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# **Confidentiality of Electronic Health Data: Methods for Protecting Personally Identifiable Information**

January 1990 through March 1996  
448 Selected Citations

Prepared by

Ione Auston, M.L.S., National Library of Medicine  
Betsy L. Humphreys, M.L.S., National Library of Medicine  
Paul D. Clayton, Ph.D., Columbia-Presbyterian Medical Center  
Isaac S. Kohane, M.D., Ph.D., Harvard Medical School  
Lance J. Hoffman, Ph.D., George Washington University  
Zdenka Geisslerova, National Library of Medicine

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Karen Patrias, Editor  
Current Bibliographies in Medicine  
Reference Section  
National Library of Medicine  
Bethesda, MD 20894  
Phone: 301-496-6097  
Fax: 301-402-1384  
Internet: patrias@nlm.nih.gov

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## **FOREWORD**

In 1995, in response to a request from the Vice-President of the United States of America, the Department of Health and Human Services assumed a leadership role in addressing four major issues surrounding the use of the National Information Infrastructure to advance health care and the public health: (1) telemedicine; (2) health data privacy; (3) health data standards; and (4) consumer access to health information. One specific health data privacy objective is the identification and dissemination of information about current best practices for ensuring the confidentiality of electronic health data. This bibliography of information sources that provide concrete guidance on the policies, procedures, and technologies useful in safeguarding electronic health data is a first step toward that objective. Although the bibliography contains many useful references, the literature search conducted to produce it has confirmed that published information about how to protect electronic health data is fragmented and incomplete. Many institutions are currently addressing the need for comprehensive policies and procedures for safeguarding electronic health, but, to date, few institutional documents have been completed and released.

Materials cited in this bibliography have been one source of input to a study of "best practices" for protecting the confidentiality of electronic health care data that is currently being undertaken by the Computer Sciences and Telecommunications Board of the National Research Council, under the chairmanship of Paul Clayton, Ph.D., Columbia-Presbyterian Medical Center. Funded by the National Library of Medicine and the Warren G. Magnuson Clinical Center, National Institutes of Health, DHHS, the study is also collecting data through a series of site visits to institutions with electronic health information systems. Its final report, scheduled for release by January 1997, will bring us a step closer to the goal of developing practical and coherent guidelines for protecting the confidentiality of electronic health data.

Nan D. Hunter  
Deputy General Counsel  
U.S. Department of Health and Human Services  
Chair, Interdepartmental Health Privacy Working Group

## **CONFIDENTIALITY OF ELECTRONIC HEALTH DATA**

Electronic health data can improve the quality and efficiency of health care, research, and public health surveillance and interventions. To achieve these benefits without unacceptable risk to patient confidentiality, electronic health data must be created, used, transmitted, aggregated, and abstracted in ways and in environments that maintain data security and accuracy; prevent inadvertent or accidental release; prevent or deter access by unauthorized users; and discourage, detect, and punish inappropriate use of health data by unauthorized users.

This selective bibliography is primarily intended for those who are responsible for protecting electronic health data and need information on appropriate strategies for doing so. It includes references to publications, organizations, and electronic sources that address methods for preserving the confidentiality and security of electronic health data. The methods covered include technical approaches, institutional policies and procedures, staff and patient education, and legal and regulatory requirements. In addition to substantive discussions of measures for preserving confidentiality and security of health data, the bibliography also has references to some recent standards and guidelines that apply to electronic data in general. Letters, editorials, news items, and general descriptions of health information systems in which security and privacy prevention are mentioned briefly generally have been excluded.

The bibliography has a tight focus on how to protect electronic health data and therefore also excludes references to the large body of literature on related topics such as: the need to protect privacy; the need for federal legislation; the potential privacy and security problems associated with computer-based patient records; the public's perceptions of privacy issues; special ethical and privacy considerations associated with genetic screening, AIDS testing, and occupational health records; the conditions under which medical and psychiatric records must or must not be disclosed to courts; the tension between privacy and the public good in cases involving infectious disease, potential violence, etc.; institutional review boards; and informed consent, except as it relates directly to consent about use of health data.

