Guidelines for Medical and Health Information Sites on the Internet

Principles Governing AMA Web Sites

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HE INTERNET HAS PERMITTED physicians, other health care professionals, patients, and other consumers to quickly access medical information in unprecedented volume. Such access has the potential to speed the transformation of the patient-physician relationship from that of physician authority ministering advice and treatment (with sometimes questionable patient understanding and adherence to recommendations) to that of shared decision making between patient and physician. However, several substantial barriers remain before this relationship can be realized. These barriers include equitable access to information, imbalance between patient health literacy and the information provided, extreme variability in the quality of the content, potential for commercial interests to influence content, and uncertain preservation of personal privacy.¹⁻⁴

Web users have been warned regarding the incomplete, misleading, or inaccurate medical information available on the Web.³ For those seeking easy ways to identify high-quality, reliable infor-

Access to medical information via the Internet has the potential to speed the transformation of the patient-physician relationship from that of physician authority ministering advice and treatment to that of shared decision making between patient and physician. However, barriers impeding this transformation include wide variations in quality of content on the Web, potential for commercial interests to influence online content, and uncertain preservation of personal privacy. To address these issues, the American Medical Association (AMA) has developed principles to guide development and posting of Web site content, govern acquisition and posting of online advertising and sponsorship, ensure site visitors' and patients' rights to privacy and confidentiality, and provide effective and secure means of e-commerce. While these guidelines were developed for the AMA Web sites and visitors to these sites, they also may be useful to other providers and users of medical information on the Web. These principles have been developed with the understanding that they will require frequent revision to keep pace with evolving technology and practices on the Internet. The AMA encourages review and feedback from readers, Web site visitors, policymakers, and all others interested in providing reliable quality information via the Web.

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mation, some Web sites and organizations have provided rating systems to evaluate quality of information on the Internet. However, these systems often do not provide the criteria used to assess quality, nor do they provide the reliability and validity of their measures. ^{2,4,5} Ultimately, assessing the quality of content depends on the same factors that readers of print publications depend on: authorship of the content, attribution to the sources of content, disclosure of funding and competing interests, and timeliness of the information presented. ³

Among Internet users who seek medical information, personal privacy was ranked as their most important concern.⁶ A recent study found that

while many Internet health information sites provide privacy policies, most do not follow them. More than nearly any other type of information provided via the Web, medical Web sites must adhere to strict personal privacy codes to prevent individuals personal medical information, including patterns of use and interests, from involuntarily entering the hands of marketers, employers, and insurers.

Information from the American Medical Association (AMA), including the tables of contents and abstracts

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1600 JAMA, March 22/29, 2000—Vol 283, No. 12

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of *JAMA* and the *Archives* Journals, has been available on the Web since 1995. Physician Select, a database of physicians that is intended for the public and is searchable by name, specialty, and location, has been online since July 1996. Health Insight, a health information site for consumers, was launched in spring 1997. *JAMA* and the *Archives* Journals have been available in full text and fully searchable online since September 30, 1999.

The AMA has developed and followed a number of guidelines to govern aspects of its Web offerings. For example, in 1995, the Principles Governing Advertising in Publications of the American Medical Association8 were revised from guidelines that addressed only print publications to guidelines addressing advertising on the Web sites of JAMA and the Archives Journals. In 1997, an editorial in JAMA proposed a set of quality standards for medical information on the Internet.3 These standards include proper identification of authors and contributors; attribution for all sources of information: disclosures of site ownership, financing, advertising, and conflicts of interest; and indication of the dates content is posted and updated. In October 1999, the AMA Board of Trustees approved Web Site Linking Guidelines.

Now, in addition to the AMA Publications site and the AMA Web site, the AMA and 6 other founding societies are preparing to launch Medem, a health information Web site for the public. To provide guidance for all these sites, the *Guidelines for the AMA Web Sites*, provided herein (see next page), address the creation and updating of content, acquisition and posting of advertising, the preservation of privacy and confi-

dentiality, and the provision of reliable and efficient e-commerce.

