

January 25, 2010

2010 Census: PROCEDURES FOR INTERVIEWING PATIENTS WHO LIVE IN HEALTH CARE FACILITIES

AT A GLANCE

The Issue:

The U.S. Census Bureau is required to count the nation's population every 10 years. In February, Census Bureau workers will contact health care facilities to ensure that some people living in certain hospitals, skilled nursing facilities and inpatient hospice facilities are accounted for appropriately in the 2010 census. While the majority of your patients will not be subject to census taking at your facility, you will need to work with the Census Bureau to determine which individuals should be interviewed.

Our Take:

While important, the 2010 census must be conducted in a fashion that minimizes burden, avoids disrupting patient care and adheres to adequate confidentiality protections. This *Regulatory Advisory* describes the 2010 census process and provides an overview of pertinent patient confidentiality issues.

What You Can Do:

- ✓ Share this advisory with your senior management team.
- ✓ Ask relevant staff to review this advisory and determine whether actions by local census workers are consistent. If there are discrepancies, contact local census officials to clarify any misunderstandings. If that does not resolve the problem, contact your state hospital association or the AHA and we will work to ensure that the Census Bureau provides better instructions to its local workers and supervisors.
- ✓ Determine what role your staff should play in obtaining information for census workers.

Further Questions:

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BACKGROUND

The federal government is required to count all U.S. residents every 10 years. The information gathered from this census determines many things, including congressional representation and allocation of about \$400 billion in federal and state funding distributed each year for health assistance, services for older adults, employment services, schools and more. Census data also are used by health care providers for strategic planning. This year, the U.S. Census Bureau is working especially hard to identify and count special populations not easily captured by the mailed census. These populations include individuals residing in group-living quarters such as hospitals, skilled nursing facilities and jails.

Beginning in February, Census Bureau enumerators will contact you to make an appointment to visit your facility to gather information about the residents in order to conduct the census count. The official counting process will take place nationwide from April to May.

This *Regulatory Advisory* describes our understanding of the process adopted by the Census Bureau for identifying which individuals in health care facilities are to be counted and how the count will be conducted. This information was reviewed by Census Bureau staff to ensure its accuracy. All regions are required to adhere to the process described below.

If your facility includes a federally assisted alcohol and drug treatment center, please pay close attention to information provided in the “*Your Role*” and “*Confidentiality Concerns*” sections of this advisory.

Who is Counted Where

In general, the Census Bureau collects information from people at their usual residence – the place where the person lives and sleeps most of the time. However, the Census Bureau is concerned that some individuals, particularly those residing in group-living

quarters such as hospitals, skilled nursing facilities and jails, could be missed. As a result, it has identified a list of specialty facilities or units that are more likely to contain such individuals. The following chart depicts our understanding of which patients will be counted at home versus at a health care facility.

Facility/Unit/Floor	Counted at Home	Counted at Facility
Acute care hospital	X	Only those patients with no disposition or exit plan.
Newborn babies	X	
Nursing facilities/skilled-nursing facilities/units/floors (long-term, non-acute care patients). Includes rehabilitation facilities.		X
Mental (psychiatric) hospitals or psychiatric units/floors (long-term, non-acute care patients)		X
Hospice facilities/units/floors		X
Dormitories for nurses, interns, etc.	X	Only those with no usual home elsewhere.
Residential treatment centers for adults (in a highly structured live-in environment). Includes alcohol and substance abuse treatment facilities.		X
Long-term care hospital		Only those with no usual home elsewhere.

Federal regulations prohibit hospitals from providing identifiable information about patients in federally assisted alcohol and substance abuse programs; please see the “*Your Role*” and “*Confidentiality Concerns*” sections of this advisory for more information.

THE PROCESS

Stage One: Initial Contact by Census Workers February 1 to March 19, 2010

Census workers will conduct advance visits to health care facilities to provide information on the census process, to identify any special care units or facilities where the census will be taken, and to estimate how many individuals will be counted at your facility for work planning purposes.

If your inpatient units provide only acute care, you will have little, if any, involvement in the census. The census residence rules explicitly state that general hospital patients and newborn babies are counted at their usual residence (that is, their homes). Census staff may seek help to identify hospital inpatients who have no other home, but they are not authorized to interview every acute-care inpatient in order to identify them.