In general, publication dates for references included in this bibliography range from January 1990 through March 1996, and publications are primarily in English. Journal articles, books and book chapters, conference proceedings and papers, meeting abstracts, laws and legal documents, and technical reports, as well as unpublished documents, have been surveyed and selected for inclusion. Arrangement of the bibliography is by subject and citations within each category are listed alphabetically by author; a citation appears under only one category.

A number of Internet sites created by various organizations that address confidentiality or computer security may be found by using various world wide web searching tools. A selected list of these are included in the Organizations section of this bibliography. All Internet addresses were functional on the date that this bibliography became available.

The compilers wish to thank Marlyn Schepartz, National Library of Medicine, for her technical assistance with production of this bibliography.

## SEARCH STRATEGY

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PEER REVIEW, HEALTH CARE OR PROFESSIONAL REVIEW ORGANIZATIONS OR  
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EXPLODE \*UTILIZATION REVIEW OR EXPLODE MEDICARE OR  
EXPLODE CLINICAL TRIALS OR EXPLODE \*MEDICAL INFORMATICS
- SS 5 = EXPLODE OFFICE MANAGEMENT OR EXPLODE \*INSURANCE
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## SAMPLE CITATIONS

Citations in this bibliographic series are formatted according to the rules established for *Index Medicus*<sup>®\*</sup>. Sample journal and monograph citations appear below. For journal articles written in a foreign language, the English translation of the title is placed in brackets; for monographs, the title is given in the original language. In both cases the language of publication is shown by a three letter abbreviation appearing at the end of the citation.

### Journal Article:

*Authors*

*Article Title*

Barrows RC Jr, Clayton PD. Privacy, confidentiality, and electronic medical records.  
J Am Med Inform Assoc 1996 Mar-Apr;3(2):139-48.

*Abbreviated Journal  
Title*

*Date*

*Volume Issue Pages*

### Monograph:

*Authors/Editors*

*Title*

Barber B, Treacher A, Louwse CP, editors. Towards security on medical telematics:  
legal  
and technical aspects. Washington: IOS Press; 1996. 252 p.

*Place of  
Publication*

*Publisher*

*Date*

*Total No.  
of Pages*

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\*For details of the formats used for references, see the following publication:

Patrias, Karen. *National Library of Medicine recommended formats for bibliographic citation*. Bethesda (MD): The Library; 1991 Apr. Available from: NTIS, Springfield, VA; PB91-182030.

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## OVERVIEW

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**ORGANIZATIONS****General**

Center for Democracy and Technology  
 1634 Eye Street NW, Suite 1100  
 Washington, DC 20006  
 202/637-9800 (Voice)  
 202/637-0968 (Fax)  
 Email: [info@cdt.org](mailto:info@cdt.org)  
<http://www.cdt.org>

CERT (Computer Emergency Response Team)  
 Coordination Center  
 Software Engineering Institute  
 Carnegie Mellon University  
 Pittsburgh, PA 15213-3890  
 412/268-7090 (24-Hour Hotline)  
 412/268-6989 (Fax)  
 Email: [cert@cert.org](mailto:cert@cert.org)  
<http://www.cert.org>

Computer Professionals for Social  
 Responsibility (CPSR)  
 P.O. Box 717  
 Palo Alto, CA 94302  
 415/322-3778 (Voice)  
 415/322-4748 (Fax)  
 Email: [admin@cpsr.org](mailto:admin@cpsr.org)  
<http://www.cpsr.org>

Computer Science and  
 Telecommunications Board  
 National Research Council  
 2101 Constitution Avenue, NW, HA560  
 Washington, DC 20418  
 202/334-2605 (Voice)  
 202/334-2318 (Fax)  
 Email: [cstb@nas.edu](mailto:cstb@nas.edu)  
<http://www.nas.edu>

Computer Security Resource  
 Clearinghouse  
 Computer Systems Laboratory  
 National Institute of Standards and  
 Technology  
 Bldg. 820, Room 426  
 Gaithersburg, MD 20899  
 301/975-2832 (Voice)  
 301/975-3282 (Voice Hotline)  
 Email: [ramona.roach@nist.gov](mailto:ramona.roach@nist.gov)  
<http://www.ncsl.nist.gov>  
<http://csrc.nist.gov>

Computer Security Technology Center  
 Lawrence Livermore National Laboratory  
 L-303  
 P.O. Box 808  
 Livermore, CA 94551  
 510/423-6224 (Voice)  
 510/423-8002 (Fax)

