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March 30, 2001

U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Attention: Privacy-P, Room G-322A
Hubert Humphrey Building
200 Independence Avenue SW
Washington DC 20201

Re: Comments on Final Privacy Rule:
Standards for Individually Identifiable Health Information

Dear Secretary Thompson:

The Women's Law Project urges you to keep the vital privacy protections described in the enclosed comments and to immediately implement the Final Privacy Rule. We submit comments on the Final Privacy Rule from the perspective of protecting women, and especially vulnerable women, from the unique harm that can result from the inappropriate disclosure of personal health information. Our comments reflect years of experience working on reproductive rights and domestic violence issues. While we endorse the comments submitted by the Health Privacy Project, we submit our own comments in order to highlight the privacy needs of women and girls and share our expertise in this area.

The Women's Law Project is a non-profit public interest legal advocacy organization located in Philadelphia, Pennsylvania that seeks to advance the legal, social, and economic status of women through litigation, public policy advocacy, public education and individual counseling. Since its founding in 1974, the Women's Law Project has worked to abolish sex discrimination in our laws and institutions and to eradicate policies and practices that are harmful to women as a matter of public policy.

Privacy is prominent in our advocacy relating to insurance discrimination against battered women, reproductive rights, and women's health generally. In our reproductive rights work, we have endeavored to protect the privacy of adults and minors seeking access to sensitive health care services. Since 1994, we have led a major campaign to protect battered women from insurance discrimination in which the privacy needs of battered women have played a major part. In addition to providing technical assistance to federal and state legislators, domestic violence advocates, and insurance regulators on

this subject, I served as an appointed consumer advocate to the National Association of Insurance Commissioners (NAIC), from 1995 through 1998, and engaged in significant advocacy with respect to the NAIC's four models on Unfair Discrimination Against Subjects of Abuse, which were finalized in January 1999. In my capacity as a consumer advocate, I also provided significant input into the NAIC's Health Information Privacy Model Act adopted in October, 1998, in particular with respect to the model's provisions relating to safety, sensitive services and minor's privacy rights.

These comments highlight the important protections the Final Privacy Rule provides for victims of domestic violence and minors. Although the rules are not perfect and we stand by the problems we identified in our initial comments on the proposed rule, we urge you to implement the Final Privacy Rule without any easing of the requirements set forth here. These comments are being submitted electronically, with paper and disc copies sent by federal express.

Thank you for your consideration of these comments.

Very truly yours,

Terry L. Fromson
Managing Attorney

**COMMENTS ON FINAL RULE: STANDARDS FOR
PRIVACY OF INDIVIDUALLY IDENTIFIABLE
HEALTH INFORMATION**

SUBMITTED BY

WOMEN'S LAW PROJECT

MARCH 30, 2001

I. PRIVACY CONCERNS OF VICTIMS OF DOMESTIC VIOLENCE

Almost one-third of American women report being a victim of domestic violence at some point in their lives. The health care system is playing an increasingly important role in responding to battered women by identifying and documenting abuse and connecting victims with domestic violence advocates and services. However, inappropriate use and disclosure of health information regarding abuse poses unique safety threats for victims. Perpetrators who discover that women have disclosed domestic violence may retaliate, further endangering the lives of battered women and their children. The health care system can also inadvertently help a perpetrator locate a victim who has fled her batterer. Additionally, employers, insurers, and other parties who discover a history of abuse through unnecessary health information disclosure often discriminate against victims. These risks have had the effect of deterring victims from obtaining necessary health care and deterring providers from documenting abuse in health care records, thus undermining the important role of the health care provider in providing necessary medical care, referral and documentation for legal proceedings. The final privacy rules offer many protections that have unique importance to victims of domestic violence.

RIGHT TO REQUEST RESTRICTIONS

Section 164.510 Uses and disclosures requiring an opportunity for the individual to agree or to object.

We are pleased that the Privacy Rule requires an individual to be informed (either in writing or orally) of his or her opportunity to agree, prohibit or restrict the disclosure of health information. There are many circumstances where an individual has a legitimate concern that the disclosure of protected health information will result in personal harm or discrimination. Victims of domestic violence need to be able to place restrictions on the use and disclosure of protected health information. Victims need to know that their health information and their whereabouts will be fully protected in order to access health care safely. We believe HHS has achieved an appropriate balance between the need for this information and the safety risks to domestic violence victims.

