



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

May 5, 2010

OHI - WHITNEY COURT
TERESA DALY
25 Freedom Parkway
Hermon, ME 04401

National Center for Health Statistics
3311 Toledo Road
Hyattsville, Maryland 20782

M16370SC

5-6-10
Brenda -
This came via FedEx today
Can I assume that
I should participate?



COPY

Let me know
Jeny

Dear TERESA DALY:

We are pleased to inform you that the first ever national study of assisted living and residential care will be conducted by The Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS). This study, the **National Survey of Residential Care Facilities (NSRCF)**, will include a representative sample of over 2,000 residential care places throughout the United States.

The purpose of the study is to develop a comprehensive understanding of the characteristics of assisted living and residential care communities and the needs of the residents they serve. NSRCF has received support from these national organizations:

- o American Association of Homes and Services for the Aging (AAHSA)
- o American Seniors Housing Association (ASHA)
- o Assisted Living Federation of America (ALFA)
- o Board and Care Quality Forum, and
- o National Center for Assisted Living (NCAL)

➤ A representative of RTI International will contact you soon to arrange an appointment for a personal, on-site interview in the hopes that you will participate in this landmark study. Your participation in this national study is voluntary, but will assist greatly in helping further our nation's understanding of assisted living and the needs of people served in these communities.

Data collected by NSRCF is authorized by Section 306 of the Public Health Service Act (Title 42, U.S. Code 242k). As required by federal law (section 308(d) of the Public Health Service Act in 42, U.S. Code, 242m(d) and the Confidential Information Protection and Statistical Efficiency Act Title 5 of PL 107-347), all information collected will be used only for statistical purposes and held in the strictest confidence. This study also conforms to the Privacy Rule as mandated by HIPAA, where disclosure of resident data is permitted for public health purposes. If you have any questions about your rights as a participant in this research study, call the Research Ethics Review Board at the National Center for Health Statistics toll-free at 1-800-223-8118.

If you would like to learn more about this study, please call (800) 334-8571 ext 2-5102. Leave a brief message with your name and phone number and say that you are calling about Protocol #2008-03. Your call will be returned as soon as possible.

Thank you in advance for your help with this important endeavor.

Sincerely,

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

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 Agency for Healthcare Research and Quality.

The survey is broadly supported by industry associations, including the American Association of Homes and Services for the Aging (AAHSA), the American Seniors Housing Association (ASHA), the Assisted Living Federation of America (ALFA), and the National Center for Assisted Living (NCAL) (see enclosed letter of support). For more information, visit <http://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 (d) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)]. No information collected in this survey may be used for any purpose other than the purpose for which it was collected. Aside from NCHS employees, the only parties that can receive your personal information are: (1) NCHS contractor(s)—hired to conduct this survey, and (2) our designated agents—persons who work under the supervision and control of NCHS.

These parties, who will use your information for statistical research only and to carry out this survey, are bound by strong restrictions designed to guarantee your privacy. By law we cannot release information that could identify your facility or residents to anyone else without your consent. If any federal employee or contractor gives out confidential information not authorized by law, he or she can be fired, fined, and/or imprisoned.

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 an hour 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 20 minutes for each person sampled. The interviewer will accommodate the schedules of your staff to complete these tasks as quickly as possible.



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Centers for Disease Control and Prevention

National Center for Health Statistics
3311 Toledo Road, Room 7204
Hyattsville, Maryland 20782

January 5, 2010

From: Stephen Blumberg, Ph.D.
Chair, NCHS Research ERB

Anjani Chandra, Ph.D.
Vice Chair, NCHS Research ERB

Continuation of Protocol #2008-03 National Survey of Residential Care Facilities

To: Manisha Sengupta, Ph.D.

The NCHS Research ERB reviewed the request for approval of Continuation of Protocol #2008-03 National Survey of Residential Care Facilities on 12/16/09. Continuation of Protocol #2008-03 is approved for the maximum allowable period of one year.

Of Note: The advance letter sent out under Dr. Sondik's name is considered a part of the approval and should be included in future continuation submissions.

IRB approval of protocol #2008-03 will expire on 01/16/11.


If it is necessary to continue the study beyond the expiration date, a request for continuation approval should be submitted about 6 weeks prior to 01/16/11.


There is no grace period beyond one year from the last approval date. In order to avoid lapses in approval of your research and the possible suspension of subject enrollment, please submit your continuation request at least six (6) weeks before the protocol's expiration date of 01/16/11. It is your responsibility to submit your research protocol for continuing review.

Any problems of a serious nature should be brought to the immediate attention of the Research ERB, and any proposed changes should be submitted for Research ERB approval before they are implemented.

Please submit "clean" copies of the revised protocol or consents and any other revised forms to this office for the official protocol file.

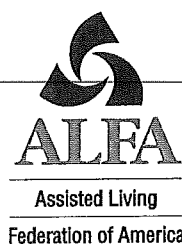
Please call or e-mail me or Verita Bule, Dr.P.H., if you have any questions.


Stephen Blumberg, Ph.D.
Chair, NCHS Research ERB


Anjani Chandra, Ph.D.
Vice Chair, NCHS Research ERB



American
Seniors
Housing
Association



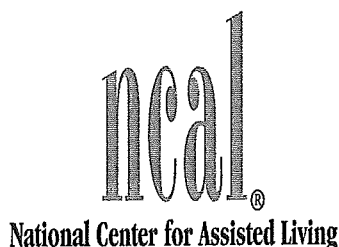
The National Survey of Residential Care Facilities (NSRCF) is the first ever federal study of residential care/assisted living communities designed to provide national information about these communities and their residents. In-person interviews will be conducted with directors and caregivers to provide information about services, staffing, and practices, and resident health, functional status, and payment sources. This information will help policy makers, health care planners, and residential care/assisted living providers better understand, plan for, and serve the future long-term care needs of the aging population. While data from this survey will be publicly available, all data will be confidential and aggregated, so that the names of the communities, respondents, and residents are not identifiable.

The study is being conducted by the National Center for Health Statistics (NCHS), an agency of the Centers for Disease Control and Prevention (CDC), and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (DHHS).

National data collection will be conducted in early 2010 following a pretest in September and October of 2008. About 2,250 communities will be selected for the national survey and 75 communities for the pretest.

The following organizations encourage your participation in this national research initiative:

- American Association of Homes and Services for the Aging (AAHSA)
- American Seniors Housing Association (ASHA)
- Assisted Living Federation of America (ALFA)
- National Center for Assisted Living/American Health Care Association (NCAL/AHCA)
- Board and Care Quality Forum (BCQF)



Board & Care Quality



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