Email: [cstc@llnl.gov](mailto:cstc@llnl.gov)  
<http://ciac.llnl.gov/>

Electronic Frontier Foundation  
 1667 K Street, NW  
 Suite 801  
 Washington, DC 20006-1650  
 202/861-7700 (Voice)  
 202/861-1258 (Fax)  
 Email: [info@eff.org](mailto:info@eff.org)  
<http://www.eff.org>

Electronic Privacy Information Center  
 666 Pennsylvania Avenue, SE  
 Suite 301  
 Washington, DC 20003  
 202/544-9240 (Voice)  
 202/547-5482 (Fax)  
 Email: [info@epic.org](mailto:info@epic.org)  
<http://epic.org>

Information Infrastructure Task Force  
 Secretariat  
 Susannah B. Schiller  
 Program Office  
 National Institute of Standards and  
 Technology  
 A1000 Admin  
 Gaithersburg, MD 20899  
 301/975-4529 (Voice)  
 301/216-0529 (Fax)  
 Email: [susannah.schiller@nist.gov](mailto:susannah.schiller@nist.gov)  
<http://iitf.doc.gov>

Internet Engineering Task Force  
 c/o Corporation for National Research  
 Initiatives (CNRI)  
 1895 Preston White Drive  
 Suite 100  
 Reston, VA 22091  
 703/620-8990 (Voice)  
 Email: [ietf-web@cnri.reston.va.us](mailto:ietf-web@cnri.reston.va.us)  
<http://www.cnri.reston.va.us>

Internet Society  
 12020 Sunrise Valley Drive  
 Suite 270  
 Reston, VA 22091  
 703/648-9888 (Voice)  
 Email: [isoc@isoc.org](mailto:isoc@isoc.org)  
<http://info.isoc.org>

National Computer Security Association  
 10 South Courthouse Avenue  
 Carlisle, PA 17013  
 717-258-1816 (Voice)  
 717-243-8642 (Fax)

Email: [mighthfoot@ncsa.com](mailto:mightfoot@ncsa.com)  
<http://www.ncsa.com>

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 Publications Office  
 INFOSEC Awareness Division  
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Privacy Forum  
 c/o Lauren Weinstein  
 Vortex Technology  
 Woodland Hills, CA  
 818/225-2800 (Voice)  
 818/225-7203 (Fax)  
 Email: [privacy@vortex.com](mailto:privacy@vortex.com)  
<http://www.vortex.com>

Privacy Journal  
 P.O. Box 28577  
 Providence, RI 02908  
 401/274-7861 (Voice)  
 Email: [0005101719@mcimail.com](mailto:0005101719@mcimail.com)

Privacy Rights Clearinghouse  
 Center for Public Interest Law  
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 San Diego, CA 92110  
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 619/260-4753 (Fax)  
 Email: [prc@teetot.acusd.edu](mailto:prc@teetot.acusd.edu)  
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## Health

American Bar Association  
 Section of Science and Technology  
 Health Care Informatics Subsection  
 Francoise Gilbert, Chair  
 Alzheimer & Gray  
 Suite 4000  
 10 South Wacker Drive  
 Chicago, IL 60606  
 312/715-4984 (Voice)  
 312/715-4800 (Fax)  
 Email: [fgilbert@interserv.com](mailto:fgilbert@interserv.com)

American Health Information  
 Management Association (AHIMA)  
 919 N. Michigan Avenue, Suite 1400  
 Chicago, IL 60611  
 312/787-2672 (Voice)  
 312/787-5926 (Fax)  
 202/218-3535 (Voice - Washington, DC

Office)  
 202/682-0078 (Fax - Washington, DC  
 Office)  
<http://www.ahima.org>

American Medical Informatics  
 Association  
 4915 St. Elmo Avenue, Suite 401  
 Bethesda, MD 20814  
 301/657-1291 (Voice)  
 301/657-1296 (Fax)  
 Email: [mail@amia2.amia.org](mailto:mail@amia2.amia.org)  
<http://amia2.amia.org>

