



and: National Health Law
Program
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**MAKING THE
HEALTH CARE
SYSTEM WORK
FOR AMERICA'S
CONSUMERS**



*In cooperation with
Alliance of Community
Health Plans,
American Hospital
Association, and
American Nurses
Association*

August 7, 2003

Richard Campanelli
Director
Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Room 515F HHH Bldg.
Washington, D.C. 20201

Dear Mr. Campanelli:

Since the HIPAA privacy regulation was last amended in August 2002, we understand that you may now be considering modifications to it. The rule provides for modifications to standards no more frequently than every 12 months.

The Health Assistance Partnership, a project of Families USA, is a national support center for consumer health assistance programs (also known as "ombudsmen") that counsel Medicaid, Medicare, and privately insured consumers. The National Health Law Program independently represents the health care interests of a broad spectrum of the low-income community, as well as supporting the advocacy of legal services attorneys and paralegals throughout the country. We are writing to suggest possible modifications to the HIPAA privacy rule to enable consumer health assistance programs and legal services programs representing health care consumers to better do their jobs. These programs counsel and assist consumers with health insurance disputes and problems with access to health care. Many of them do their work through telephone hotlines. These programs have expressed the following problems regarding HIPAA compliance:

- 1) Problems compelling providers to treat program staff the same as they treat the individual when the program is acting on the individual's behalf, with written authorization, in order to assist the individual in obtaining her/his own records;

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- 2) Potential problems getting medical records for use in administrative appeals concerning denials of health insurance coverage or public benefits;
- 3) Programs that are within government or under contract with government and charged with assisting consumers have questions about when they can be considered health oversight agencies or business associates or otherwise obtain information about individuals' public coverage status;
- 4) Programs representing particularly vulnerable consumers (such as mental health consumers) have expressed difficulties in getting consumers to sign multiple authorization forms - e.g., separate authorizations for release of physical health records and mental health records, as well as a general authorization to represent someone in, for example, a social security disability case. These consumers may want an advocate to represent them, yet have low literacy, mental health problems, or other limited tolerance for bureaucracy and form signing.
- 5) The need for alternatives to written authorization forms to establish that consumers for whom programs are advocating by phone want a covered entity to release oral information related to the health insurance dispute.

Each of these is discussed below, along with suggested modifications.

1) Getting records on behalf of an individual

Under the regulation (§§164.502(a)(2) and 164.524), providers must release records to an individual about himself or herself, or to the individual's "personal representative." However, if a consumer assistance program requests an individual's records on behalf of the individual, providers are saying that the covered entities are permitted but not required to release those records. In one instance, a blind and ill consumer was not physically able to receive her own records and the provider refused to release them to the advocate working on her behalf to get Medicare coverage of her services.

Section 164.502(g) says that a covered entity "must...treat a personal representative as the individual" and that a person who has authority under other law "to act on behalf of an individual who is an adult or an emancipated minor in making decisions related to health care" must be treated as a personal representative. "Health care" is defined as care, services, or supplies related to the health of an individual. Some providers and agencies have not been willing to consider people who have authority to act on behalf of an individual in making decisions only related to health care *payment* as representatives. Further, the definition of personal representative does not match well with the services provided by an attorney or paralegal representing an individual, who needs access to her client's medical records in order to provide competent representation. Such advocates do not, and should not, normally have the authority to act on behalf of the individual, other than to relay to others the client's decisions. As currently written, therefore, the regulation puts the

consumer and advocate in a difficult position – the consumer may give the advocate more authority over health care decisions than he/she wishes to relinquish in order to make the advocate a “personal representative” entitled to receive records, or the consumer may have to get copies of her medical records personally, often at great expense (in the form of travel) and inconvenience. Moreover, many health care consumer assistance programs and other advocates advocating for access to care do not want and should not have the authority to exercise decision-making over actual care decisions, as these decisions are far outside the scope of their advocacy and expertise.