The development of these guidelines began in 1999. An AMA staff committee, composed of the listed authors, was organized to review the existing individual guidelines and draft a single document that would provide principles to govern the presentation and functionality of the 4 major areas for which quality standards were needed: content, advertising and sponsorship, privacy and confidentiality, and e-commerce. Initial drafts were reviewed by committee members and consensus was reached on the content of each of the 4 principles. The document was then reviewed internally and externally by experts in ethics, publishing, government regulations, law, and medical informatics and by the AMA Online Oversight Panel. After subsequent revision, the document was reviewed by the Executive Committee of the AMA Board of Trustees and was approved on February 28, 2000.

The dissemination of medical and health information via the AMA Web sites has been evolving since 1995. During the last 5 years, the AMA has had substantial experience providing online content, some experience with online advertising and sponsorship, and limited experience with e-commerce. The Guidelines for AMA Web Sites were created to facilitate the maturation and implementation of these and other Web-based functions, while simultaneously assuring site visitors' rights to privacy and confidentiality. Many of the principles outlined in these guidelines have served the AMA Web sites during their 5-year evolution. However, the guidelines will be fully operational on the AMA Web sites in conjunction with

the implementation of registration and access control in the near future.

The primary goal in creating these guidelines was to guide the development and maintenance of the AMA Web sites. However, these guidelines may be helpful to others providing medical information on the Web, as well as to viewers who want to know what to look for as they search for reliable high-quality medical information.

These guidelines are not static; the constant evolution of the Web ensures that guidelines will need ongoing reevaluation and frequent revision. We encourage readers, viewers, others interested in the provision of online medical information, and policymakers to review and comment on these guidelines. Future revisions will consider these comments while retaining the guidelines' fundamental principles: authorship, attribution, and disclosure must always be clearly provided; editorial content must be current and the way in which quality is ensured explicitly stated; advertising and commercial sponsorship must not influence any editorial content and advertising must be easily discernible from editorial content; privacy and confidentiality policies must be explicit and adhered to, ensuring that individuals' rights to privacy and confidentiality are preserved; and e-commerce must function efficiently and securely. Adherence to these fundamental principles will facilitate acquisition and application of medical information by patients, the public, physicians, and other health care professionals.

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REFERENCES

- **1.** Jadad AR. Promoting partnerships: challenges for the Internet age. *BMJ*. 1999;319:761-764.
- Eysenbach G, Diepgen TL. Towards quality management of medical information on the Internet: evaluation, labelling, and filtering of information. *BMJ*. 1998; 317:1496-1500.
- **3.** Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling, and assuring the quality of medical information on the Internet: caveant lector et viewor—let the reader and viewer beware. *JAMA*. 1997;277:1244-1245.
- **4.** Federal Trade Commission privacy initiatives. Available at: http://www.ftc.gov/privacy/index.html.
- **5.** Jadad AR, Gagliardi A. Rating health information on the Internet: navigating to knowledge or to Babel? *JAMA*. 1998:279:611-614.
- 6. Ethics survey of consumer attitudes about health Web sites: new survey shows Internet users wary of health information privacy; California Health Care Foundation says industry wide guidelines necessary. Available at: http://ehealth.chcf.org/index
- _show.cfm?doc_id = 7. Accessed February 25, 2000.
- 7. Goldman J, Hudson Z, Smith RM. Report on the privacy policies and practices of health Web sites. Available at: http://ehealth.chcf.org/priv_pol3/index_show.cfm?doc_id = 33. Accessed February 25, 2000
- 8. Principles governing advertising in publications of the American Medical Association (revised May 1999). Available at: http://pubs.ama-assn.org/how_principl.html.

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JAMA, March 22/29, 2000—Vol 283, No. 12 **1601**

Guidelines for AMA Web Sites

HE FOLLOWING GUIDELINES APply to all American Medical Association (AMA) Web sites, including any Web sites with which the AMA's name is associated in any way other than a simple link to any of the AMA Web sites. These guidelines are the AMA's policy for its Web sites but also are intended to provide guidance for creators of Web sites that provide medical and health information for professionals and consumers. These guidelines are established with the understanding that the World Wide Web is a constantly evolving technology, and the guidelines must be reviewed and revised frequently to ensure that they reflect the current state of technology and practice on the Web.

