

# FOR THE RECORD

## DECLARE YOUR MEDICAL PRIVACY INTENTIONS

### Health Care Services

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
  - quality assessments
  - outcomes research
  - clinical guideline development
  - utilization review
  - litigation/lawsuits
- *Permits* disclosure of individually-identifiable patient data, including social security numbers, without patient consent for many purposes:
  - public policy and medical research
  - law enforcement
  - organ and tissue donation
  - judicial and administrative proceedings
  - “public health activities”
  - health oversight activities
  - government health databases
  - 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:**

Insurer/Health Plan	Pharmacy	Hospital	Physician	Healthcare Provider	Dentist	School
Government Agencies	Nursing Home	Attorney	Clinic	Data Clearinghouse	Employer	Psychologist

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](http://www.cchconline.org).

**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 \_\_\_\_\_.  
*Name of self, child, or guardian responsibility*

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> Payment and Treatment                     | <input type="checkbox"/> Newborn metabolic testing data collection       | <input type="checkbox"/> Law enforcement officers/agencies |
| <input type="checkbox"/> Health care operations                    | <input type="checkbox"/> Birth defect registries/data collection         | <input type="checkbox"/> Public policy researchers         |
| <input type="checkbox"/> Hospital and facility patient directories | <input type="checkbox"/> Immunization registries/data collection         | <input type="checkbox"/> National security                 |
| <input type="checkbox"/> Public safety                             | <input type="checkbox"/> Cancer registries/data collection               | <input type="checkbox"/> Medical/Scientific researchers    |
| <input type="checkbox"/> Environmental Protection Agency           | <input type="checkbox"/> Public health surveillance                      | <input type="checkbox"/> Peer review organizations         |
| <input type="checkbox"/> Central Intelligence Agency               | <input type="checkbox"/> Workforce/Injury data collection                | <input type="checkbox"/> Certification processes           |
| <input type="checkbox"/> National Transportation Safety Board      | <input type="checkbox"/> Indian health registries                        | <input type="checkbox"/> Marketing of services or products |
| <input type="checkbox"/> Food and Drug Administration              | <input type="checkbox"/> Minority, race, or health disparities databases | <input type="checkbox"/> Accreditation and licensing       |
| <input type="checkbox"/> Occupational Safety & Health Admin.       | <input type="checkbox"/> Newborn hearing screening database              | <input type="checkbox"/> Clinical guideline development    |
| <input type="checkbox"/> State departments of health               | <input type="checkbox"/> Genetic testing/DNA databases                   | <input type="checkbox"/> Training programs                 |
| <input type="checkbox"/> Medical or other review boards            | <input type="checkbox"/> Medical error reporting systems                 | <input type="checkbox"/> Social service agencies           |
| <input type="checkbox"/> Federal Bureau of Investigation           | <input type="checkbox"/> Private registries/data collections             | <input type="checkbox"/> Pharmaceutical companies          |
| <input type="checkbox"/> Departments of agriculture                | <input type="checkbox"/> Health status databases                         | <input type="checkbox"/> Litigation/Lawyers                |
| <input type="checkbox"/> Mine Safety and Health Administration     | <input type="checkbox"/> OASIS - home health database/collection         | <input type="checkbox"/> Judges/Administrative law staff   |
| <input type="checkbox"/> Government oversight agencies             | <input type="checkbox"/> Computerized smart cards                        | <input type="checkbox"/> Members of the clergy             |
| <input type="checkbox"/> Community agencies/groups                 | <input type="checkbox"/> Disease-specific organizations                  | <input type="checkbox"/> Coroners/Medical examiners        |
| <input type="checkbox"/> Government welfare departments            | <input type="checkbox"/> Centers for Disease Control & Prevention        | <input type="checkbox"/> State fire marshals               |
| <input type="checkbox"/> Government education agencies             | <input type="checkbox"/> U.S. Dept. of Health and Human Services         | <input type="checkbox"/> Health boards                     |
| <input type="checkbox"/> Government human services departments     | <input type="checkbox"/> Pharmaceutical benefit management co.           | <input type="checkbox"/> State or other ombudsman          |
| <input type="checkbox"/> Government contractors                    | <input type="checkbox"/> Disease management companies                    | <input type="checkbox"/> Workman's Compensation            |
| <input type="checkbox"/> Any government agency/department          | <input type="checkbox"/> Tissue or organ donation organizations          | <input type="checkbox"/> Banks/credit card payments        |
| <input type="checkbox"/> Foreign governments/organizations.        | <input type="checkbox"/> Public health agencies/officials                | <input type="checkbox"/> Media/Press/News Services         |
| <input type="checkbox"/> Fundraising                               | <input type="checkbox"/> Any government database/data collection         | <input type="checkbox"/> 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**

\_\_\_\_\_  
**Printed Full Name**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Relationship to Above**

\_\_\_\_\_  
**Address**

Form created and distributed for CCHC's:  
 "For the Record" Medical Privacy Project  
 **Citizens' Council on Health Care**  
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 St. Paul, MN 55104, 651-646-8935  
 info@cchconline.org  
**Website: www.cchconline.org**

**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.