Another section of the regulation (§164.510) *allows* covered entities to disclose information relevant to another person's involvement in payment for care if the individual agrees or does not object. However, since this disclosure is an option and not a requirement, the regulation does not compel an unwilling provider to disclose information to a counselor or individual's attorney, even when requested on the individual's behalf.

We suggest modifying §164.502(a) (2) to say “A covered entity is required to disclose protected health information: (i) To an individual, or a person acting on behalf of an individual who has a valid authorization, when requested under and as required by §§ 164.524 or 164.528....” Similarly, §164.524 (a)(1) should say: “Except as otherwise provided in paragraph (a)(2) or (a)(3) of this section an individual, or a person acting on behalf of an individual who has a valid authorization, has a right of access to inspect and obtain a copy of protected health information about the individual in a designated record set....”

2) Access to information used in an administrative appeal

Section 164.524(a)(1)(ii) contains an exception to the individual's right of access to protected health information. The individual does not have a right of access to “Information compiled in reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding.” Consumers frequently need their medical records in order to pursue administrative appeals regarding denials of Medicaid or Medicare benefits, especially in the context of managed care decisions in those programs, or to pursue external reviews of a private managed care plan's decisions. Likewise, consumers need their medical records to pursue administrative appeals regarding their entitlement to disability benefits. Frequently, other laws do give consumers access to certain health records in the context of these administrative appeals, and the privacy regulation will at best confuse covered entities as to their responsibilities. We suggest striking “administrative action or proceeding” from this section, or otherwise making clear that this exception does not apply when the individual has an independent right to view the records in question, either pursuant to the statutes or rules of other federal, state or local agencies, or applicable court rules.

3) Business associates and oversight agencies

Prior to HIPAA, some ombudsmen that worked within state government or that contracted with state government had online access to information about a person's Medicaid eligibility status and Medicaid managed care plan enrollment. Confidentiality statutes or contracts prevented them from redisclosing this information. The information enabled an ombudsman, for example, to take urgent calls from consumers at the drug store whose Medicaid cards were not working and find out instantly whether there was some problem with Medicaid or managed care plan enrollment that could be remedied by phone. This helped the consumer get prescriptions filled.

Since HIPAA, programs have had differing experiences with their access to online Medicaid eligibility and managed care enrollment information. Programs that were within Medicaid agencies or contractors of Medicaid agencies can sometimes get business associate agreements, because they are performing a customer services function for the Medicaid agency. However, at least one program – a mental health ombudsman authorized by state statute but set up in a Governor's office to provide independent investigations of mental health consumers' problems – was told that she could not be considered a business associate because her function was to investigate problems for consumers as part of the Governor's office, not the Medicaid agency and that her access to online information would therefore be terminated.

This ombudsman program's next step was to see if she could retain access to Medicaid information as an oversight agency. Some agencies that investigate problems for consumers are considered "oversight agencies" under the regulation and have access to records pursuant to that role. Section 164.501 of the regulation defines an oversight agency as a government agency or contractor "authorized by law to oversee the health care system (whether public or private) or government programs in which health information is necessary to determine eligibility or compliance, or to enforce civil rights laws for which health information is relevant." OCR and the Administration on Aging have found that Long Term Care Ombudsman Programs, which are authorized by law to investigate complaints regarding "the health, safety, welfare, or rights of [nursing home] residents," meet this definition.

In the case of this state mental health ombudsman, the statute that created the program requires that it "represent the interests of individuals with regard to the need for public mental health services, including individuals in transition from public to private services." The state statute expressly gives her access to mental health records "when necessary to perform the ombudsman functions as provided in [state law]" (the statute is silent about whether written authorization is required for these records) and compels her to keep individual's names and records from her investigations confidential. Records kept by the ombudsman can only be obtained by another party pursuant to a subpoena if there is a

“compelling state interest.” However, the state privacy officer in consultation with OCR determined that the ombudsman could not be considered a health oversight agency because the state authorizing statute did not explicitly reference “civil rights” or “oversight.”