A standing committee composed of AMA staff members from the Scientific Publications and Multimedia, Publishing and Business Development, Ethical Standards, and Internet and Database Services areas will review the guidelines regularly and revise as necessary. The committee will seek review and comment from an advisory panel of individuals outside the AMA with expertise in Web-based content, advertising, privacy and confidentiality, and e-commerce.

I. PRINCIPLES FOR CONTENT

The AMA is committed to providing medical and health information of high quality via its Web sites. Visitors to AMA Web sites will be given information, navigational direction, and tools needed to judge the quality, reliability, objectivity, sources, and funding of content and to make effective use of content.

Definition of Content

Content is defined as all material (including text, graphics, tables, equations, audio, and video) and menu/directional icons, bars, indicators, listings, and indexes. These principles also address functions that support con-

tent (eg, links, navigation, searches, calculations).

Site Ownership

Website ownership, including affiliations, strategic alliances, and significant investors, should be clearly indicated on the home screen or directly accessible from a link on the home screen.

Copyright ownership of specific content should be clearly indicated on screen and on items printed from the site.

Site Viewing

The site should provide information about the platform(s) and browser(s) that permit optimal viewing in a location that is easy to find.

Viewer Access, Payment, and Privacy

Information about restrictions on access to content, required registration, and password protection (if applicable) should be provided and easy to find.

Information about payment (ie, subscriptions, document delivery, pay per view, etc) should be provided and easy to find. See "Principles for E-commerce" herein.

Information about privacy should be provided and easy to find. See "Principles for Privacy and Confidentiality" herein.

Funding and Sponsorship

Funding or other sponsorship for any specific content should be clearly indicated and should comply with the "Principles for Advertising and Sponsorship" herein.

Content should be easily distinguished from advertising as described in "Principles for Advertising and Sponsorship."

Quality of Editorial Content

Guidelines for editorial content review, posting dates, and sources were

developed based on experience with the AMA Scientific Publications' sites. All scientific publications and consumer site information adhere to these guidelines. As of publication of these guidelines, content posted on the AMA corporate site will adhere to these guidelines as well.

Review. Content should be reviewed for quality (including originality, accuracy, and reliability) before posting. Clinical editorial content should be reviewed by content experts not involved in creation of the content, and the content should be revised appropriately in response to such review. The method of review will be determined by individual sites. (For example, Scientific Publications sites include peer review. Other sites rely on review by editorial boards.)

The language complexity of the content should be appropriate for the site's audience. Content should be reviewed for grammar, spelling, and composition before posting.

A description of the editorial process and method of content review should be posted on the site.

A list of staff members and other individuals (eg, editorial board) responsible for content quality, other than anonymous peer reviewers, should be posted on the site.

Date of Posting, Revising, and Updating and Timeliness of Editorial Content. The dates that content is posted, revised, and updated should be clearly indicated. Procedures for updating and removing time-sensitive content should be developed, implemented, and periodically reviewed to ensure that the updating and review schedule is appropriate. (For example, content can be sorted by date posted and all content older than 6 months reviewed for timeliness and accuracy.) An indication of significant revisions to any specific content should

1602 JAMA, March 22/29, 2000—Vol 283, No. 12

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be posted and may include instructions to discard copies of versions previously printed or downloaded.

Sources of Editorial Content. Source for specific content should be clearly identified (ie, author byline or names of individual, organizational, departmental, institutional, agency, or commercial provider/producer).

Affiliations and relevant financial disclosures for authors and content producers should be clearly indicated.

Individuals who post content in online discussions, chat rooms, and e-lists should be instructed to disclose financial interests and commercial funding or affiliations related to the subject of the posted content discussion, chat, or list.

Reference material used to develop content should be cited in a manner appropriate for the site's audience.

Linking

Intrasite content links should be reviewed before posting and maintained and monitored. If links are not functional, links should be repaired in a timely manner.