American National Standards Institute  
 Healthcare Informatics Standards  
 Planning Panel  
 11 West 42nd Street  
 New York, NY 10036  
 212/642-4969 (Voice)  
 212/398-0023 (Fax)  
 Email: [scornish@ansi.org](mailto:scornish@ansi.org)  
<http://www.ansi.org>

American Society for Testing and  
 Materials  
 Committee on Healthcare Informatics  
 (E31)  
 (with Subcommittees:  
 E31.17 - Access, Privacy &  
 Confidentiality of Medical Records;  
 E31.20 - Authentication of Computer-  
 Based Health Information;  
 E31.21 - Health Information Networks)  
 100 Barr Harbor Drive  
 West Conshohocken, PA 19428-2959  
 610/832-9555 (Voice)  
 610/832-9666 (Fax)  
 Email: [tluthy@local.astm.org](mailto:tluthy@local.astm.org)

Arent Fox Kintner Plotkin & Kahn  
 Advisors in Technology and Information  
 Law  
 (including Telemedicine)  
 1050 Connecticut Avenue, NW  
 Washington, DC 20036-5339  
 202/857-6000 (Voice)  
 202/857-6395 (Fax)  
 Email: [infolaw@arentfox.com](mailto:infolaw@arentfox.com)  
<http://www.arentfox.com/>

American Telemedicine Association  
 901 15th Street, NW, Suite 230  
 Washington, DC 20005  
 202/408-1400 (Voice)  
 202/408-1134 (Fax)  
 Email: [jlinkous@idi.net](mailto:jlinkous@idi.net)

Community Medical Network Society



5500 Interstate North Parkway, Suite  
435  
Atlanta, GA 30328  
770/850-0540 (Voice)  
770/850-9616 (Fax)  
Email: [comnet@comnetsociety.org](mailto:comnet@comnetsociety.org)  
<http://www.comnetsociety.org/~comnet>

Computer-Based Patient Record Institute  
(CPRI)  
1000 E. Woodfield Road, Suite 102  
Schaumburg, IL 60173  
847/706-6746 (Voice)  
847/706-6747 (Fax)  
Email: [cprinet@aol.com](mailto:cprinet@aol.com)  
<http://www.cpri.org>

European Committee for Standardisation  
Technical Committee 251 (Medical  
Informatics)  
Working Group 6 (Healthcare Security,  
Privacy, Quality & Safety)  
Dr. Gunnar Klein, Chair  
Swedish Institute for Health Services  
Development (SPRI)  
P.O. Box 70487 S-10726  
Stockholm, Sweden  
46-8-7024745 (Voice)  
46-8-7024799 (Fax)  
Email: [gunnar.klein@spri.se](mailto:gunnar.klein@spri.se)  
[http://miginfo.rug.ac.be:8001/centc251/  
prestand/wg6/wg6.htm](http://miginfo.rug.ac.be:8001/centc251/prestand/wg6/wg6.htm)

Health Information Confidentiality  
Resource Center  
Health Information Administration  
Health Services Department

School of Public Health and Community  
Medicine  
University of Washington  
1107 NE 45th Street, Suite 355 JD-02  
Seattle, WA 98105  
206/543-8810 (Voice)  
206/685-4719 (Fax)  
Email: [mahanken@u.washington.edu](mailto:mahanken@u.washington.edu)

Interdepartmental Health Privacy  
Working Group  
Nan D. Hunter, Chair  
Deputy General Counsel  
Department of Health and Human  
Services  
Room 713 Humphrey Building  
200 Independence Avenue  
Washington, DC 20201  
202/690-7780 (Voice)  
202/690-7998 (Fax)  
Email: [nhunter@ospag.ssw.dhhs.gov](mailto:nhunter@ospag.ssw.dhhs.gov)

Medical Records Institute  
567 Walnut Street  
P.O. Box 289  
Newton, MA 02160  
617/964-3923 (Voice)  
617/964-3926 (Fax)  
Email: [cust\\_serv@medrecinst.com](mailto:cust_serv@medrecinst.com)  
<http://www.medrecinst.com>

Workgroup for Electronic Data  
Interchange (WEDI)  
10 Rogers Street, Unit 321  
Cambridge, MA 02142  
617/374-9170 (Voice)  
617/494-0727 (Fax)  
Email: [wedi@shore.net](mailto:wedi@shore.net)