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Patient use of websites

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DISCLAIMER

This paper was produced for a meeting organised by Health & Consumer Protection DG and represents the views of its author on the subject. These views have not been adopted or in any way approved by the Commission and should not be relied upon as a statement of the Commission's or Health & Consumer Protection DG's views. The European Commission does not guarantee the accuracy of the data included in this paper, nor does it accept responsibility for any use made thereof.
“Cybermedicine is the science of applying Internet and global networking technologies to the area of medicine and public health, of studying the impact and implications of the Internet and of evaluating opportunities and the challenges for health care.”

Eysenbach G et al. Shopping around the Internet. BMJ 319: 1294 (13 Nov 1999)
Professional care as apex of a system of care that hardly recognises self care

Professional care as support of a system that emphasises self care


Interactive Solutions Inc.

million this year, said Michael Brown, a partner in

percent, in 1996 and is projected to grow to 27.1

Internet users. That’s up from 13.8 million, or 38

online health information, including 43 percent of all

LAST YEAR, about 15.6 million adults searched for

43 percent of Net users looking

Consumers looking for health online

April 28, 1998

MSNBC STAFF AND WIRE REPORTS

for medical information

43 percent of Net users looking

Consumers looking for health online
Information needs of (cancer) patients

- Often, information needs are not fully addressed:
  - in one study, 48% of cancer patients reported that they had not enough information (Turner et al. 1996)
  - another survey of 525 cancer patients (309 with breast cancer, 129 with prostate cancer, 22 with cervical cancer, 65 with laryngeal cancer), 80% stated that they wanted as much information as possible, 20% were not satisfied with the information given. (Jones et al. 1999)
  - of 2331 cancer patients surveyed, 87% stated that they want as much information as possible about treatment and illness (Jenkins et al. 2001)
  - in another study, 39% of breast cancer patients indicated that they “wished that they had help with knowing what questions to ask” (Silliman et al. 1998)
Impact of information on patients?

- Provision of information to cancer patients has been shown to help gaining control, reducing anxiety, improving compliance, creating realistic expectations, promoting self-care and participation, and generate feelings of safety and security (Mills and Sullivan, 1999; Mossman et al. 1999).
- Satisfaction with information has been shown to correlate with quality of life (Annunziata et al. 1998)
- Patients who feel satisfied with the adequacy of information given are more likely to feel happy with their level of participation in the overall process of decision-making (Turner et al. 1996)
- About 15 randomised trials have evaluated interventions to provide (printed) information to cancer patients so far (Mohide et al. 1996)
Role of the Internet (1)

- Internet is/will be primary medium to obtain information for patients in the 21st century
- Internet is a vast resource for information about cancer (Mizsur, 1997; Pinker, 1999)
- Internet also facilitates communication with peers in online self-support groups (mailing lists and chatrooms), where members may be getting information, share experiences, receive general support, and vent feelings (Larkin, 2000; Weinberg et al. 1996; Sharf, 1997; Ferguson, 2000; Smith, 1998; Klemm et al. 1998; Klemm et al. 1999; Han and Belcher, 2001).
Recent patient narratives have provided anecdotal evidence that access and use of the Internet can have positive effects including promoting empowerment, shared decision making, augments social support and can perhaps even improve outcomes (Forbriger, 2001; Goldmann-Posch, 2000).

However, the “net effect” of the Internet on patients has never been studied systematically.
Internet Health Consumer Map

Hey, I'm pretty healthy!

60%

- 60% of the Internet health care population
- Convenience concerns
- Fickle
- Not thinking about health explicitly
- Perceived health - some care and pay much more attention to their health

Source: IFTF
INTERNET HEALTH CONSUMER MAP

NEWLY DIAGNOSED
This could be serious...

