September 21, 2010

Mr. Jay Angoff
Director, Office of Consumer Information and Insurance Oversight
Department of Health and Human Services
Attention: OCIIO-9993-IFC
P.O. Box 8016
Baltimore, MD 21244-1850

RIN 0991-AB70

Submitted electronically via www.regulations.gov

Dear Director Angoff,

The National Partnership for Women & Families (National Partnership) and the Center for Democracy & Technology (CDT), through its Health Privacy Project, promote comprehensive privacy and security policies to protect health data, in addition to supporting transparency in the health care system in order to promote informed patient decision-making.

The Patient Protection and Affordable Care Act (Affordable Care Act) amended the Public Health Service Act (PHS Act) to require implementation of new requirements relating to internal claims and appeals and external review processes for group health plans and health insurance coverage. The National Partnership and CDT submit these comments in response to the July 23, 2010 interim final rules issued by the Department of Health and Human Services (IFR).  

Although we support the Affordable Care Act’s efforts to ensure that patients have access to a full and fair appeals process for handling health information, we are concerned that new requirements set forth by these regulations related to the content of notices of adverse benefits determinations raise significant privacy concerns that may impinge upon patients’ rights to confidentiality of their medical information.

As such, we urge the Department to rescind the new diagnosis and treatment code content requirements. We propose instead that plans be required to provide such coding information to an enrollee only when he or she specifically requests it.

New Requirements

The IFR specifically requires a health plan to supply new and additional information related to “adverse benefit determinations” by the plan. The regulation’s stated goal is to provide consumers with information “sufficient to identify the claim involved,” including the date of service, the name of the provider and the amount of the claim. However, pursuant to the new

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1 75 Fed. Reg. 43330 (July 23, 2010).
2 As part of the requirements to establish and maintain reasonable appeals procedures, the Department of Labor has regulations currently in effect that mandate what information must be included in notices of benefits. See 29 C.F.R. 2560.503-1. These requirements are extensive and comprehensive, and do not require the inclusion of diagnosis or treatment codes.
3 Id. at 43333.
regulation, health plans must also provide the diagnosis code (specifically ICD-9 code, ICD-10 code or DSM-IV code) and the treatment code (such as a CPT code), as well as the meanings of each code.\(^4\)

**Implications for Patient Privacy**

These newly-required codes provide very specific information about diagnosis and treatment. Sensitive health issues and conditions (which could include information about, for example, drug treatment, abortion, AIDS and other sexually transmitted disease diagnoses, cancer or other sensitive conditions) could be identified by an ICD-9 or CPT code pursuant to a quick internet search. However, given the regulation’s requirement that the “corresponding meanings of these codes” be included on the notice as well, such an internet search would not even be necessary.\(^5\) The obvious privacy concerns raised by such disclosures may have a particular impact on dependents up to age 26 who, under the new requirements in the Affordable Care Act, may be covered by their parents’ health plan.

Although these new requirements apply only to “adverse benefit determinations,” in practice they will apply to almost every bill or statement of benefits sent by a health plan. An “adverse benefit determination” is defined by the Department of Labor to include any time a health plan applies a co-payment, which happens frequently and commonly.\(^6\) Given this broad application, documents with sensitive and previously private diagnosis and treatment information now will be routinely and widely distributed, making it highly vulnerable to inappropriate disclosure.

Health plans regularly send Explanations of Benefits (EOBs) to consumers following each visit to a physician, lab test or treatment at a hospital. Currently, such information is provided in a general form to avoid privacy concerns. The new rules would require private and potentially sensitive information about the health status of patients to be distributed through the mail, where it could end up in the wrong hands. Mail is frequently misdelivered or labeled with the wrong address, meaning a patient’s HIV status or substance abuse treatment could easily become known by one’s neighbors or other members of the community. Even when it arrives at the correct house and is addressed to the correct individual, there is no guarantee that the patient at issue will be the only one with access to his or her EOB. One can imagine, for example, a situation in which a child comes across her parent’s cancer diagnosis by reading an EOB, when the parent may not previously have shared such information with the child; or a situation where an abusive spouse discovers previously confidential health information about his or her partner.

Further, it is important to note that physicians will often conduct tests in order to rule out a particular diagnosis. Yet under these new requirements, the diagnosis codes for each test will be included on a patient’s EOB. This means that, for example, tests for a particular mental health disorder that a patient is found not to have may be listed on his notice, potentially leading a reader

\(^4\) *Id.* The rule specifically states: “A plan or issuer must ensure that any notice of adverse benefit determination or final internal adverse benefit determination includes information sufficient to identify the claim involved. This includes the date of service, the health care provider, and the claim amount (if applicable), as well as the diagnosis code (such as an ICD–9 code, ICD–10 code, or DSM–IV code), the treatment code (such as a CPT code), and the corresponding meanings of these codes.”

\(^5\) 75 Fed. Reg. at 43333.

to mistakenly understand the patient’s health status. Previously, all tests would be listed simply as, for example, “outpt lab/x-ray,” rather than listing not only all procedure codes and descriptions, but each associated diagnosis code and diagnosis code description.

Although we appreciate the Department’s effort to provide consumers with information sufficient to identify a particular claim, the inclusion in EOBs of diagnosis and treatment codes goes well beyond what consumers either need or expect to be included in their claims statements. In order to consider whether a claim warrants an appeal, members need to know basic information related to the date of service, the name of the provider, the general service provided and the reason for denial. Current EOB documents supply this necessary information in a general way, sufficient to identify the service, but lacking any information linking the service to a diagnosis or treatment. As such, existing requirements do not jeopardize patient privacy the way these new specifications do.

Conclusion

In summary, we understand that consumers need the information necessary for them to appeal an adverse benefit determination and we support the need for a transparent and fair appeals process. However, when balancing the danger of including this powerful information on common insurance forms against the need to supplement existing federal and state laws that appear to work relatively effectively, we believe the strong interest in consumer privacy outweighs the need for this additional requirement.

We urge HHS to rescind the requirement that treatment and diagnosis code information be included on notices of adverse benefit determinations. A more reasonable alternative would be to require that plans provide such coding information to an enrollee in the event an enrollee specifically requests it. This compromise strikes a crucial balance between providing transparency of information and protecting patient privacy.

Sincerely,

Christine Bechtel
Vice President
National Partnership for Women & Families

Deven McGraw
Director, Health Privacy Project
Center for Democracy & Technology