The new federal medical privacy rule expands access to personal medical records and individually-identifiable patient data without patient consent, permitting and authorizing activities once considered unethical, unconstitutional, and impermissible.

In 1996, Congress passed the Health Insurance Portability and Accountability Act (HIPAA) which included a section called Administrative Simplification (AS) meant to rapidly advance the computerization and electronic transfer of health care information in the United States and around the world. The law requires creation of national codes and standards to enable electronic transactions of medical data, and mandates that unique identification numbers be issued to all citizens, health care practitioners, health care institutions, employers, and insurance companies—to facilitate linking and tracking of information. As recorded in House Report No. 496, 104th Congress, 2nd Sess., at 99, a member of Congress admits that facilitating access to medical data was the goal of AS:

“Health information is considered relatively ‘safe’ today, not because it is secure, but because it is difficult to access. These standards improve access and establish strict privacy protections.”

**PRIVACY IN NAME ONLY**

Congress understood that requiring data to be computerized—and issuing a national medical ID number to all citizens—would generate great public concern over medical privacy. To address privacy concerns, they required the Department of Health and Human Services (HHS) to make medical privacy recommendations to Congress. But HHS’s recommendations purported a new ‘public responsibility’ to share medical data for ‘national priority activities.’ When Congress failed to pass federal privacy legislation by August 21, 1999, HHS was required to write regulations to protect medical privacy. HHS received nearly 52,000 public comments on the proposed rule and over 11,000 comments and two citizen protest petitions on the final medical privacy rule. Despite citizen opposition to required and permitted disclosures of medical data, the final rule took effect April 14, 2001. Enforcement and implementation are set to begin April 14, 2003. The final medical “privacy” rule:

- Requires medical record disclosure to HHS inspectors at any hour on any day without patient consent or a search warrant, thus violating Fourth Amendment protections against warrantless government search and seizure of ‘persons, houses, papers and effects.’
- Has a coercive consent provision that requires patient consent for sharing and using patient information for payment, treatment, and ‘health care operations,’ and allows providers and insurers to deny access to health care and insurance if the patient refuses to sign. The rule does however allow patients to request, but not necessarily receive, restrictions of uses and disclosures of data for hospital and facility patient directories, and restrictions of uses and disclosures of data to carry out payment, treatment and health care operations.
- Provides a broad definition of ‘health care operations’ that includes but is not limited to:
  - medical necessity determinations
  - clinical guideline development
  - quality assessments
  - utilization review
  - outcomes research
  - litigation/lawsuits
- Permits disclosure of individually-identifiable patient data, including social security numbers, without patient consent for many purposes:
  - public policy and medical research
  - judicial and administrative proceedings
  - government health databases
  - law enforcement
  - “public health activities”
  - organ and tissue donation
  - health oversight activities
  - serious threat to health or safety
  - “emergency treatment situations”
- Encourages disclosures of medical information for ‘critical national priorities’ and the ‘needs and rights of society as a whole.’
- Does not protect patient DNA, blood, organs, sperm, or other DNA-identifiable tissues and body fluids.
- Permits use of patient data for marketing by health care providers and health plans, and more limited use for fundraising purposes.
- Can only be enforced against entities covered by the rule: health plans, health care providers, health care facilities, and health care clearinghouses. The rule does not have authority over the use, re-use, or re-disclosure of data by law enforcement agencies, researchers, non-profit disease-specific organizations, foreign governments, business partners, organ donor organizations, most government agencies, and others who have data or are permitted to receive patient data from these ‘covered entities.’
- Provides no individual right of legal action against persons or entities that violate the privacy and confidentiality of medical information.

**Individuals should consider providing the following entities with CCHC’s Health Care Services Declaration form:**

<table>
<thead>
<tr>
<th>Insurer/Health Plan</th>
<th>Pharmacy</th>
<th>Government Agencies</th>
<th>Hospital</th>
<th>Healthcare Provider</th>
<th>School</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>Nursing Home</td>
<td>Physician Clinic</td>
<td>Attorney</td>
<td>Data Clearinghouse</td>
<td>Dentist</td>
</tr>
<tr>
<td>Data Clearinghouse</td>
<td>Employer</td>
<td>Psychologist</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Separate declaration forms addressing medical and personal data disclosures permitted by banks, creditors, life insurers, investment firms, and home health agencies by the 1999 Financial Modernization Act and the federal home health data collection system, called OASIS, can be found at the CCHC website: www.cchconline.org.