To us, it seems that this state statute protects consumers’ privacy because it indicates that the mental health ombudsman’s duty is to act in individuals’ interests and because it protects the records obtained from redisclosure. We suggest that the HIPAA regulation definition of oversight agency be broadened to include government agencies or contractors authorized by law to represent individuals in health care matters, investigate concerns on behalf of those individuals and obtain records relevant to the investigation. These government agencies or contractors should be given access to records of other branches of government when necessary to represent the interests of individuals, provided that laws or contracts also bind the agency itself to maintain confidential records.

4) Multiple authorizations

Section 164.508 prohibits “compound authorizations.” It states, “An authorization for the use or disclosure of protected health information may not be combined with any other document to create a compound authorization, except as follows.” Three specified exceptions allow the following: (i) Consent to participate in a research study can be combined with use or disclosure of protected health information for such research; (ii) Authorization for use or disclosure of psychotherapy notes can be combined only with another authorization for use or disclosure of psychotherapy notes; and (iii) Authorization for use or disclosure of protected health information other than therapy notes can be combined with another authorization for use or disclosure of other protected health information, as long as the health care entity does not condition treatment, payment, or enrollment in the health plan or eligibility for benefits on the disclosure.

Consumer health assistance programs have raised two problems with this section of the rule. First, mental health ombudsmen and protection and advocacy programs representing consumers with mental illness say that many consumers they work with balk at and lose patience with signing multiple forms. Sometimes, mentally ill consumers will forego help with a health care problem if the paperwork seems too cumbersome. These programs recognize the need to seek specific authorization for release of psychotherapy notes, but believe this could be accomplished within the same document that authorizes release of other medical information. For example, a single form could contain one check-off authorizing release of psychotherapy notes and listing the provider from which notes would be obtained, one check-off authorizing release of other medical records, other information that is required by HIPAA, and the individual’s signature.

Second, in the past, it has been common practice for some consumer health assistance programs to use a single authorization form that authorizes the program to, for example, represent an individual in a Medicare appeal and obtain records necessary for such representation. In fact, since medical records are essential to a Medicare appeal, the program could not represent the individual without authorization to obtain medical records. It seems to us that this situation is analogous to the research exception described in the regulation – without use or disclosure of health information, research would be meaningless, and without use or disclosure of health information, representation in a health care appeal would be meaningless. Rather than generating multiple authorization forms, could a program have a single form that otherwise complies with HIPAA requirements, explicitly stating the matter in which the program agreed to represent the individual and enumerating the types of health records that it would obtain for that purpose?

5) Alternatives to written authorization

It is not always practical for a health advocacy program that, for example, serves a wide region from a single office, and does its work primarily by phone, to get written authorizations from consumers. Often, programs are able to get information and comply with HIPAA by making three-way calls with a consumer and covered entity. However, three-way calls are not always practical—sometimes a health advocacy program must leave a message for a covered entity and the consumer is not available when the call is returned. Some vulnerable consumers rely on public phones, making callbacks particularly difficult. Few have access to fax machines and mailing an authorization form will often delay advocacy for more than a week.

Would it be appropriate to have a higher standard for exchange of written medical records than for oral information about the consumer's health insurance claim? For written medical records, the regulation could continue to require written authorization. For oral information (such as whether a claim for coverage has been denied and the reasons or whether the claim is pending, whether a person has current public coverage or needs to recertify, etc.) could the regulation allow for alternative means for the consumer to verify that he or she wishes the covered entity to talk with the advocate about his or her case?

For example, in other settings, such as credit card issues, consumers often have to give a piece of information that only they are likely to know (their mother's maiden name or a password) to verify their identity to a business. It seems that covered entities (or OCR itself) could similarly develop procedures for consumers to identify both themselves and the consumer representatives to whom the entity should divulge limited information.

Thank you for considering our comments and please contact us if you want further information.

Sincerely,

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