5%

- 5% of the Internet health care population
- Urgency: Speed is key
- Transient population

Source: IFTF
INTERNET HEALTH CONSUMER MAP

35% of the Internet health care population
Privacy concerns
Fear of discrimination
Loyal to information source

Source: IFTF
Age distribution visitors to dermatology site - all diagnoses (n=9606)
Age distribution "ask-the-doc" Netdoctor UK
(n=11211)
"I'M SORRY DOCTOR, BUT AGAIN I HAVE TO DISAGREE."
Survey among 160 GPs and 96 Practice Nurses in Scotland

Have been approached by patients with Internet healthcare information:

✦ 58% of GPs
✦ 34% of practice nurses

Survey about consultation with patients holding Internet healthcare information

<table>
<thead>
<tr>
<th></th>
<th>General Practitioner</th>
<th>Practice Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient participates more actively in his treatment</td>
<td>65 (78.3%)</td>
<td>26 (83.9%)</td>
</tr>
<tr>
<td>The patient has higher expectations</td>
<td>75 (85.2%)</td>
<td>26 (78.8%)</td>
</tr>
<tr>
<td>The information is accurate</td>
<td>59 (73.8%)</td>
<td>24 (75%)</td>
</tr>
<tr>
<td>The length of consultation is increased</td>
<td>68 (77.3%)</td>
<td>24 (72.7%)</td>
</tr>
<tr>
<td>This type of patient is a welcome challenge</td>
<td>46 (55.4%)</td>
<td>24 (72.7%)</td>
</tr>
<tr>
<td>The consultation is more interactive than usual</td>
<td>43 (50.6%)</td>
<td>22 (68.8%)</td>
</tr>
<tr>
<td>The patient correctly interpreted information</td>
<td>38 (44.7%)</td>
<td>19 (59.4%)</td>
</tr>
<tr>
<td>The patient is more demanding</td>
<td>50 (58.8%)</td>
<td>14 (42.4%)</td>
</tr>
<tr>
<td>The information is new to the clinician</td>
<td>55 (64.7%)</td>
<td>13 (40.6%)</td>
</tr>
<tr>
<td>The clinician was able to use the time more effectively</td>
<td>16 (19.0%)</td>
<td>12 (38.7%)</td>
</tr>
</tbody>
</table>

Impact of the Internet on Primary Care Staff in Glasgow.  
Journal of Medical Internet Research 1(2):e2
Major barriers

- **Accessibility**
  - Physical accessibility, conditions of access (privacy, filters, costs)
  - Findability
  - Readability
  - Design and usability
  - Lack of skills

- **Quality**
  - What is the quality out there?
  - How are consumers assessing the quality?
  - How can we guide consumers to the best available evidence to support decision-making?
Accessibility barriers

= the ability of the user to retrieve and understand information which is available on the web

Skills / Education Level

- Physical accessibility
- At home
- School
- Kiosk/Library

- Findability
- privacy
- convenience

- Asdsjg?
- Reading level

- Design + Usability
- Search engine developers
- site developers
- content developers
CAUSES OF DISEASES: You will find the following information very interesting.

Parasites and toxins. Have you ever thought about them? Traditional medical care doesn’t give them much thought, but we do. They ARE THE MAIN

Parasites are animals living in your body who should not be there.

Due to travel and immigration, all the parasites of the world are present in every

Parasitic diseases are very common. Have you ever thought about them? They are the main cause of illness in the world.

Learn how simple techniques and natural products have

Announcing a Cure for Almost All

Diseases!“

A Breakthrough at Last!

Solutions Ltd

Altemative

Self Health
Quality of health information on the internet

- Branding
  - Consumers spend money

- Building Trust
  - Consumers change behaviour

Business perspective

Public Health perspective
Systematic review of studies evaluating health information on the web
(Eysenbach et al., submitted 2001)

Inaccurate / non-evidence based information on the web

<table>
<thead>
<tr>
<th>Davison 1996 - Nutrition</th>
</tr>
</thead>
<tbody>
<tr>
<td>McClung 1998 - Diarrhea</td>
</tr>
<tr>
<td>Hatfield 1999 - Drug</td>
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<tr>
<td>Pandolfini 2000 - Cough</td>
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<tr>
<td>Tamm 2000 - Mammography</td>
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<td>Biermann 1999 - Ewing</td>
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<td>Miles 2000 - Diet</td>
</tr>
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<td>Griffith 2000 - Depression</td>
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<tr>
<td>Li 2001 - Back pain 1996</td>
</tr>
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<tr>
<td>Wright 1999 - Etiology CFS</td>
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<tr>
<td>Abbott 2000 - MMR vaccine</td>
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<td>Beredjiklian 2000 - Carpal tunnel</td>
</tr>
<tr>
<td>Bogenschutz 2000 - Hallucinogens</td>
</tr>
<tr>
<td>Hellaway 2000 - prostate cancer</td>
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<td>Hellaway 2000 - testicular cancer</td>
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<td>Stone 2001 - macular degen</td>
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n=1781 websites
27 studies
Systematic review of studies evaluating health information on the web
(Eysenbach et al., submitted 2001)