Stage Two: Inventory
February 1 to April 1, 2010

In preparation for the official count in April, census staff will create an inventory of the individuals at a facility. This inventory is used to determine which individuals will be required to fill out the *Individual Census Report*, a packet that must be completed for each individual who will be counted as a resident of the facility. The inventory also is used to track receipt of completed forms. The needed information should be readily obtainable from administrative records systems, subject to the *Health Insurance Portability and Accountability Act's* (HIPAA) privacy regulations as well as federal requirements pertaining to confidentiality for patients receiving treatment in federally assisted alcohol and drug abuse programs. See the “*Your Role*” and “*Confidentiality Concerns*” sections below for more information on how federal regulations interact with the 2010 census.

Stage Three: Census Taking
April 1, 2010 to May 14, 2010

Between April 1 and May 14, the official census will be conducted for those individuals included in the inventory. Each individual who will be counted as a resident of the facility will be given a questionnaire packet that consists of the *Individual Census Report* and an envelope. Each resident is required to fill out an Individual Census Report and to seal it in the envelope.

YOUR ROLE

Hospitals and health care facilities are *required by federal law to cooperate with the census process*. Specifically, hospitals are required to work with census staff to identify any inpatients who have no other home and, therefore, must be counted as residents of the facility. Hospitals also must work with census staff to conduct the official count of these individuals. If a hospital elects, census workers can delegate census-taking functions to hospital staff – this is known as *self-enumeration*. In making that decision, consider what will be least intrusive to patients and staff, the size and nature of the patient group to be counted, and the confidentiality issues discussed below. Facilities that want to self-enumerate will be asked to have selected staff go through a short training session and then be sworn in as census takers.

Hospitals will be assigned a *Census Bureau Crew Leader*, who will facilitate the counting process at the facility. The Crew Leader will provide all the materials needed and – for hospitals that choose to self-enumerate – will train and swear-in staff delegated the census-taking function.

In all, hospital responsibilities will include:

- Selecting personnel to help with the count.
- Creating lists of all persons living at the facility on April 1, 2010. These lists are required to conduct a complete enumeration.
- Getting materials from the Census Bureau Crew Leader.

- Working with the Crew Leader on preparing the Individual Census Report packets for each resident counted in your facility.
- Making sure that each resident who must be counted at the facility completes the Individual Census Report packet.
- Completing Individual Census Reports from administrative records for any individual who is not present or able to complete it at the time of the count, but was still a resident of the facility on April 1, 2010.
- Reviewing completed materials for accuracy and legibility.
- Turning in completed materials to the Census Bureau Crew Leader.

Patients in Alcohol and Drug Treatment Centers

Please note that federal law prohibits hospitals from providing identifiable information about any patient in an alcohol and drug treatment center who is subject to federal rules protecting the identity of patients in those centers. To determine if your alcohol or substance abuse treatment center is classified as a “federally assisted” drug or alcohol abuse treatment center, see 42 U.S.C. 290dd–3 and 42 CFR Chapter 1, Part 2. The statute and rules can be found at <http://www.law.cornell.edu/uscode/42/290dd-2.html> and http://www.access.gpo.gov/nara/cfr/waisidx_02/42cfr2_02.html), respectively. For more information, please see the “*Confidentiality Concerns*” section below.

CONFIDENTIALITY CONCERNS

When counting health care facility residents, the Census Bureau will collect only each resident’s name, gender, age, date of birth, race and ethnicity, as well as sometimes the address of their usual residence. Census Bureau workers are not authorized to collect any *health-related information* about individuals. Census workers must follow strict protocols on the handling of information and are required to go through a swearing-in process that commits them to strict census confidentiality requirements. Failure to adhere to those requirements carries stiff penalties in the form of imprisonment and/or fines.

The chief concern for hospitals is how to cooperate in the census process without violating the privacy laws that apply to health care providers. While the information collected by the census is demographic in nature, confidentiality requirements applicable to health care providers are not always limited to individual *health* information and can extend to protecting the fact that an individual is even receiving treatment. The HIPAA privacy regulations, as well as federal requirements pertaining to confidentiality for patients receiving treatment in federally assisted alcohol and drug abuse programs, are examples of such protections. Additionally, some state confidentiality requirements, particularly related to mental health treatment, may impose special rules on health care providers about the use and disclosure of individually identified information, including whether an individual is receiving such treatment.

