editorial policy,
- Accessibility, including:
 - attention to guidelines on physical accessibility
 - findability
 - searchability
 - readability
 - usability

Health on the Net Foundation: HON Code⁶⁴

- Authority
- Complementarity
- Confidentiality
- Attribution
- Justifiability
- Transparency of authorship
- Transparency of sponsorship
- Honesty in editorial and advertising policy

Health Summit Working Group⁶⁵

- Credibility
- Content
- Disclosure
- Links
- Design
- Interactivity
- Caveats

JUDGE⁶⁶

- Trust and reputation, Who produced the site, Funding sources
- Purpose of the site
- Date
- How the information is written
- Descriptions of conditions and treatments, Medical research, Personal experiences
- Foreign sites
- Communication, Links, Disclaimers, Kitemarks
- Design
- Interactive facilities, for example e-mail lists, bulletin boards, chat rooms
- Other guidelines

MedCIRCLE Metadata Tool⁶⁷

- Doesn't currently provide specific guidance on quality
- Stipulates that providers must use HIDDEN (medPICS) metadata to disclose quality information

National Cancer Institute⁶⁸

- Who runs the site?
- Who pays for the site?
- What is the purpose of the site?
- What is the original source of the information on the site?
- How is the information in the web site documented?
- How is information reviewed before it is posted on the site?
- How current is the information on the site?
- How does the site choose links to other sites?
- What information about users does the site collect and why?
- How does the site manage interactions with users?

NHS / North Cumbria⁶⁹

- Quality, authority and accuracy of content
 - The source of the content is known and respected in the field and names of those involved are published on the site.
 - The information provided is appropriate to the audience level, well organized and easy to use.
 - Information is from primary resources (i.e., text, abstracts, web pages).
 - Lists of links are evaluated/reviewed/quality-filtered.
- Availability and maintenance of website
 - The web site is consistently available.
 - Links from the site are maintained.
 - The source for the contents of the web page(s) and the entity responsible for maintaining the web site is clear.
 - Information is current or an update date is included.
 - Registration is not required to view the information on the site.
- Special features
 - The site contains special features such as graphics/diagrams, glossary, or other unique information.
 - The content of the site is accessible to persons with disabilities
- Disclaimer

Silberg et al^{70;71}

- Authorship - authors, contributors, affiliation and credentials provided
- Attribution - references, sources, and copyright noted
- Disclosure - "ownership", sponsorship, advertising, commercial funding arrangements, or other conflicts of interest fully disclosed
- Currency - dates content posted and updated

Smith AG⁷²

- Scope
- Content
- Accuracy
 - Authority
 - Currency
 - Uniqueness
 - Links
- Quality of writing
- Design
- Purpose and Audience
- Reviews
- Workability
 - User friendliness
 - Computing equipment required
 - Searching
 - Browsability and organisation
 - Interactivity
 - Connectivity
- Cost

Of these, only Design appeared on all instances in a review of 7 other schemes

Evidence Appraisal and Guidelines Schemes

There are many tools; the most commonly used are cited here.

- An evidence-based approach led to more reliable clinical guidelines which were adopted more quickly.^{73;74}

AGREE Tool for evaluating guidelines⁷⁵

- Scope and purpose
- Stakeholder involvement
- Rigour of development
- Clarity and presentation
- Applicability
- Editorial Independence

CASP Critical Appraisal Tools⁷⁶

- For systematic reviews, RCTs, case-control studies, cohort studies, qualitative research and economic evaluations.

GRADE⁷⁷

- For assessing clinical practice guidelines

National Institute for Health and Clinical Excellence⁷⁸

- Reviewing and grading the evidence

Oxford Centre for Evidence-Based Medicine⁷⁹

- Levels of evidence by question type

Scottish Intercollegiate Guidelines Network (SIGN)⁸⁰

Bibliometric approaches

Some people suggest using bibliometric measures (number of links from other sites) as a means of reflecting peer review processes^{81;82}

- Peer review is unreliable⁸³
- Some web site usage statistics (esp inbound links) correlated with quality scores⁸⁴
- Google ranking correlated with type of (breast cancer) information (e.g. information about research) but not with quality⁸⁵
- A quality rating scheme was found to correlate with search engine rank⁸⁶

Kitemarking

Because of uncertainty around medical information, "trustmarks" should aim to mark the reliability of the information provider, not the accuracy of the information⁸⁷

- However, there is plenty of evidence that information providers are inconsistent in how they apply their own standards⁸⁸
- No evidence that kitemarking works⁸⁷; Kitemarking is impractical and non-viable (editorial)⁸⁹
- Liability issues for kitemarking⁹⁰

Most users don't check the About Us page.²³

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