2020 Census: Procedures for Interviewing Patients Who Live in Health Care Facilities

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 certain people living in hospitals, skilled nursing facilities (SNFs), and psychiatric hospital or psychiatric units for long-term care are accounted for appropriately in the 2020 census. While the majority of your patients will not be subjected to census taking at your facility, you will need to work with the Census Bureau to determine which individuals should be interviewed.

AHA Take:
The 2020 census is important, but it needs to be conducted in a manner that minimizes burden, avoids disrupting patient care and adheres to adequate confidentiality protections. This advisory describes the 2020 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:
Please contact Kristina Weger at kweger@aha.org or Lawrence Hughes at lhughes@aha.org.

Key Takeaways
- This year the federal government will take a census of the U.S. population, including individuals living in health care facilities.
- Hospitals and health care facilities are required by federal law to cooperate with the census process.
- The Census Bureau will contact your facility in February to obtain identifying information about the facility, including a preferred enumeration method.
- Federal regulations prohibit hospitals from providing identifiable information about patients in federally assisted alcohol and substance use disorders treatment programs.
Overview

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 $675 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. The 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, SNFs and jails. This population is counted through the U.S. Census Group Quarters Enumeration.

Beginning in February, Census Bureau enumerators will contact health care facilities to obtain important identifying information about the facility, including a preferred enumeration method. The official counting process will take place nationwide from April 1 through June 5.

This 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 substance use disorders 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, including hospitals, SNFs and residential treatment centers, could be missed. As a result, the agency 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. Please note that patients at inpatient hospice facilities should be counted at the residence where they live and sleep most of the time, rather than at the facility.
<table>
<thead>
<tr>
<th>Facility/Unit/Floor</th>
<th>Counted at Home</th>
<th>Counted at Facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute care hospital</td>
<td>X</td>
<td>Only those patients with no disposition or exit</td>
</tr>
<tr>
<td>Newborn babies</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Nursing facilities/skilled-nursing facilities/units/floors (long-term, non-acute care patients). Includes rehabilitation facilities</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Mental (psychiatric) hospitals or psychiatric units/floors (long-term, non-acute care patients)</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Hospice facilities/units/floors</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Residential treatment centers for adults (in a highly structured live-in environment). Includes alcohol and substance use disorders treatment facilities.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Long-term care hospital</td>
<td></td>
<td>Only those with no usual home elsewhere</td>
</tr>
</tbody>
</table>

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

**The Process/Timing**

For the 2020 census, the overall Group Quarters operations will involve two components: Group Quarters Advance Contact operation and Group Quarters Enumeration operation. The Group Quarters Advance Contact operation will involve three phases and the Group Quarters Enumeration consists of only one phase.

**Phase One: Outreach by Mail – January 2020**
The Census Bureau has mailed letters to facilities informing them of the 2020 census, explaining the steps in the Group Quarters Enumeration process, and notifying them that Census Bureau representatives will be calling or visiting their facility.

**Phase Two: Outreach by Phone – Feb. 3 – March 6**
Census Bureau representatives will call each facility to explain the enumeration process.
and collect certain identifying information about the facility. They also will ask for your preferred enumeration method.

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 place to live, but they are not authorized to interview every acute-care inpatient in order to identify them.

**Phase Three: Facility Visits (if needed) – Feb. 21 – March 6**

Census Bureau representatives will conduct a personal visit to facilities across the United States and Puerto Rico that could not be contacted by phone or were unable to complete the phone interview. The personal visit phase of the operation will be conducted Feb. 21 through March 6, 2020.

For Remote areas of Alaska, the above phases will take place Jan. 13 through Feb. 25, 2020.

**Phase Four: Census Taking - April 1 – June 5, 2020**

Group Quarters Enumeration for the 2020 census will be conducted across the U.S., including in Puerto Rico, between April 1 and June 5, 2020. Late Group Quarters Enumeration for the 2020 Census will be conducted July 1 through July 24, 2020.