Inaccurate / non-evidence based information on the web

Cancer ~5% inaccurate

Davison 1996 - Nutrition
McClung 1998 - Diarrhea
Hatfield 1999 - Drug
Pandolfini 2000 - Cough
Tamm 2000 - Mammography
Biermann 1999 - Ewing
Miles 2000 - Diet
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Li 2001 - Back pain 1996
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<th>Study</th>
<th>Field</th>
<th>Accuracy</th>
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</tr>
<tr>
<td>Suarez-Almazor 2001 - rheumatoid arthritis</td>
<td>Nutrition</td>
<td>100%</td>
</tr>
<tr>
<td>Nutrition ~45% inaccurate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet ~89% inaccurate</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

n=1781 websites
27 studies
What consumers/webmasters say is important......

... doesn’t play out in reality

(% of sites not disclosing authors, according to 14 studies, n=1487 sites)
Policy Proposal

e-Health Code of Ethics (May 24)

e-Health Ethics Initiative*

(*see acknowledgements)

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Email: nfc@thephpz.com

Abstract and Keywords
Introduction
Definitions
Guiding Principles
Acknowledgements
References

ABSTRACT

The Internet is changing how people receive health information and health care. All who use the Internet for health-related purposes must join together to create an environment of trusted relationships to assure high quality information and services, protect privacy, and...
Quality criteria for health websites

Source Criteria (process)

Technical criteria

- Disclosure/Metainformation
- Features/Design
  - Disclosure, Candor
  - Authorship-Disclosure (Affil,Degr)
  - Currency-Disclosure
  - Sponsorship-Disclosure
  - Advertising Policy
  - Editorial Policy
  - Privacy Policy
  - Target Audience, Purpose, Scope

Content Criteria

- Accessability
- Readability
- Usability
- Accuracy/Not misleading
- Comprehensiveness/Completeness

Characteristics considered

- „ethical“ + create context

Knowledge/Attitude/Behaviour + Health outcome +
health information

determining the credibility of
Internet and
How are users accessing the
How are consumers searching for and digesting information?

CHIFoG
Consumer Health Information Focus Groups
How are consumers searching for and digesting information?

Usability studies
Consumer Health Information Retrieval Experiment

- Gave health questions to consumers
- Let participants search the web and try to come up with an answer from the web
- Sessions logged, videotaped
- Post-interview with consumer
- Qualitative analysis
How are users searching the web

- Users found answers to their question in an average of only 5 minutes
- Consumers used search engines (Google etc.) ...
  - 71% clicked on one of the first 5 links displayed
  - Only 2.8% moved on to the 2nd page of the search results
  - 2/3 User operated with one search term only
Links clicked in a search engine

![Graph showing the distribution of clicks for different search result link positions](image)

- **Anzahl Clicks**
- **Linkposition der Suchresultate**
We observed none of the participants checking “about us” sections, trying to find out who authors/owners of the site were, or reading disclaimers or disclosure statements.

In only 20% consumers could tell after the surfing experience from which websites they retrieved information from, or who stood behind the sites.