External site links should be reviewed before posting and maintained and monitored. If links are not functional, these links should be repaired in a timely manner.

External links to commercial sites must comply with the "Principles for Advertising and Sponsorship."

Intersite Navigation

Sites should not prevent viewers from returning to a previous site.

Sites should not redirect the viewer to a site the viewer did not intend to visit.

Sites should not frame other sites without permission.

Downloading Files

If content can be downloaded in a portable document file (PDF) format, instructions regarding how to download the PDF file and how to obtain the necessary software should be provided and easy to find. A link to such software should be provided.

Navigation of Content

Features that facilitate use of the site should be provided and easy to find, and should include a site map or other site organizational guide, a help function or frequently-asked-questions page, a feedback mechanism, and customer service information (if available).

Each distinct site should provide a search engine or appropriate navigation tool to facilitate use. If the site provides a search engine, instructions specifying how to use the search function and how to conduct different types of searches may be provided.

Graphics files should include a "mouse over" indication of the graphical content. For large files, the space where the file resides should include the size of the file. As a courtesy to the viewer, when possible, when a large file can be downloaded by clicking, the viewer may be informed of the size of the file before the file begins downloading and should have the opportunity to cancel the download.

II. PRINCIPLES FOR ADVERTISING AND SPONSORSHIP

These principles are revised from the Principles Governing Advertising in Publications of the American Medical Association, previously revised in May 1999.

These principles are applied by the AMA to ensure adherence to the highest ethical standards of advertising and to determine the eligibility of products and services for advertising on the AMA Web sites.

The appearance of advertising on the AMA Web sites is neither a guarantee nor an endorsement by the AMA of the product, service, or company or the claims made for the product in such advertising. The fact that an advertisement for a product, service, or company has appeared on the AMA Web sites shall not be referred to in collateral advertising.

As a matter of policy, the AMA will sell advertising space on its Web sites when the inclusion of advertising does not interfere with the mission or objectives of the AMA or its publications.

To maintain the integrity of the AMA Web sites, advertising (ie, promotional material, advertising representatives, companies, or manufacturers) cannot influence editorial decisions or editorial content (as defined in "Principles for Content"). Decisions to sell advertising space are made independently of and without information pertinent to specific editorial content. The AMA Web sites' advertising sales representatives have no prior knowledge of specific editorial content before it is published.

Placement of advertising adjacent to (ie, next to or within) editorial content on the same topic is prohibited (for the table of contents, a banner advertisement must not appear next to the title of a related article). Just as a print advertisement should not be placed next to an editorial page on the same topic, a digital advertisement should not be adjacent to editorial content on the same topic, either by linking or appearing adjacent in the content section of the same screen. Similarly, just as a print reader can choose to read an advertisement or skip over it, a computer user should have the option to click or not click on an advertisement. Viewers will not be sent to a commercial site unless they choose to do so by clicking on an advertisement.

The AMA, in its sole discretion, retains the right to decline any submitted advertisement or to discontinue posting of any advertisement previously accepted.

Advertising

- 1. Digital advertising may be placed on the AMA Web site.
- 2. Digital advertisements must be readily distinguishable from editorial content. If the distinction is unclear, the word "advertisement" should be added.
- 3. Digital advertisements may appear as fixed banners or as rotating advertisements.
- 4. Digital advertisements may not be juxtaposed with, appear in line with, or appear adjacent to editorial content on the same topic, or be linked with editorial content on the same topic.
- 5. Digital advertisements that are fixed in relation to the viewer's screen

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JAMA, March 22/29, 2000—Vol 283, No. 12 **1603**

or that rotate should be placed to ensure that juxtaposition (as defined in item 4 above) will not occur as screen content changes.