The following enumeration methods are available to health care facilities and each administrator should select the method best suited for their facility:

- **Electronic Response Data Transfer (eResponse)** – The group quarters administrator fills in a template with group quarters data and respondent level data for each person who is staying at the facility on Census Day (April 1, 2020). The group quarters administrator electronically sends the census response data to the Census Bureau.

- **In-Person Interview** – A census worker conducts a face-to-face in-person interview with each person who is served or staying at the facility on April 1, 2020.

- **Drop-Off/Pickup of Questionnaire** – A census worker leaves census questionnaires to be completed by or for each person who is staying at the facility on April 1, 2020. The census worker then picks up the completed questionnaires at an agreed-upon time.

- **Paper Response Data Collection** – A census worker meets with the administrator of the facility to obtain a paper listing of census response data for each person who is served or staying at the facility on April 1, 2020.

- **Facility Self-Enumeration** – A census worker swears in and trains the group quarters facility administrator and then leaves behind census materials so that the administrator can conduct the enumeration for each person who is living or staying at the facility on April 1, 2020. A census worker then returns to pick up the completed questionnaires at an agreed-upon time. Only health care facilities,
military installation group quarters and correctional facilities can select this option.

The needed patient information should be readily obtainable from administrative records systems, subject to the HIPAA privacy regulations as well as federal requirements pertaining to confidentiality for patients receiving treatment in federally assisted alcohol and substance use disorders treatment programs. See the “Your Role” and “Confidentiality Concerns” sections below for more information on how federal regulations interact with the 2020 census.

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.

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. These lists are required to conduct a complete enumeration.
- Determining the best enumeration method for your facility, as needed.
- Obtaining necessary materials from the Census Bureau staff.
- Working with the Census Bureau staff to prepare the Individual Census Questionnaire packets for each resident counted in your facility.
- Making sure that each resident who must be counted at the facility completes the appropriate census questionnaire packet.
- Completing census questionnaires 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.
- Reviewing completed materials for accuracy and legibility.
- Turning in completed materials to the Census Bureau staff.

Patients in Alcohol and Substance Use Disorders Treatment Centers

Please note that federal law prohibits hospitals from providing identifiable information about any patient in an alcohol and substance use disorders treatment center who is subject to federal rules protecting the identity of patients in those centers. To determine if your alcohol or substance use disorders treatment center is classified as a “federally
assisted” drug or substance use disorders treatment center, see 42 U.S.C. 290dd–3 and 42 CFR Chapter 1, Part 2. The statute and rules can be found at https://www.govinfo.gov/content/pkg/USCODE-2011-title42/pdf/USCODE-2011-title42-chap6A-subchapIII-A-partD-sec290dd-2.pdf 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 or substance use disorders treatment 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. HIPAA permits a covered entity to disclose protected health information to the Census Bureau to the extent required by Title 13, as contemplated in the federal law found at 13 U.S.C. sec 224.

Requirements for Federally Assisted Alcohol and Substance Use Disorders Treatment Centers

The federal confidentiality requirements applicable to federally assisted alcohol and substance use disorders 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 agency or other official;
• Has obtained a subpoena; or
• Asserts any other justification for a disclosure or use which is not permitted by the 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 substance use disorders 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 substance use disorders 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 substance use disorders diagnosis, treatment or referral facility, and if the acknowledgement itself does not reveal that the patient is receiving treatment for alcohol or substance use disorder.

Therefore, hospitals will need to determine whether they are considered to be a “federally assisted” alcohol or substance use disorders treatment center in order to determine the best way to respond to census inquiries related to patients receiving alcohol and substance use disorders 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 substance use disorders diagnosis, treatment or referral facility, and that no patients are revealed to be alcohol or substance use disorders patients if the federal restrictions on federally assisted alcohol and substance use disorders 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-counting responsibility as described in the “Your Role” section of this advisory.

Further Questions


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 Kristina Weger at kweger@aha.org or Lawrence Hughes at lhughes@aha.org.