JUDICIAL AND ADMINISTRATIVE PROCEEDINGS

Sec. 164.512(f)(1) Uses and disclosures pursuant to judicial and administrative proceedings.

We support the Privacy Rule requirements regarding judicial and administrative proceedings. We believe that these protections are necessary to ensure that information about victims is not improperly disclosed in these proceedings.

LAW ENFORCEMENT

Sec. 164.510(f)(3) Disclosures for law enforcement purposes: Information about a victim of crime or abuse.

We are pleased that the provisions regarding disclosure of information about domestic violence apply to disclosures to law enforcement officials. This approach is necessary because the safety of many victims may be jeopardized by disclosures to law enforcement officials.

DIRECTORY INFORMATION AND PERSONAL SAFETY

Sec. 164.510(a) Use and disclosure for facility directories.

Health care facilities, including hospitals, often maintain directories of their patients that are used in part to provide information regarding a patient's condition and location to family and friends. Such directories can pose a real threat to victims of domestic violence by enabling batterers to learn the whereabouts of their victims. The regulation provides important protections that should help prevent this problem.

PERSONAL REPRESENTATIVES

Sec. 164.512(c)(2)(ii) Disclosures to personal representatives (individual authorization not required).

We believe that HHS has appropriately taken into consideration the safety concerns of domestic violence victims even if a person is generally treated as a patient's personal representative. Under the Final Privacy Rule, an entity may deny the personal representative (including a parent or spouse) access to the patient's health information if the entity believes that the disclosure is reasonably likely to cause substantial harm to the

patient or another person. We strongly support the requirement that covered entities should be given discretion to not treat an individual as a personal representative if there is reason to believe that substantial harm may result.

II. PRIVACY RIGHTS OF MINORS

As numerous studies have found, access to confidential services is one of the prime determinants of whether an adolescent seeks and obtains timely health care related to sensitive topics such as sexuality and substance abuse. For example, studies show that somewhere between eight and thirty-one percent of teens delay or entirely forego health care because of concerns that their private information will be revealed to parents or others. In addition, research confirms that teens who believe that their health care provider will maintain their confidentiality are more likely to discuss sensitive health topics, such as sexually transmitted diseases, pregnancy prevention, and substance abuse, with their provider. In general, the proposed regulations succeed in achieving the proper balance with respect to the privacy rights of minors and the need for parents to have access to their children's health information.

A parent, guardian, or other person acting in loco parentis who has the authority to consent to treatment on behalf of an unemancipated minor is treated as the person's personal representative. Under the Privacy Rule, personal representatives exercise all of the individual's rights to protected health information, including rights of access and control. Parents, guardians and other persons acting in loco parentis are not treated as personal representatives with respect to certain services. The minor exercises the right of the individual when:

- the minor consents to such health care service and no other consent to the health care is required by law unless the minor has requested that the parent be treated as a personal representative; or
- the minor may lawfully obtain health care without the consent of the parent or guardian, and the minor, a court or another person authorized by law consents to such health care; or
- a parent or guardian assents to an agreement of confidentiality between the provider and the minor.

The Privacy Rule takes the general approach that the "individual" who is the subject of the protected health information exercises the rights provided in the regulation. The regulation also contains provisions allowing a personal representative to act on behalf of an individual in certain circumstances. Specifically, section 164.502(g) allows parents to be recognized as personal representatives of unemancipated minors. Under current law and practice, parents generally consent to care on behalf of their children and have access to their medical records (at least when anyone has access to those records). It is appropriate in such cases for parents to exercise the rights specified in the regulation.

But in many situations, information about a minor's receipt of health care services now remains confidential and is not shared with the parent without the minor's consent. It is appropriate in such cases for the minor to be the one to exercise the rights under this regulation. The final regulation keeps intact this delicate balance between parents and minors that exists in the real world today by recognizing the three distinct circumstances under which unemancipated minors exercise their own rights.

These aspects of the final regulation strike the appropriate balance. They respect the important role that parents generally play in obtaining health care for their children, while at the same time recognizing the need to let minors continue to control their protected health information in particular and narrow circumstances.