- 6. Digital banner advertisements should be limited to 1 advertisement per screen view.
- 7. Advertisements and promotional icons may not appear on the home page of the AMA Web site (http://www.ama-assn.org) or the home pages of *JAMA* (http://www.jama.com) or the AMA *Archives* Journals (http://pubs.ama-assn.org/archives_home.html).
- 8. AMA, *JAMA*, and *Archives* Journals logos may not appear on commercial Web sites as a logo or in any other form without prior written approval by the individuals responsible for the respective areas within AMA.
- 9. Advertisements may link to additional promotional content that resides on the AMA Web site.
- 10. Advertisements may link off-site to a commercial Web site, provided that the viewer is clearly informed with a buffer page that to proceed by clicking would mean the viewer would leave the AMA Web site and that the AMA Web site does not vouch for or assume any responsibility for any material contained on the Web site to which it links. The buffer page will display the following statement:

You are leaving the AMA Web site. If you wish to link to a Web site maintained by [company name], please click below. If you do not wish to leave the AMA Web site, please click on the "back" button of your browser to return to the site. The AMA does not assume responsibility for content of other Web sites.

The AMA will not link to Web sites that frame the AMA Web site content without express permission of the AMA; prevent the viewer from returning to the AMA Web site or other previously viewed screens, such as by disabling the viewer's "back" button; or redirect the viewer to a Web site the viewer did not intend to visit.

The AMA reserves the right to not link to or to remove links to other Web sites.

11. Methods of corporate funding should be described in the Web site's

information about advertising or the digital rate card.

Sponsorship

- 1. All financial or material support for electronic collections of articles, Web site content, and other types of online products (such as condition-specific Web sites, online databases, or material on CD-ROM) will be acknowledged and clearly indicated on the home screen or via a link from the home screen.
- 2. Acknowledgment of support will appear on the home page, on the running foot of all pages, on any packaging and collateral material included (eg, CD-ROM jewel case and companion print insert), and on any materials used to publicize the online product. Content accessed through the site that does not reside on the site (eg, abstracts or articles from another site) will not include sponsorship information.
- 3. These acknowledgments will not make any claim for any supporting company product(s). The final wording and positioning of the acknowledgment will be determined by the AMA. The wording will be similar to "Produced by [AMA publication] with support from [Company]."
- 4. The home page acknowledgment of digital products may be linked to an on-site "About [Company]" page or may link to the company's Web site through the intervening buffer page referred to in "Advertising." item 10.
- 5. The "About [Company]" page may be linked to other on-site pages provided by the supporting company. These pages must be readily distinguishable from editorial content, must be clearly labeled as provided by the supporting company, and must not be linked to related AMA editorial content.
- 6. The running foot acknowledgment will not be linked to any other materials.
- 7. Other acknowledgments and disclosures may be required, as deemed necessary by the AMA.
- 8. AMA, *JAMA*, and *Archives* Journals logos may not appear on the spon-

soring company Web site as a logo or in any other form without prior written approval by the individuals responsible for the respective areas within the AMA.

III. PRINCIPLES FOR PRIVACY AND CONFIDENTIALITY

The following principles reflect the AMA's commitment to maintain the Web site visitor's rights to privacy and the confidentiality of personal information. In this context, privacy refers to the right of the individual site visitor to choose whether to allow personal information to be collected, by the host site (in this case, the AMA) or by third parties, and to know what type of information is collected and how that information is used. Confidentiality is the right of an individual to not have personally identifiable medical or other information disclosed to others without that individual's express informed consent.

The Internet has the potential to allow information about Web site use to be tracked in aggregate (which can help site developers understand site use and improve the experience of the viewer) and at the individual user level. Individual user information can improve the visitor's experience of the site by permitting personalization of the site related to the individual's particular interests or concerns. However, tracking of personal medical and health information (ie, medical conditions, healthseeking behaviors and questions, and requests about drug therapies or medical devices or information pertaining to them) could breach an individual's personal privacy and reveal an individual's health data.

Thus, health and medical Web sites have a particular obligation to protect the privacy and confidentiality of individuals. Patients and individuals with interest in particular medical conditions should feel confident in obtaining information and using resources on the site, without concern that such use will be identified with them without their permission. The AMA believes that all site visitors should have the opportunity to opt in or out of allowing per-

1604 JAMA, March 22/29, 2000—Vol 283, No. 12

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sonal information to be tracked. In addition, the AMA takes extensive measures to ensure the safety and security of its Web site servers and to guard against divulging private information. The AMA believes that Web site visitors should know who (eg, the site organization or third party) is tracking personal information and the types of personal information that are tracked and should have the right to opt out of such information being collected at any time.