When assessing the credibility of a site, consumers primarily look for a professional design and language.
Strategies used by consumers to assess the „quality“

- „Comparison on various sites“
- „No side-effects“
- „Natural, no chemistry“
- „Design looks professional“
- „Sounds plausible“
- „Sounds scientific“
- „References cited“
- „Picture of the site owner – the site owner looks trustworthy“
Mock-up websites presented to consumers with different pictures
## Study 2a: Results

<table>
<thead>
<tr>
<th>Credibility Measure</th>
<th>Casual Author Photo (mean)</th>
<th>No Author Photo (mean)</th>
<th>Formal Author Photo (mean)</th>
<th>Statistically Significant?</th>
</tr>
</thead>
<tbody>
<tr>
<td>How believable is article?</td>
<td>.41</td>
<td>.70</td>
<td>.92</td>
<td>(P=.03)</td>
</tr>
<tr>
<td>How trustworthy is article?</td>
<td>-.17</td>
<td>.17</td>
<td>.41</td>
<td>(P=.003)</td>
</tr>
<tr>
<td>How competent is article?</td>
<td>.15</td>
<td>.35</td>
<td>.67</td>
<td>(P=.02)</td>
</tr>
<tr>
<td>How credible is article?</td>
<td>.15</td>
<td>.34</td>
<td>.47</td>
<td>ns</td>
</tr>
<tr>
<td>How unbiased is article?</td>
<td>.58</td>
<td>.76</td>
<td>.63</td>
<td>ns</td>
</tr>
<tr>
<td>How expert is article?</td>
<td>.09</td>
<td>.27</td>
<td>.47</td>
<td>(P=.009)</td>
</tr>
<tr>
<td>Composite Measure</td>
<td>.17</td>
<td>.42</td>
<td>.60</td>
<td>(P=.02)</td>
</tr>
</tbody>
</table>
Welcome to Natural Physician

Dr. Bob Sanders MD

Dr. Marc Sanders MD
South China Morning Post

ASIA

Thursday, July 20, 2000

AUSTRALIA

Medic blames suicides on Net diagnosis

ROGER MAYNARD in Sydney

An elderly Australian couple committed suicide after taking medical advice from the Internet and wrongly diagnosing a terminal disease, it was revealed yesterday.

The couple, from rural New South Wales, made the suicide pact after the man’s wife came to believe she had terminal cancer. The husband could not bear to be parted from his wife and chose to commit suicide with her. An autopsy showed the woman did not have cancer.

Dr David Rivett, chairman of the Australian Medical Association’s Council of General Practitioners, said that people should be cautious when using the Internet for medical purposes. He said the case highlighted the dangers of self-diagnosis.

http://www.scmp.com/News/Asia/Article/FullText_asp_ArticleID-20000720034447523.asp
Database of Adverse Events related to the Internet

Systematic collection of incidents related to Internet information – in analogy to post-marketing surveillance / pharmaco-vigilance systems
Database of Adverse Events Related to the Internet (DAERI)

About the project
Case Description - Online Form
Case Description - Download Form

Über das Projekt
Fallbeschreibung - Online Formular
Fallbeschreibung - Formular zum Download

A project initiated by
the Research Unit for Cybermedicine & E-health
Dept. of Clinical Social Medicine
University of Heidelberg

For any additional information, questions or comments please contact us

Disclaimer:
Database of Adverse Events Related to the Internet (DAERI)

1. Which kind of adverse event do you want to report?

- patient has been harmed (psychologically or physically) by misinformation on the Internet
- patient has misinterpreted information on the Internet, leading to considerable harm
- patient was seeing a physician too late because of Internet research or Internet diagnosis
- patient misdiagnosed him/herself or received a wrong diagnosis on the Internet
- patient consulted his/her physician recurrently or needlessly due to Internet-searches ("Cyberhypochondria")
- patient ordered drugs or products, which have been harmful for his health
- patient attempted or committed suicide due to the visit of websites or newsgroups containing suicide instructions
- Other

2. What is your role?
The future

✧ Patient accessible electronic health records on the Web
✧ Cyberpharmacies, „OTI“ drugs?
✧ Intelligent agents on the web will make use of the semantic web and answer consumer questions
✧ Decentralised quality management on the web harnessing the „semantic web“ (prototyped in the MedCERTAIN / MedCIRCLE projects)
About MyHealth.net
A MedicalLogic Network

This About MyHealth.net tour is from the point of view of our sample patient, Linda Purcell. You are welcome to walk through the tour as Linda does, screen by screen, or skip around if you'd like. If you have any questions, please send them to: info@aboutmyhealth.net

As you'll find in the tour, About MyHealth.net contains four sections:

- **Message Center**: In this section, you can review incoming messages, request an appointment with your doctor, request medication refills, and send messages to your doctors' offices.