III. COMMENTS OF GENERAL APPLICABILITY

The Final Privacy Rule includes many provisions of general applicability that should not be scaled back (see the Health Privacy Project's more comprehensive comments).

APPLICABILITY TO ALL FORMATS OF HEALTH INFORMATION

We believe that HHS has appropriately exercised its authority to cover health information in any format. This is a significant improvement over the proposed rule which only covered health information maintained or transmitted in electronic format. The effect of the proposed rule was to leave a large portion of health information, including information in paper form, unprotected.

There are important reasons to cover all health information. If the regulations were to cover only electronic information, the same concerns about patient confidence that exist today will continue, and many patients will remain reluctant to discuss sensitive health information, even for treatment. Because of the complexity of the health care system, most patients will never know what information, if any, is stored electronically. We are especially concerned that many domestic violence victims will continue to hide the real cause of their injuries or not seek care at all because they fear for their safety. Even if patients are able to determine what information is maintained electronically, they will likely fear that some portion of the information is in another format. The only way to ensure patient confidence in the health care system and adequate protections for victims of domestic violence is to make the rule applicable to all information.

CONSENT REQUIREMENT

We are pleased that the Privacy Rule includes a general requirement that health care providers obtain consent to use and disclose health information for treatment, payment and health care operations. While some groups will inevitably disagree with this approach, we believe that a consent requirement is necessary to ensure that patients are given an "initial moment" to learn about how their information may be used and disclosed. Even though in many instances under the Privacy Rule providers may condition treatment on the patient providing consent, for many domestic violence victims, the "knowledge" of how information is used and disclosed may save lives.

For domestic violence victims, it is extremely important to offer this initial moment as an opening to discuss and consider privacy and safety. The moment can also serve as the forum for an individual to further restrict use and disclosure of information as provided by the Privacy Rule. Having an initial moment will strengthen the victim's confidence that their information will only be used for specified purposes and will not be disclosed to the perpetrator or other parties that do not need it.

We commend HHS for taking special care to craft a workable rule to deal with situations when the provider may need to treat a patient but cannot practicably obtain consent prior to use or disclose of the patient's information.

ORGANIZATIONAL REQUIREMENTS

Most people get their health insurance through employer-sponsored health plans governed by ERISA (the Employee Retirement Income Security Act). Many fear that employers know more than they should about their (and their dependents') private medical information and may use that information inappropriately to make employment decisions. The Privacy Rule goes as far as it can to protect workers and their dependents from inappropriate disclosures to employers and from inappropriate uses by employers. This improves significantly upon the approach taken in the proposed regulation. These safeguards are essential to protect privacy given HIPAA's failure to allow HHS to reach employers/plan sponsors directly and the genuine concerns of the public about access to personal health information by employers.

Under the Privacy Rule, protected health information can be shared with an employer/plan sponsor only in limited circumstances and only when certain requirements are met. The regulation does this by reconciling the employer/plan sponsor's legitimate need for access to some information with the need to ensure that protected health information is not used for employment-related purposes or purposes unrelated to the management of the group health plan. Of particular importance are the provisions that require the erection of firewalls to separate the group health plan functions of the employer/plan sponsor from the rest of the employer/plan sponsor. Firewalls are

essential whether employees of the plan sponsor perform only functions related to the administration of the group health plan or combine those responsibilities with other job functions.

We also fully support the Privacy Rule's imposing several administrative requirements on covered entities, including designating a privacy official, training, implementing safeguards, developing a method for handling complaints and developing sanctions. In general, these requirements are necessary to ensure that the appropriate members of the covered entity are familiar with and comply with the Privacy Rule, and that covered entities are held accountable for the actions of their employees. We believe that these Rules have struck the proper balance between ensuring compliance with the Privacy Rule and cost concerns.

RESEARCH

Research initiatives that would improve access to and the quality of health care are important, and we strongly support the continuation of such initiatives. There has been some concern that the Privacy Rule will significantly impede research. Protecting privacy and confidentiality and promoting research, however, are values that go hand-in-hand. Rather than prevent the flow of health information for research purposes, the Privacy Rule will build public trust in research and help ensure that researchers receive complete and accurate health information for their studies.