HIPAA

Under federal law, hospitals are required to cooperate with the census. Therefore, HIPAA would seem to permit hospitals to use and disclose minimum necessary patient information

to comply with requirements for organizational cooperation with information requests by Census Bureau officials, as contemplated in the federal law found at 13 U.S.C. sec. 224.

Requirements for Federally Assisted Alcohol and Drug Abuse Treatment Centers

The federal confidentiality requirements applicable to federally assisted alcohol and drug abuse treatment are more stringent than the HIPAA requirements and pose greater challenges for compliance. This regulation restricts the use or disclosure of patient information without a patient's consent, unless an exception specifically outlined in the regulation applies. The regulation's use and disclosure restrictions apply whether the holder of the information:

- believes that the person seeking the information already has it;
- has other means of obtaining it;
- is a law enforcement or other official;
- has obtained a subpoena; or
- asserts any other justification for a disclosure or use which is not permitted by these regulations.

Our examination of the regulation does not seem to reveal any specific exceptions permitting the use and disclosure of patient information without a patient's consent that are directly applicable in the case of the census. In fact, the regulations are explicit that "[a]ny answer to a request for a disclosure of patient records which is not permissible . . . must be made in a way that will not affirmatively reveal that an identified individual has been, or is being diagnosed or treated for alcohol or drug abuse."

Where the facility or a component of the facility is publicly identified as a place where only alcohol or drug abuse diagnosis, treatment or referral is provided, the presence of an identified patient may be acknowledged only if the patient's written consent is obtained, as outlined in the regulations, or if an authorizing court order is entered in accordance with the regulation's precise requirements. In such circumstances, the regulation only allows an inquiring party to be given a copy of the regulations and be advised that the regulations restrict the disclosure of alcohol or drug abuse patient records. However, even this procedure cannot be used if doing so affirmatively reveals that the regulations restrict the disclosure of the records of an identified patient. The regulation, however, would permit acknowledgement of the presence of an identified patient in a facility or part of a facility if the facility is not publicly identified as only an alcohol or drug abuse diagnosis, treatment or referral facility, and if the acknowledgement itself does not reveal that the patient is receiving treatment for alcohol or substance abuse. *Therefore, hospitals will need to determine whether they are considered to be a "federally assisted" alcohol or substance abuse treatment center in order to determine the best way to respond to census inquiries related to patients receiving alcohol and drug abuse treatment, and whether it may be necessary to obtain patient consent to use and disclose information.*

Options for Maintaining Confidentiality

When asked to identify individuals to be counted, hospitals may be able to obtain the needed information easily from computerized administrative records, so long as no federal

and/or state requirements prohibit the identification of any patient to anyone outside the facility staff without the patient's consent.

If hospitals are prohibited from sharing identifying information, the hospital may consider whether a “*blinding*” approach can be used that codes patients by location within the facility (e.g., by room and bed number) rather than by the individual's name. Hospitals will need to ensure that coding by location does not identify the facility and/or unit as only an alcohol or drug abuse diagnosis, treatment or referral facility, and that no patients are revealed to be alcohol or drug abusers if the federal restrictions on federally assisted alcohol and drug treatment programs are applicable.

To maintain patient confidentiality during the actual count, hospitals have several options:

- Act only as distributor of the census packages, leaving the rest to the census workers. By completing a census form, individuals are providing their consent to release of the information to the Census Bureau. Since the distribution of forms to patients is likely to trigger questions, hospitals should ensure that the distribution date is scheduled when census workers are available onsite to answer questions. Hospitals should be prepared to help obtain consents, where needed, for incapacitated or other patients and then to assist in providing information to the census workers.
- Facilitate providing the census information directly, rather than relying on patients to complete census forms. It may be possible to generate a computerized list with all of the information needed to complete the census forms. Depending on confidentiality restrictions, this list could identify patients by name or could use the blinding approach described above. Census workers could then complete the individual census forms based on the list.
- Accept the delegated self-enumeration responsibility as described in the “*Your Role*” section of this advisory.

FURTHER QUESTIONS

For more information on the 2010 census, visit the Census Bureau's Web site at <http://www.2010.census.gov>. The rules about residence and special populations can be found at <http://2010.census.gov/2010census/how/index.php>. Section 11 of those rules is the most pertinent.

If you have questions about the census, please call your local census office at the telephone number provided in your census materials. If you have questions about this advisory, please contact Elizabeth Baskett, AHA associate director of policy, at (202) 626-2294 or ebaskett@aha.org.