COPYRIGHT © CITIZENS’ COUNCIL ON HEALTH CARE

“FOR THE RECORD” MEDICAL PRIVACY PROJECT, 2001
FOR THE RECORD:

Declaration of Medical Privacy Intent

For Healthcare Services & Information

To:

Fill in name of institution/person (Physician/Health care practitioner/Health plan/Hospital/Clinic/School/Pharmacy/Other)

I reject the government’s claim that citizens have a public responsibility to disclose private and personal medical information as stated in the medical privacy recommendations written by the U.S. Department of Health and Human Services (9/11/97).

I also find the federally permitted use and disclosure of personal, medical and health data by various institutions, corporations, and individuals under the Health Insurance Portability and Accountability Act (Public Law 104-191-August 21 1996) and the subsequent federal medical privacy rule (Standards for Privacy of Individually Identifiable Health Information, 45 CFR Parts 160 and 164) to be detrimental to medical privacy and the confidentiality of medical records and individually-identifiable health data. The federal medical privacy rule took effective April 14, 2001 with implementation and enforcement set for April 14, 2003. Only stricter state medical privacy laws can supersede the requirements of the federal rule.

For the record, I therefore and hereby declare my express wish and intent for the truly confidential treatment of medical records, health information, psychological testing, genetic testing, and all other information received, heard, said, written, or stored in the course of interactions with the above named person/corporation/agency. Please keep this form on file. To be specific, without written, specific, informed and voluntary consent, I ask you (the above) not to disclose, sell, or otherwise release, to the following agencies/groups or for the following purposes (as checked below), the personal, medical, psychological, financial, genetic, demographic, or health data, or body parts and tissues of _______________________________.

☐ Payment and Treatment
☐ Health care operations
☐ Hospital and facility patient directories
☐ Public safety
☐ Environmental Protection Agency
☐ Central Intelligence Agency
☐ National Transportation Safety Board
☐ Food and Drug Administration
☐ Occupational Safety & Health Admin.
☐ State departments of health
☐ Medical or other review boards
☐ Federal Bureau of Investigation
☐ Departments of agriculture
☐ Mine Safety and Health Administration
☐ Government oversight agencies
☐ Community agencies/groups
☐ Government welfare departments
☐ Government education agencies
☐ Government human services departments
☐ Government contractors
☐ Any government agency/department
☐ Foreign governments/organizations.
☐ Fundraising

☐ Newborn metabolic testing data collection
☐ Birth defect registries/data collection
☐ Immunization registries/data collection
☐ Cancer registries/data collection
☐ Public health surveillance
☐ Workforce/Injury data collection
☐ Indian health registries
☐ Minority, race, or health disparities databases
☐ Newborn hearing screening database
☐ Genetic testing/DNA databases
☐ Medical error reporting systems
☐ Private registries/data collections
☐ Health status databases
☐ OASIS - home health database/collection
☐ Computerized smart cards
☐ Disease-specific organizations
☐ Centers for Disease Control & Prevention
☐ U.S. Dept. of Health and Human Services
☐ Pharmaceutical benefit management co.
☐ Disease management companies
☐ Tissue or organ donation organizations
☐ Public health agencies/officials
☐ Any government database/data collection

☐ Law enforcement officers/agencies
☐ Public policy researchers
☐ National security
☐ Medical/Scientific researchers
☐ Peer review organizations
☐ Certification processes
☐ Marketing of services or products
☐ Accreditation and licensing
☐ Clinical guideline development
☐ Training programs
☐ Social service agencies
☐ Pharmaceutical companies
☐ Litigation/Lawyers
☐ Judges/Administrative law staff
☐ Members of the clergy
☐ Coroners/Medical examiners
☐ State fire marshals
☐ Health boards
☐ State or other ombudsman
☐ Workman’s Compensation
☐ Banks/credit card payments
☐ Media/Press/News Services
☐ Other

This restriction on data disclosure, use and access shall be valid until otherwise removed by written authorization of the subject (or parent or guardian of subject if subject is a minor or under guardianship) of the information.

Signature

Relationship to Above

Printed Full Name

Date

Address

CCHC DISCLAIMER: CCHC is a non-profit 501(c)3 organization. CCHC provides this form only as information to assist individuals in restricting access to or use of their individually identifiable medical or financial information. CCHC specifically does not warrant the effectiveness of said form in restricting access to or use of personal information by government agencies or private organizations. CCHC is not liable for any injury, either in whole or in part, caused, directly or indirectly, by use of this form. With the advice to the user that under the law this form may not be binding, it does however express your desire for medical, financial and personal privacy. It also expresses your protest if your medical records and other personal information are accessed, used or disclosed without your written, informed and voluntary consent.

Copyright © Citizens’ Council on Health Care 2001