- **Doctors & Charts**: In this section, you can review your chart, as well as additional detailed information.

- **Health News**: Here, you can read featured articles and search for other news within About MyHealth.net or on the Internet.

- **Search**: The medical library at About MyHealth.net can help you research topics or find answers to questions.

**Begin Tour**
Within her chart, Linda reviews her Medical Summary. She can select from any of the links within the Medical Summary list. On this visit, Linda is interested in finding out about her recent diagnosis of Acute Sinusitis. To do so, she selects "Health Problems" from the Health Info list at the left.
Disintermediation

Personal health information

Patient data

Information relevant to informed choice (available options)

External evidence

Medical knowledge

Health Record

Physician as infomediary

Patient accessible electronic health records

Patient

Literature

Mass Media

Internet
Disintermediation and new infomediaries

Consumer → Intermediary (e.g. travel agent) → Product (e.g. airline ticket)
Disintermediation and new infomediaries

E-commerce

Consumer → Intermediary (e.g. travel agent) → Product (e.g. airline ticket)
Disintermediation and new infomediaries

E-commerce

Consumer

Intermediary (e.g. travel agent)

Product (e.g. airline ticket)

New Infomediary (e.g. portal)
Disintermediation and new infomediaries

E-commerce

- Consumer
- Intermediary (e.g. travel agent)
- Product (e.g. airline ticket)
- New Infomediary (e.g. portal)

E-health

- Consumer
- Intermediary (e.g. health prof.)
- Health Information
- New Infomediary (e.g. portal)
MedCERTAIN
Certification and Rating of Trustworthy and Assessed Health Information on the Net
- EU funding 2000-2001
- University of Heidelberg (Ger), ILRT Bristol (UK), FinOHTA/STAKES (Fin)

MedCIRCLE
Collaboration for Internet Rating, Certification, Labelling and Evaluation
- EU funding 2002-2003
- University of Heidelberg (Ger), ÄZQ (German Medical Association/KBV) (Ger), Medical College Barcelona (Spain), CISMEF (France)
MedCERTAIN is not...

...yet another „award“ or „kitemark“
...rather it is a technical and organizational infrastructure harnessing the power of metadata and the "semantic web"
Decentralised 3rd party rating

- User
- Needs
- Meta-data (HIDDEL)
- Wide gap
- Low quality
- Narrow gap
- High quality
- Meta-data (HIDDEL)
- Site/information properties
- Rater
- Expertise
- Gateway / Rater

Information Provider
Surviving Cancer Cure Leiomysarcoma Survive K

Cool Links

What I'm Taking!

HealthGate

Hope Through Education!

Surviving Cancer
(Leiomysarcoma)

Cat's Claw
Selenium
Essiac Tea
Echinacea
Coenzyme Q-10

Colloidal Silver
Black Walnut Hulls
Avoid Coffee
Avoid Alcohol
Avoid Bone-meal
"I'm Surviving Cancer!"
(leiomyosarcoma)

The HIDDEL self-disclosure statement of this site shows that the content is intended for users from the US, while your health information needs profile shows that you prefer that the content is intended for users from the UK.

- Essiac Tea
- Avoid Coffee
- Echinacea
- Avoid Alcohol
- Coenzyme Q-10
- Avoid Bone-meal
Target_group = adult layperson

Funding_Source ≠ pharmaceutical company

HIDDEL (XML/RDF): Health Information Disclosure, Description and Evaluation Language
User sets preferences

Electronic, automatic „negotiation“ between client and host computer

HIDDEL (XML) encoded disclosure information of the information provider + third party statements

Target_group = adult layperson
Funding_Source ≠ pharmaceutical company

Target_group = physicians
Funding_Source = pharmaceutical company

Downstream-Filtering

Client

Target_group = adult layperson
Funding_Source ≠ pharmaceutical company

Host
Eysenbach G et al.
Website labels are analogous to food labels. BMJ 2001 322(7289): 794
A collection of medical, dental and veterinary images for use in teaching

