American Bar Association

ADOPTED BY THE HOUSE OF DELEGATES

February 8, 1999

Individual Rights and Responsibilities (Report No. 109A)

RESOLVED, That the American Bar Association supports federal legislation that explicitly acknowledges individuals' rights to privacy of their health care information; protects the confidentiality of personally identifiable health information from any source, including medical record, electronic data and genetic material; and ensures that:

1. Individuals have the right to prevent others from generating personally identifiable health information about them without their consent;

2. Individuals have the right to see, copy, and correct their personally identifiable health information and to delegate this right to others;

3. Disclosure of personally identifiable health information is not permitted without informed, voluntary, written authorization by the individual who is the subject of the information, except for limited, specific purposes where it is reasonably determined that disclosure is necessary (a) to prevent serious jeopardy to the life or health of the individual; (b) to allow for the sharing of information among the individual's caregivers; (c) to process a claim for payment for health care services or insurance benefits received by the individual; (d) to comply with a court order, proper discovery request or subpoena, or other constitutional request by a law enforcement or regulatory agency; (e) to enable a health care provider to obtain advice of counsel regarding matters directly related to health care services provided to the individual (subject to counsel's continuing obligation to refrain from further disclosure); or (f) to comply with applicable law;

4. Disclosures of personally identifiable health information are tracked;

5. Those who possess personally identifiable health information have a continuing obligation to refrain from misusing it; and

6. Parties who violate the law knowingly or, in the case of corporate entities, with reckless disregard, are subject to meaningful penalties, and a person aggrieved by a violation of the law has a private right of action.

FURTHER RESOLVED, That the American Bar Association encourages, in the absence of a federal legislative mandate, the development of strong institutional and organizational policies that adhere to the above principles to protect the privacy and confidentiality of doctor/patient communication and protect against misuse of personally identifiable health information.
Introduction

This recommendation supports the passage of federal legislation protecting the privacy of health care decisionmaking and the confidentiality of personally identifiable health care information from any source.

Both the public and policymakers increasingly are aware that there is no comprehensive federal law governing the privacy of health care information. As Congress debates how best to protect the confidentiality of health care information, it is critical for the American Bar Association to provide guidance. Although the ABA already has policy on certain aspects of the privacy of health information, recent developments in several areas have triggered the need to clarify that policy. These areas, discussed in detail below, include: a) advances in genetic capabilities; b) the increasing prevalence of computerized health information; and c) the growing disparity among state laws addressing these issues. In addition, this recommendation includes clarification of current ABA policy provisions addressing circumstances in which disclosure of personally identifiable health information is permissible without informed consent.

The Association’s support of federal legislation protecting personal health information is important to building a consensus around federal legislation and creating a set of recommendations concerning legislative proposals. The Association’s attention to this issue at this time is critical, given that the Kennedy-Kassebaum health care reform law of 1996 mandates federal regulations addressing privacy of health care information by August 1999 if Congress fails to take action by that time.

Background

Current ABA policy supports federal legislation that protects the confidentiality of personally identifiable health information in either paper or electronic form. Technological and genetic advances now make it necessary to call explicitly for the confidentiality of personally identifiable health information from any source. As technological and genetic capabilities evolve, the ease with which individuals can obtain and generate personal information about others, as well as the possibility that discrimination may occur as a result of misuse of such information (including genetic information), raises increasingly critical issues. Equally important, unauthorized access to an individual’s genetic information may reveal private information about the individual’s relatives without their consent. The proposed resolution therefore favors legislation that explicitly protects the confidentiality of personally identifiable health information from any source and that ensures that individuals have the right to prevent others from generating identifiable health information about them without their consent.

Current ABA policy also endorses legislative privacy protections that ensure that individuals have the right to see, copy, and correct their personally identifiable health information; that disclosure of personally identifiable health information is not permitted without authorization by the individual who is the subject of the information, except for limited, specific
purposes; that parties who violate the law are subject to meaningful penalties; and that a person aggrieved by a violation of the law has a private right of action.

The proposed resolution would supplement this policy in several specific ways. First, the recommendation would specify that an individual has the right to delegate to others his or her right to see, copy, and correct personally identifiable health information. This change accommodates individuals' autonomy rights to control the management of their health care information even in circumstances where they are unable to do so themselves (e.g., in the event of decision-making incapacity) by delegating these rights to others. The proposed resolution also urges that in cases when individuals' personally identifiable health information is disclosed, the disclosure is tracked. This addition facilitates accountability and compliance with disclosure rules.