Protection of patients' rights to confidentiality is fundamental to medical publishing. Health care professionals must adhere to privacy and confidentiality principles to legally and ethically share important information about medical conditions of individual patients. The sharing of such information may improve clinical care for the individual or improve the general state of knowledge about medical and health care through medical research. Medical publications, whether in print or online, must not reveal identifiable information about an individual without that person's express informed consent. These principles apply to information in medical publications (eg, JAMA) as well as less formal venues used by health care professionals, such as online discussion groups, chat rooms, and e-lists.

Privacy

- 1. A link to the privacy policy of the Web site should be provided on the home page or the site navigational bar and should be easily accessible to the user. The Web site should adhere to the privacy principles posted.
- 2. Individuals responsible for Web sites that post advertising should be aware of current technology and access possessed by third parties that post or link to advertisements. Web sites should ensure that the technology and access used by third parties adheres to the Web site's privacy policies.
- 3. The site should not collect name, e-mail address, or any other personal information unless voluntarily provided by the visitor after the visitor is informed about the potential use of such information.

- 4. The process of opting in to any functionality that includes collection of personal information should include an explicit notice that personal information will be saved, with explanation of how the information will be used and by whom. The opt-in statement should not be embedded in a lengthy document and should be explicit and clear to the viewer.
- 5. Collection, retention, and use of nonmedical personal information about site visitors may be offered to viewers when the AMA believes that such information would be useful in providing site visitors with products, services, and other opportunities, provided such use adheres to these principles and is within bounds of current regalations and law (http: //www.ftc.gov/privacy/index.html). Individuals may agree to have such nonmedical personal information collected or may choose not to, with the understanding that opting out of having such information collected prevents the site from being tailored to their particular needs and interests. Such information will not include personal health information, such as any information about medical conditions or medications purchased.
- 6. Names and e-mail addresses of site visitors should not be provided or released to a third party without the site visitor's express permission.
- 7. E-mail information, personal information about specific visitor's access and navigation, and information volunteered by site visitors, such as survey information and site registration information, may be used by the site owner to improve the site but should not be shared with or sold to other organizations for commercial purposes without the site visitor's express permission.
- 8. The AMA will use e-mail addresses voluntarily provided by site visitors to notify them about updates, products, services, activities, or upcoming events. Site visitors who do not wish to receive such notifications via e-mail should be able to opt out of receiving such information at any time.
- 9. The AMA has licensed its physician and medical student list to third

- parties for more than 50 years. This information is licensed to database licensees under strict guidelines. The names and addresses of physicians in the AMA Physician Masterfile are made available only for communications that are germane to the practice of medicine or of interest to physicians or medical students as consumers. E-mail addresses are excluded from such licensing agreements.
- 10. Nonidentifiable Web site visitor data may be collected and used in aggregate to help shape and direct the creation and maintenance of content and to determine the type of advertisement to be seen by site visitors while on the AMA site.
- 11. The AMA will not collect and will not allow third parties to collect personal medical information (medical conditions, health-seeking behaviors and questions, and use of or requests for information about drugs, therapies, or medical devices) without the express consent of the site visitor after explanation of the potential uses of such information.
- 12. A *cookie* is a small file stored on the site user's computer or Web server and is used to aid Web page navigation. Two types of cookies are commonly used. A *session cookie* is a temporary file created whenever a Web site is accessed and is self-terminated based either on an expiration date (eg, 3 hours from creation of the cookie) or by closing the Web browser. A *persistent cookie* is a permanent file and must be deleted manually. Cookies referred to in the context of these Guidelines are persistent cookies.