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General registration info

Title: Bristol Biomedical Image Archive
Type of Health Information provider: Universities and higher educational institutions
Web server location: Bristol, UK
Company location: Bristol, UK
Country in which most employees work: UK
Main target country: UK
Internal procedures to ensure quality: Individual checking and repairing of images, making list for user feedback.
Broad subject categories of service: medicine, dentistry, veterinary medicine

A collection of
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Take two in the morning and don’t ask questions

Holy land of the knowing

No trespassing

Hole of ignorance

physician patient

Eysenbach G, Jadad AR.
Consumer health informatics in the internet age.
<URL: http://www.jmir.org/2001/2/e19/>
Let me educate* you

*(ex ducere = to lead out)

Hole of ignorance

Holy land of the knowing

No trespassing without professional guidance

Eysenbach G, Jadad AR.
Consumer health informatics in the internet age.
<URL: http://www.jmir.org/2001/2/e19/>
Welcome!

Watch your step

Internet patient education

physician patient

Eysenbach G, Jadad AR.
Consumer health informatics in the internet age.
<URL: http://www.jmir.org/2001/2/e19/>
Thank you!

Dr. G. Eysenbach,
Email: ey@yi.com,
http://yi.com/ey/

MedCERTAIN home: http://www.medcertain.org
Heidelberg Consensus Definition of „Trustmark“

Any certificate, symbol, sign, based on information or meta-information (information about information) provided by a third-party that is aiming

- to enhance peoples trust into a certain product, service, relationship, information provider or piece of information perceived as being trustworthy by the organisation issuing the trustmark.
- to enhance the ability of people to evaluate the trustworthiness of information, services or products.

Heidelberg Consensus Recommendations
Principles
To improve the consumer's experience with online health information, we have adopted the following ethical principles. We believe that in living by these principles, we can inform the consumer of our commitment to offering high-quality and ethical standards:

1. Providing health information that is trustworthy and up-to-date:
   - Keeping personal information private and secure, and employing special precautions for any personal health information:
   - Empowering consumers to distinguish online health services that follow our principles from those that do not:

Our commitment to offering high-quality and ethical services is reflected in our membership in the Hi-Health Ethics Council. As members, we are committed to ensuring that individual consumers can realize the full benefits of the Internet to improve their health and that of their families.
HI-Ethics Principles

- Privacy Policies in Conformance with Fair Information Practices
- Enhanced Privacy Protection for Health-Related Personal Information
- Safeguarding Consumer Privacy in Health Web site's Relationship with Third Parties
- Disclosure of Ownership and Financial Sponsorship
- Identifying Advertising and Health Information Content Sponsored by Third Parties
- Promotional Offers, Rebates and Free Items or Services
- Accuracy and Reliability of Health Information Content; Editorial Policy
- Authorship and Accountability
- Disclosure of Source and Validation for Assessment Services
- Professional Policies on the Internet
- Qualifications
- Transparency of Interactions, Candor and Trustworthiness
- Disclosure of Limitations
- Mechanism for Consumer Feedback
HI-Ethics

✧ 15 führende Gesundheitsportale in USA
✧ befolgen freiwillig 14 Prinzipien
✧ Mitglieder zahlen $20,000 pro Jahr
✧ zukünftig externe Zertifizierung durch URAC (früher angedacht: eTRUST)
LEAER/ACcreditation Awards Highlight Commitment to Quality and Accountability

Consumers want more assurance of the reliability of health care providers. Here's how they
health care quality is an international issue. Consumers want assurance of reliability. Says LEAER
Healthcare: First Order Internal Policy for Accreditation (HICs)

LEAER Releases Performance Measurement Tools for Hospitals, Healthcare Providers

LEAER awards highlight commitment to quality and accountability

Find out more about LEAER.

Read LEAER's New Code Standards.

Updated 2001 Education Schedule

LEAER offers Accreditation and Quality Improvement Training. LEAER's 2001 education offerings include:

LEAER website links to accreditation program.

Visit the LEAER website for more information.

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LEAER logo and website link.
Welcome to the VIPPS Information and Verification site of the National Association of Boards of Pharmacy.