The proposed resolution also would clarify the circumstances in which disclosure of personally identifiable health information is permissible without informed, voluntary, specific, written authorization by the individual who is the subject of the information. Because most individuals generally receive health care from a number of health care providers, the proposed resolution states that such information about an individual may be shared among those caring for the individual; it is recognized that undue restrictions on information sharing could threaten quality of care. In addition, in acknowledgment of the need for efficient payment for health care services, the recommendation states that an individual's health care information may be disclosed in order to permit the processing of claims for payment for health care services received by that individual. In such circumstances, however, only that information necessary for claims processing should be disclosed. The proposed policy also specifically addresses the need for disclosure of personally identifiable information in the context of a legal proceeding by stating that disclosure should be permissible "to comply with a court order, proper discovery request or subpoena, or other constitutional request by a law enforcement agency."1

Finally, under the proposed resolution, those who possess health information would have a continuing obligation to refrain from misusing it. Misuse would include an authorized recipient's use of health information for an unauthorized purpose, as well as redisclosure by an authorized recipient to unauthorized third parties in violation of the guidelines incorporated in the recommendation.

Genetic Advances

Significant genetic advances make it necessary to reassess health information privacy protections. Because of the highly personal nature of genetic information, and the seriousness of its potentially unauthorized use, such information requires explicit protection in federal law. Genetic information discloses not only probabilistic information about one's medical future, but

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1 This provision is intended to be interpreted to be consistent with already existing ABA policy, which states that disclosure of personally identifiable health information should be permitted for "limited, specific purposes," including, "in the case of a law enforcement investigation, in response to a court order issued pursuant to Fourth Amendment warrant requirements[.]"
also personal information about one's siblings, parents, and children. A variety of individuals  
and groups, including insurers and employers, often have keen interest in such information; some  
such groups reportedly already have used such information to discriminate against those  
perceived as genetically unfit. The proposed recommendation supports federal legislation that  
specifically addresses these special concerns through protections that 1) call for the  
confidentiality of personally identifiable health information from any source; 2) ensure that  
individuals have the right to prevent others from generating identifiable health information about  
them without their consent (e.g., through testing of stored genetic material); and 3) prohibit  
 misuse of health information (including genetic information).  

**Computerized Health Information**  

Current ABA policy supports legislative protection of personally identifiable health  
information in electronic form. With the help of improvements in computer technology,  
declining costs for data storage, and steady increases in computer processing speeds, managed  
care has spurred greatly expanded electronic collection, transmission, and centralization of vast  
amounts of personally identifiable health care information, in the process raising significant  
privacy issues that differ in degree, if not in kind, from those implicit in all medical  
recordkeeping activities. For example, large pharmacy benefit management firms, which have  
established electronic links to pharmacies throughout the United States, routinely gather detailed  
prescription information about the 150 million Americans who use prescription cards. Whether  
the pharmacy benefits manager has an immediate legitimate use for the information in order to  
determine whether the drug is covered by the patient’s health plan and whether it is safe for the  
patient to use, once stored, the same information can be used for other unauthorized purposes  
(e.g., to contact physicians about care of individual patients without the patient’s knowledge once  
stored, or to sell to health industry companies, including drug manufacturers and health research  
groups). Presently, in the absence of comprehensive federal or state oversight, protection of  
patient privacy depends solely upon the self-discipline of the individual pharmacy benefit  
company. As Justice Brennan warned in his concurrence in *Whalen v. Roe*, 429 U.S. 589, 606-  
07 (1977), “The central storage and easy accessibility of computerized data vastly increase the  
potential for abuse of that information, and I am not prepared to say that future developments  
will not demonstrate the necessity of some curb on such technology.”  

In light of this concern, the proposed policy supports federal legislation that would  
 enhance individual privacy protections by 1) explicitly acknowledging individuals’ rights to  
privacy of their health care information; 2) generally requiring informed, voluntary, specific.  

2 The importance of the privacy and security of automated records is widely acknowledged by  
other entities. (See, e.g., Office of Technology Assessment, U.S. Congress, OTA-TCT-576  
“Protecting Privacy in Computerized Medical Information” (1993); Molla Donaldson &  
Kathleen Lohr, Institute of Medicine, *Health Data in the Information Age: Use, Disclosure and  
Privacy* (1994); Reardon, “Patient Privacy and Confidentiality,” Report of the Board of  

3 See individual case examples discussed in R. O’Harrow Jr., “Plans’ Access to Pharmacy Data  
written authorization for disclosure of personally identifiable health care information;
3) accommodating exceptions to informed, voluntary, specific written authorization for
disclosures that serve compelling, limited, specific purposes; 4) requiring tracking of disclosures
of personally identifiable health information so that violations can be detected; and 5) imposing
upon those who possess health information a continuing obligation to refrain from misusing it.

