

AHIMA Releases E-health Tenets

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In August 2000, AHIMA released a set of fundamental principles and operating tenets for placing consumer health records on the Internet. An excerpted version of these tenets follows. The document can be found in its entirety on AHIMA's Web site at www.ahima.org/hot.topics/ [web page no longer available].

In recent years, the efforts of the Association have expanded to encompass issues concerning individually identifiable health information on the Internet. AHIMA created a task force of association professionals to develop tenets to address concerns regarding personal health information on the Internet.

Tenets and Principles

Out of these collaborative efforts, the task force developed 39 tenets on e-health that are summarized below. The tenets are grouped according to these fundamental principles:

- **Educate consumer:** E-health organizations (organizations that collect and display individually identifiable health information via the Internet) should conspicuously provide an easily understandable notice of their health information practices. Such notices should inform e-health consumers (individuals whose individually identifiable health information is collected, maintained, or displayed via the Internet) what personal health information is being collected, who is collecting the data, and how it is being used
- **Facilitate information collection:** E-health organizations should facilitate the collection of authentic, accurate, timely, and complete individually identifiable personal health information
- **Maintain private, secure information:** E-health organizations should maintain individually identifiable personal health information in a manner that ensures the information is private, secure, and retained or destroyed only in accordance with the e-health consumer's authorization or applicable federal and state laws

AHIMA acknowledges and thanks the efforts of the team who co-authored these recommendations:

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AHIMA's Basic Operational Tenets for Protecting the Privacy of Personal Health Information on the Internet

Tenet	Applicability			Purpose		
	Provider	Consumer	Third-party	Educate Consumers	Facilitate Info. Collection	Maintain Private, Secure Info.
1. Inform consumers about what information is collected, by whom, and how it will be used. The notice of information practices should be conspicuously provided in language the lay-person can understand.	X	X	X	X		X
2. Web site ownership, or relationships a reasonable person would believe likely to influence the site's information or services, should be clearly indicated on the home page or on a page directly accessible from the home page.	X	X	X	X		X

3. Provide users with reference information for contacting customer support (e-mail address or phone number, hours available, and time zone).	X	X	X	X		
4. Site owners should provide a mechanism for assistance in interpreting medical abbreviations and terminology.	X		X	X		
5. Provide users with a clear explanation of the content of the record, in addition to instructions for navigating the site.	X	X	X	X		
6. Inform consumers as to the security measures that sites use to protect their information from unauthorized access and use. This security information should be placed on the home page or a page directly accessible from the home page.	X	X	X	X		X
7. Obtain and maintain a list of authorized users.	X	X	X			X
8. Notify users on screen when they enter or leave the e-health owner's Web site.	X	X	X	X		X
9. Give consumers meaningful opportunities to make choices about what information is collected and how the information will be used. ¹ Sites should collect no information without the user's knowledge. Give Web site consumers the right to opt into or out of specific uses and disclosures of information.	X	X	X	X		X
10. Restrict the health information collected to what is necessary to carry out the legitimate purpose for which it was collected. ²	X	X	X			X
11. Collect and use healthcare information only for a necessary lawful purpose. ³	X	X	X			X
12. Privacy protections should follow consumers' data. ⁴	X	X	X			X
13. Web sites should maintain a consumer-specific log of information disclosures. This log should be available for review by the consumer.	X	X	X	X		X
14. E-health sites should develop, implement, and adhere to a rigorous information security infrastructure that includes appropriate policies, procedures, technology, and architecture to protect information against threats to data integrity and repudiation.	X	X	X		X	X
15. Collect, maintain, and disclose information in a manner that safeguards personal information and complies with applicable federal and state laws and regulations. ^{5,6}	X	X	X		X	X
16. Give consumers the opportunity to see, copy, and append their records. ⁷ Tools for appending should be easy to find and use.	X	X	X	X	X	X
17. E-health site owners have an obligation to make sure that the information they collect and display at their site is of high quality.	X	X	X		X	
18. E-health sites should establish and implement methods to assure data recovery after intentional or unintentional loss.					X	X
19. E-health sites should develop and maintain a data dictionary that is available to consumers. The data dictionary should define what will be collected, explain the aim or purpose of each data element, provide clear and concise data definitions, set acceptable values or value ranges, and state when and who will enter the data, and how it will be authenticated.	X	X	X	X	X	
20. E-health owners shall specify data element definitions that conform to standard nomenclature and formally approved standards.	X	X	X		X	
21. Regardless of format, information must be decipherable and readable.	X	X	X		X	
22. Record data at or near the time of the event or observation.	X		X		X	

23. Consumers who provide their own health information for access by others on the Web will be advised as to the importance of providing the information in a timely manner.		X		X	X	
24. The length of time between an event that produces data and when the data is available at the Web site to those who need the information should be minimal.	X	X	X		X	
25. Data should be authentic and represent what was intended or defined by the official source. It should be objective, unbiased, and comply with known standards. ⁸	X	X	X		X	
26. Data should yield the same results on repeated collection, processing, storing, and displaying of information.	X	X	X		X	
27. Make data available to authorized internal and external users when and where it is needed.	X	X	X		X	
28. Edits, validation checks, procedures, and controls should be established and implemented to ensure errors are avoided when reviewing, recording, or updating information.	X	X	X		X	
29. Appropriate hyperlinks to directories, references, additional information, and other applications should be established and maintained.	X	X	X	X	X	
30. E-health sites should develop, implement, and adhere to policies that define whom, how, and when data can be entered or modified.	X	X	X		X	X
31. Advise consumers as to the importance of accurate data entry. Methods for checking the accuracy of the information entered should be suggested and their use encouraged.		X		X	X	
32. Continuous data quality validation activities should be performed, including periodic quantitative, legal, and qualitative analysis.	X		X		X	
33. Implement appropriate education and training.	X	X	X	X	X	X
34. E-health sites that collect or display individually identifiable consumer health information should make sure that the data is documented, authenticated, corrected, stored, retained, and destroyed in a manner that is consistent with the requirements of federal and state law and regulation.	X	X	X		X	X
35. E-health site owners should ensure the record's content conforms to known health data standards. ⁹	X	X	X		X	
36. Each record should indicate the date when the displayed information was recorded, last updated, and last substantially changed.	X	X	X	X	X	X
37. Systems should be in place to ensure that data collected and displayed is complete unless otherwise stated.	X	X	X	X	X	
38. The site should specify whether the information available is the primary healthcare record or a subset of information collected and maintained elsewhere.	X			X	X	
39. The site should specify when, where, and how to access individually identifiable consumer health information that is collected and maintained, but which is not available at the particular e-health site.	X	X	X	X	X	

Notes

1. Fair Information Practice Principles, published in the 1973 government report *Records, Computers, and the Rights of Citizens*.

2. AHIMA Tenet on Confidentiality and Federal Legislation.
 3. AHIMA Tenet relative to Confidentiality and Federal Legislation.
 4. Fair Information Practice Principles.
 5. Fair Information Practice Principles.
 6. See Appendix A for a list of applicable federal laws and regulations, available on AHIMA's Web site.
 7. Fair Information Practice Principles.
 8. See Appendix B for a list of standards that may be applicable to e-health sites, available on AHIMA's Web site.
 9. *Ibid.*
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