

FOR THE RECORD

DECLARE YOUR MEDICAL PRIVACY INTENTIONS

Home Health Agencies

By federal mandate and without patient consent, 15 or more *pages* of personal, behavioral, and health information about most patients who receive home health services is collected and sent to the federal government by home health agencies (HHA). This data is first transmitted electronically to a State government database and then sent to the U.S. Department of Health and Human Services (HHS). The data is entered and resides permanently in a **national database called OASIS (Outcome and Assessment Information System)** where it is available for use and disclosure—again without patient consent.

Data is collected on all non-maternity adults ages 18 and older, who obtain care from home health agencies that participate in the Medicare and Medicaid programs—whether the patient’s services are paid by private insurance, cash, Medicare or Medicaid. Only pregnant women, children, and those who receive only housekeeping services are excluded.

In 1987, Congress passed a law (*Public Law 100-203, the 1987 Omnibus Budget Reconciliation Act*) requiring HHS to develop a ‘standardized reproducible assessment instrument’ for the purpose of evaluating quality of care received by home health patients. The law specified that the survey be done by ‘the appropriate State or local agency’ that there be ‘reasonable steps to avoid giving notice of such a survey’ that the survey be done by an individual ‘who is not serving (or has not served within the previous 2 years) as a member of the staff’ of the home health agency, and that the survey be done ‘only with the consent of such individuals.’ (42 U.S.C. 1395bbb)

HHS followed few of these mandates when they published the rule requiring the data collection (42 CFR Part 484, *Medicare and Medicaid Programs: Comprehensive Assessment and Use of the OASIS as Part of the Conditions of Participation for Home Health Agencies, January 25, 1999; as amended June 18, 1999*). Instead, the “survey” is done on virtually all patients in Medicare-participating agencies, and home health agencies are expected to use their own staff to do it. After initially requiring no patient notification or consent, HHS responded to privacy concerns by requiring patients to be notified, but no consent is required. Collection began July 19, 1999 and transmission to state and federal government began August 18, 1999.

DATA COLLECTED

To gather data for the OASIS assessment, HHA staff (nurses and therapists) question and observe patients during the first visit, and at various intervals thereafter. Staff responses to the 95 required data items are recorded on multi-page forms. HHS requires financial data to be collected but, due to negative media attention, it is not yet transmitted. Certain assessments can be open to subjective bias, for example: “*Behaviors Demonstrated at Least Twice a Week (Reported or Observed)*” and “*High Risk Factors*” (heavy smoking, obesity, alcohol or drug dependency). At this time, data collected and transmitted includes:

- behavior
- medical diagnoses
- emotional stability
- prognosis/life expectancy
- functional status
- educational level
- relationships/family
- living arrangements
- housing conditions
- safety hazards

Demographic data (name, address, social security number) is also collected. However, for patients who are privately insured, pay cash, or whose care, for whatever reason, is not reimbursed by Medicare or Medicaid, the data will be transmitted minus four identifiers. Name, Social Security Number, Medicare number, and Medicaid number will be ‘masked’ by the home health agency. All other identifiers, many of which can be crossmatched with public databases to uncover individual identities, will not be masked. Address, age, sex, birth date, zip code, and other personal information will remain visible and available. The collected data can then be disclosed under federal ‘routine use’ provisions to seven (7) categories of entities:

- The Department of Justice, court or adjudicatory body with an interest in litigation
- Agency contractors or consultants hired for services related to the OASIS system of records
- Federal and state oversight agencies for assessment of cost, effectiveness, and quality of care
- Federal and state Medicare and Medicaid agencies
- Peer Review Organizations to assess quality of care of individual providers and health care facilities
- Individuals or organizations for research related to prevention of disease or disability, restoration or maintenance of health, or payment-related projects
- A member of Congress or a Congressional staff member in response to an inquiry made at the written request of the constituent about whom the record is maintained. (*Federal Register*, June 18, 1999, Volume 64, Number 117, *Notice of new system of records*)

Separate declaration forms addressing additional health, financial, medical and personal data disclosures by banks, insurers, health care facilities, and health care, as allowed by the 2001 federal medical privacy rule and the 2000 Financial Modernization Act (Gramm-Leach-Bliley Act), are on the CCHC website: www.cchconline.org.

**FOR THE RECORD:
DECLARATION OF MEDICAL PRIVACY INTENT
RE: HOME HEALTH DATA COLLECTION**

To:

Home Health Agency

Other

Government Agency (State Health Dept., U.S. Dept. of Health and Human Services) - **use only if already collected (see below)**

I find the federally-required collection of personal, financial, and medical data to be detrimental to medical privacy, personal privacy, financial privacy, and the confidentiality of medical records and individually-identifiable health, financial, and personal data. Section 1395bb of the Social Security Act (42 U.S.C. 1395bbb) and the subsequent 1999 federal regulation (42 CFR Part 484, Medicare and Medicaid Programs: Comprehensive Assessment and Use of the OASIS as Part of the Conditions of Participation for Home Health Agencies, January 25, 1999; as amended June 18, 1999) became effective August 19, 1999 and has allowed the collection and transmission of patient and family data to state departments of health and the U.S. Department of Health and Human Services without the consent of patients or family members.

For the record, I therefore and hereby declare my express wish and intent to prevent disclosure or transmission of medical, personal, health, psychological and financial information to State or Federal government agencies, or the Outcome and Assessment Information System. Please keep this form on file. To be specific, without written, specific, informed and voluntary consent, information in the list below labeled "Collection Categories" or any other information on _____ shall not be collected or disclosed for the OASIS system.

Name of self or guardian responsibility

Collection Categories:

- behavior
- educational level
- medications
- sensory status
- transportation options
- use of the emergency room
- medical diagnoses
- relationships
- race/ethnic background
- ability to breath
- hospitalizations
- psychological status
- emotional stability
- living arrangements
- type of insurance
- ability to urinate/defecate
- use of nursing home
- financial status (*not yet disclosed*)
- medical conditions
- housing
- treatments received
- integrity of skin
- neurological status
- functional status
- safety hazards
- ability to speak
- ability to eat/walk
- prognosis

FOR STATE OR FEDERAL AGENCIES (as named above): If any data for OASIS has already been collected and transmitted to State or Federal government agencies on _____, I hereby declare my

Name of self or guardian responsibility

express wish and intent that the data held by HHS or other government agencies/contractors be **deleted and destroyed**, and that entities in the seven 'routine use' categories either not receive the data or, if they have received it, be required to destroy and delete the data as well. These include, but are not limited to:

- The Department of Justice, court or adjudicatory body with an interest in litigation
- Agency contractors or consultants hired for services related to the OASIS system of records
- Federal and state oversight agencies for assessment of cost, effectiveness, and quality of care
- Federal and state Medicare and Medicaid agencies
- Peer Review Organization to assess quality of care of individual providers and health care facilities
- Individuals or organizations for research related to prevention of disease or disability, restoration or maintenance of health, or payment-related projects
- A member of Congress or a Congressional staff member in response to an inquiry made at the written request of the constituent about whom the record is maintained. (*Federal Register*, June 18, 1999)

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
1954 University Ave. W., Suite 8
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.