State Law Disparity

Currently, there is great disparity among state laws that address patient privacy and the
confidentiality of personally identifiable health information. For the most part, state laws that do
exist reflect a patchwork of inconsistent and inadequate protection of informational privacy. For
example, many state medical record statutes contemplate maintenance of manual patient records,
making the protection afforded to automated records uncertain. Moreover, a state law that
attempts to regulate information physically contained within the state’s own borders may not
provide protection if the information is included in a database accessible by users in remote
locations.

Federal legislation therefore is required to assure patients of a uniform, minimum
national standard for privacy and confidentiality of health information. At the same time, such
legislation must not thwart state legislatures’ efforts to meaningfully grapple with the need to
protect the privacy of patient information. In order to assure that heightened state standards will
not be lost to federal legislation, the proposed policy calls for federal legislation that creates a
"floor," rather than a "ceiling," for patient information protection, providing for preemption of
state laws only to the extent that they are less stringent than federal law. These minimum federal
standards would be intended to work together with more stringent standards voluntarily adopted
by the health care industry.

CONCLUSION

The protection of personally identifiable health records information is critical to ensuring
public trust and confidence in the increasingly complex and centralized health information
infrastructure. Individuals seek medical attention for intrinsically personal problems—chronic
conditions, mental health counseling, pregnancy, abortion, AIDS, domestic abuse injuries. We
and other members of the American public must be assured that the highly sensitive and personal
information contained in our medical records, including genetic information, will be protected
from abuse and misuse.

The proposed policy is an important step in helping define the appropriate course for
achieving these results. It is also particularly important that the Association act now, in
preparation for the renewed debate and essential consideration of privacy protections in the 106th
Congress. Finally, and perhaps most important, if we are to embrace and participate in a health
care system, the price of our participation must not be the loss of control over sensitive personal
information. In the end, any system that fails to win public trust will fail to win public support,
creating the unacceptable risk that we as individuals will withdraw from full and honest
participation in our own health care decision-making. The ABA must lead now, as it has in the
past, to help ensure that developing law in this area speaks to all our concerns.

Respectfully submitted,

Walter H. White, Jr., Chair
Section of Individual Rights and Responsibilities

February 1999
General Information Form

Submitting Entity: Section of Individual Rights and Responsibilities
Submitted By: Walter H. White, Jr., Chair

1. Summary of Recommendation(s).

This recommendation supports federal legislation that acknowledges individuals' rights to privacy of their health care information and protects the confidentiality of personally identifiable health information from any source, including electronic data and genetic material. It urges that such legislation include provisions ensuring that:

a) individuals have the right to prevent others from generating identifiable health information about them without their consent;

b) individuals have the right to see, copy, and correct their personally identifiable health information and to delegate this right to others;

c) disclosure of personally identifiable health information is not permitted without informed, voluntary, specific, written authorization except for compelling, limited, specific purposes;

d) disclosures of personally identifiable health information are tracked;

e) those who possess health information refrain from misusing it; and

f) parties who violate the law are subject to meaningful penalties.

In addition, the recommendation supports federal law preemption of state laws to the extent that state laws are less stringent than federal law in protecting health records privacy.

Finally, the recommendation encourages, in the absence of federal legislative mandate, the development of strong institutional and organizational policies to protect the privacy and confidentiality of doctor/patient communication and to protect against misuse of personally identifiable health information.
This recommendation was approved by the Council of the Section of Individual Rights and Responsibilities on Oct. 24, 1998, during its fall meeting in Milwaukee, Wisc.

3. Has this or a similar recommendation been submitted to the House or Board previously?

Over the last 25 years, the ABA has adopted numerous policies relating to privacy and to the confidentiality of records other than medical records. In 1979, for example, the ABA adopted a broad policy supporting various principles to protect the privacy of personal records kept by the government or by organizations. Other ABA policies involving privacy rights include a 1975 resolution supporting amendments to the Bank Secrecy Act that would ensure the confidentiality of financial records without hindering law enforcement investigations. A second 1975 policy supports legislation to facilitate and regulate the exchange of criminal justice information to protect against unauthorized use and ensure privacy. In addition, the ABA adopted a 1975 policy addressing Federal Bureau of Investigation access to records involving individuals; a 1983 resolution endorsing amendments to the Freedom of Information Act, including one that would extend FOIA exemptions involving personal information; a 1986 resolution supporting an amendment involving personal information practices by government agencies; and a 1986 resolution supporting amendments to the federal electronic surveillance law to safeguard the transmission of information in all forms, including voice, data, and video. In addition, the ABA has adopted comprehensive policies relating to health records of persons with HIV/AIDS (1988-1990) and persons with mental disabilities (1978).

