

Attachment E
Advance Letter

(ON NCHS LETTERHEAD)

DATE

NAME OF FACILITY
ADDRESS OF FACILITY
CITY, ST, ZIP CODE

Dear NAME

The National Center for Health Statistics of the Centers for Disease Control and Prevention is conducting a nationwide survey of residential care facilities, such as assisted living facilities and board and care homes. This study collects information about the characteristics of residential care facilities and the types of services they provide. The survey will also gather information on the characteristics of people who live in residential care facilities.

The purpose of this letter is to invite your participation in the 2008 National Survey of Residential Care Facilities (NSRCF). This survey includes a randomly selected nationwide sample of residential care facilities, each of which represents a number of similar facilities. These facilities are an important and growing component of the long-term care system.

Your participation is voluntary, there are no penalties for refusing to answer any questions, and you may stop at any time. However, it is essential that we obtain data from all sampled facilities in order to achieve accurate and complete statistics. The survey is being conducted nationwide primarily by personal interview with administrators and staff. No residents will be contacted at any time. You may be asked to take part in other government surveys sometime in the future. Taking part in any other survey is also voluntary.

Please be assured that the identity of facilities and of sampled residents will be protected and the questions will not include any information that could be used to identify individual residents. Also be assured that there are several ways that the Privacy Rule (as mandated by the Health Insurance Portability and Accountability Act [HIPAA]) allows you to participate. In particular, disclosures of resident data are permitted for public health purposes and for research that has been approved by an Ethics Review Board – both of which apply to this survey. The enclosed materials explain that this survey does not retain protected health information under HIPAA and does not require signed consent by the resident.

I want to emphasize further that the information you and your staff supply will be used solely for statistical research and reporting purposes. The only parties that can receive information that could identify facilities or residents are those we have told you about on the back of this letter

In a few days a representative of RTI International, the contractor conducting the survey on our behalf, will call you to arrange an appointment for an in-person interview. Your cooperation in this survey will be very much appreciated. Your participation will help to provide a valuable picture of the residential care industry. If you have questions, please call a NSRCF representative at 1-800-XXX-XXXX.

Sincerely,

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics

Attachment E (back of Advance Letter)
National Survey of Residential Care Facilities (NSRCF)
Frequently Asked Questions

I'm asked to participate in studies all the time. What makes this one any different?

The NSRCF is a large national study that, because of its size and design, can provide information that is representative of all residential care facilities in the United States. The National Center for Health Statistics, the federal agency responsible for providing statistical information that will guide actions and policies to improve the health of the American people, developed this survey collaboratively with several other government agencies: Office of the Assistant Secretary for Planning and Evaluation (DHHS), Department of Veteran Affairs and the Agency for Healthcare Research and Quality.

The survey is broadly supported by industry associations, including the American Health Care Association, the American Association of Homes and Services for the Aging, and the Assisted Living Federation of America (see enclosed endorsement letters). **For more information and to see a short video about the NSRCF, visit www.cdc.gov/nchs/nsrcf.htm**

What other residential care facilities are you going to visit?

This is a random national sample and we do not release the names of these facilities to anyone. This is to protect individual facilities and the residents they serve.

Why can't some other facility take our place?

If you do not participate, the unique qualities of your facility will be lost. The survey will be used by Congress and decision makers who will formulate policy for the next decade. You represent other facilities like yours. If you don't participate, there is no guarantee that residential care facilities like yours will be adequately represented. We don't want industry decisions based on this survey to be made without all types of facilities, including those like yours, represented.

Will the data be held confidential?

The NSRCF is authorized by Congress in Section 306 of the Public Health Service Act (42 USC 242K). All information collected in this survey will be held in strict confidence according to law [Section 308(d) of the Public Health Service Act (42 United States Code 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)].

Any identifiable information will be held confidential and will be used only by NCHS staff, contractors or agents, only when necessary and with strict controls, and will not be disclosed to anyone else without the consent of your facility. By law, every employee as well as every agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you."

My staff is incredibly overworked right now. I need to know how much of their time will be required for this survey. How long will this take?

We will need about 40 minutes with you or someone you designate to answer questions about your facility. We will also collect information about a small sample of current residents that will take approximately 30 minutes for each person sampled. The interviewer will accommodate the schedules of your staff to complete these tasks as quickly as possible.