A cookie function may be used on the site to track visitor practices to help determine which site features and services are most important and guide editorial direction. The cookie makes it possible for the user to access the site without requiring entry of a user name or password, allows the user to view different restricted areas of the site without reregistering, allows the user to personalize the site for future use, and permits the user to make subsequent purchases without reentering credit

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JAMA, March 22/29, 2000—Vol 283, No. 12 **1605**

card information. Users who do not desire the functionality created by the cookie should have the option to disable the cookie function, either by indicating when asked that they do not wish to have a cookie created or by disabling the cookie function on their browser. Individuals should be able to opt out of cookie functions that permit tracking of personal information at any time.

- 13. E-mail messages sent to a Web site may not be secure. Site visitors should be discouraged from sending confidential information by e-mail. Site visitors sending e-mail accept the risk that a third party may intercept e-mail messages.
- 14. Market research conducted by the site or its agent to enhance the site should be clearly identified as such.
- 15. E-mail alerts and newsletters should contain an "unsubscribe" option.

Confidentiality

Content published within the AMA Web sites that includes patient information should adhere to the patient privacy and anonymity principles followed by *JAMA* and the *Archives* Journals, which are based on the recommendations of the International Committee of Medical Journal Editors (http://jama.ama-assn.org/info/auinst_req.html). These principles apply equally to formal medical publications and the informal interactive communication permitted by the Web, including online discussion groups, chat rooms, or e-lists.

Patients should be aware when they provide information about their individual medical conditions in the context of such discussions that information may be linked with a personal identifier. However, AMA Web sites will not collect information about individual medical conditions without the express permission of the site visitor. Physicians and other health care professionals should be aware that any patient information reported in the context of such venues must adhere to the

confidentiality principles listed herein. Moderators of such sessions should make every effort to ensure that listed material adheres to the principles stated herein and, when in doubt, should query the individual providing the information. If the individual is a patient providing such information, the moderator should query the patient as to whether the patient intends for the sensitive medical information to be revealed. If the individual providing the information is a health care professional, the moderator should query the professional as to whether the patient reported has provided informed consent and state so.

Patients have a right to privacy that should not be infringed without express informed consent. Identifying patient information should not be published in print or online descriptions, photographs, or pedigrees (illustrations of how a disease is expressed within an extended family for purposes of determining possible inheritance) unless the information is essential for scientific purposes and the patient (or parent or guardian) gives express informed consent for publication.

Identifying details should be omitted if they are not essential, but patient data should never be altered or falsified in an attempt to attain anonymity. Complete anonymity is difficult to achieve, and informed consent should be obtained if there is any possibility as to whether identifiable information may be disclosed.

When express informed consent has been obtained, it should be indicated in the posted Web content.

IV. PRINCIPLES FOR E-COMMERCE

The AMA e-commerce principles are intended to ensure that users and purchasers of information, products, and services on the site will have access to secure, efficient transactions for online and remote customer fulfillment. All such transactions should adhere to

the AMA "Principles for Privacy and Confidentiality."

- 1. A link or reference to the site's policies on privacy should be clearly visible.
- 2. The security software and encryption protocol used on the site for financial transactions should be described.
- 3. Users should be able to select whether or not the Web host will retain the user name and password (ie, disable cookie function, as described in "Principles for Privacy and Confidentiality"). Users should be able to opt in or opt out of functions that track personal information at any time.
- 4. A link or reference to customer service contact information (e-mail, telephone, fax, mail), including hours of operation and time zone, should be clearly visible.
- 5. The terms of use for e-commerce should require a deliberate selection (accept/not accept).
- 6. Users should be able to review transaction information prior to execution (information, products, and services listed; prices; totals; shipping and handling expenses).
- 7. As a courtesy, following execution of the transaction, users should be provided, on a page or by e-mail, purchase information (see item 6 above) as well as shipping tracking number, if appropriate.
- 8. Users will be notified on-screen when entering or leaving a secure site and will have the option to proceed or remain on the current site.
- 9. If a user's browser does not support a secure connection, no financial transactions will be permitted over the Internet.
- 10. Response times for feedback and fulfillment should be clearly stated.
- 11. Products and services will not be endorsed or cobranded by the AMA or AMA publications. Any product promotions must adhere to the "Principles for Advertising and Sponsorship."