Most recently, in 1996, the ABA adopted a Section-sponsored resolution that built upon and updated the privacy principles adopted in 1979 by addressing their applicability in the specific context of medical records maintained in computer databases, as well as paper files. The recommendation currently being proposed would supplement this most recent policy by:

a) explicitly addressing privacy issues surrounding genetic material;

b) further elaborating on circumstances in which disclosure of confidential health care information may be indicated;

c) urging the incorporation of specific safeguards in health care privacy information legislation;

d) more specifically suggesting penalties for violation of legislative privacy provisions; and
e) urging a federal legislative preemption of less stringent state laws in order to facilitate development of minimum requirements and uniformity across state lines, in light of increased use of computerized health care information.

This proposed Report with Recommendation is a slightly revised version of the similar Report with Recommendation originally submitted for consideration at the 1998 ABA Annual Meeting, but withdrawn at the meeting to permit interested entities more time to review the proposal.

4. What existing Association policies are relevant to this recommendation and how would they be affected by its adoption?

See #3 above.

5. What urgency exists which requires action at this meeting of the House?

On May 14, 1998, Vice President Al Gore announced that the Administration supports a new "Electronic Bill of Rights" to help ensure privacy of consumers' medical records and other computerized personal data. The White House, worried that the Internet and computerized databases threaten constitutionally protected privacy, has called upon Congress to enact legislation protecting the privacy of medical records.

In recent months, Congress has heard testimony that pharmacies have sold individuals' prescription records to drug companies and that health insurers have shared medical data with marketers, violating consumers' medical privacy.

Various legislative proposals addressing health care privacy issues have been considered by both the House of Representatives and the Senate. In the 105th Congress, major bills included S. 1368, the Medical Information Privacy and Security Act, introduced by Senator Patrick J. Leahy (D-VT) on Nov. 4, 1997; H.R. 3900, introduced by Representative Stays (R-CT) on May 19, 1998; S. 1921, introduced by Sen. Jeffords on Apr. 2, 1998; H.R. 4250, introduced by Rep. Thomas on July 16, 1998; and S. 2609, introduced by Sen. Bennett on Oct. 9, 1998. S. 1368 was designed to provide individuals with access to health information of which they are the subject, ensure personal privacy with respect to personal medical records and health care-related information, impose criminal and civil penalties for unauthorized use of personal health information, and provide for the strong enforcement of these rights. H.R. 3900 would have established federal penalties for prohibited uses and disclosures of individually identifiable health information and would have established the right of an individual to inspect and copy his
or her health information. S. 1921, H. R. 4250, and S. 2609 aimed to establish comprehensive federal standards for protecting the confidentiality of all "protected health information."

The newly convened 106th Congress is likely to consider these or similar proposals early in the session. If the Congress does not act, the Administration must do so through Regulation by August 1999 pursuant to requirements of the Kennedy-Kassebaum health care reform law of 1996. With this proposed resolution, the ABA can help guide analysis and evaluation of proposals to address the range of health records privacy issues of particular concern to the public.

6. **Status of Legislation.** (If applicable.)

The Senate Committee on Labor and Human Resources held hearings on S. 1368 on Feb. 26, 1998. H.R. 3900 was referred to the Committee on Commerce on May 19, 1998. S. 1921 was referred to the Committee on Labor and Human Resources on Apr. 2, 1998. H.R. 4250 was passed by the House on July 24, 1998, but was not voted on in the Senate. S. 2609 was referred to the Committee on Labor and Human Resources on Oct. 9, 1998.

7. **Cost to the Association.** (Both direct and indirect costs.)

Adoption of the recommendation would result in only minor indirect costs associated with Governmental Affairs and Section staff time devoted to the policy subject matter as part of the staff members' overall substantive responsibilities.

8. **Disclosure of Interest.** (If applicable.)

None.

9. **Referrals.**

Following its submission for consideration by the House of Delegates, this Report with Recommendation is being sent to the following entities deemed to have a specific interest in the proposal for their support or co-sponsorship:

- Section of Science and Technology
- Administrative Law Section
- Business Law Section
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Criminal Justice Section
Health Law Section
Tort and Insurance Practice Section

In addition, the Report with Recommendation is being circulated to the Young Lawyers Division, the ABA Commission on Legal Problems of the Elderly, the Senior Lawyers Division, the Commission on Domestic Violence, and the Commission on Mental and Physical Disability Law, which expressed support for the resolution in August 1998, for confirmation of their continued support of the proposal, as well as to the Coordinating Group on Bioethics and the Law for its information.

10. **Contact Person.** (Prior to the meeting.)

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11. **Contact Person.** (Who will present the report to the House.)

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12. **Contact Person Regarding Amendments to This Recommendation.**
   (Are there any known proposed amendments at this time? If so, please provide the name, address, telephone, fax and ABA/net number of the person to contact below.)

   No proposed amendments known at this time.