

Attachment G-1 - Advance Package-NCHS Cover Letter with FAQs

[NCHS Letterhead]

RCC/ADSC-NCHS Advance Letter (Groups A and B)

Date

Name of Director

Name of Community/Center

Community/Center Address

Community/Center City, State, Zip

Dear <Name of director>,

The Centers for Disease Control and Prevention's National Center for Health Statistics is conducting the **2018 National Study of Long-Term Care Providers** (NSLTCP). You have been randomly selected to participate and you will represent other [residential care communities/adult day services centers] like yours. We will be calling you soon to see if you are eligible to participate.

NSLTCP tracks trends in five major long-term care services sectors—adult day services centers, assisted living and similar residential care communities, home health agencies, hospices, and nursing homes. NSLTCP collects information about the characteristics of [residential care providers/adult day services centers], the services they offer, their staffing profile, and the demographics, functional status, and health of the [residents/participants] they serve. By participating you will help to improve the value of critical national information used by long-term care providers, planners, researchers, and policymakers. See the enclosed NCHS data brief or visit https://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm for examples.

[IF RCC: These national organizations support NSLTCP: the Center for Excellence in Assisted Living (CEAL), American Seniors Housing Association (ASHA), Argentum, LeadingAge, and the National Center for Assisted Living/American Health Care Association (NCAL/AHCA). See the enclosed letter of support.]

[IF ADSC: The National Adult Day Services Association (NADSA), LeadingAge, and the National Association of States United for Aging and Disabilities (NASUAD) are in support of NSLTCP. See the enclosed letter of support.]

Participating in this study will involve you completing a provider questionnaire by web or mail and, with the help of a telephone interviewer, selecting two [residents/participants] using random sampling procedures and completing a questionnaire for each of the two [residents/participants]. We ask for approximately one hour of your time to participate. Your participation in this survey is voluntary, but will assist greatly in helping to further our nation's understanding and planning for the long-term care needs of older adults and people with disabilities. Refusal to participate will involve no loss of benefits and participation can be discontinued at any time. Enclosed is a letter of approval from the Research Ethics Review Board at the National Center for Health Statistics. If you have questions about your rights as a participant in this research study, call the Research Ethics Review Board toll-free at 1-800-223-8118.

Data collection is authorized under Section 306 of the Public Health Service Act (42 U.S.C. 242k). NCHS is required to keep your survey data confidential in accordance with Section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act (CIPSEA, Title 5 of PL 107-347). Data collected will be used for statistical purposes only. In addition, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 & 151 note). See reverse for more information. This study also conforms to the Privacy Rule as mandated by HIPAA, where disclosure of [resident/participant] data is permitted for public health purposes. Enclosed is an NCHS confidentiality brochure. If you have any questions about confidentiality, call NCHS' Confidentiality Officer at (888) 642-4159.

On the back of this letter are Frequently Asked Questions. To learn more about this study, please visit <https://www.cdc.gov/nchs/nsltcp/> or call an NSLTCP representative at (XXX) XXX-XXXX.

Thank you, in advance, for your help with this important research study.

Sincerely,

Charles J. Rothwell
Director, National Center for Health Statistics

National Study of Long-Term Care Providers (NSLTCP) Residential Care Community Frequently Asked Questions (FAQs)

Why should I participate in this survey?

CDC's National Center for Health Statistics (NCHS) recognizes that residential care communities are an important component of the long-term care spectrum in the United States. NCHS' National Study of Long-Term Care Providers (NSLTCP) tracks changes, every two years, in the supply and use of five major sectors of long-term care services—assisted living and similar residential care, adult day, home health, nursing home, and hospice. When you participate in NSLTCP, you help ensure that the survey data for residential care communities and current residents are up-to-date and accurately portray your industry to health care planners and policymakers.

Should I participate if I participated in NSLTCP a couple of years ago?

Yes. Your participation in this 2018 survey is important. NSLTCP is conducted every two years to obtain accurate, up-to-date information about residential care communities, other long-term care providers, and the people they serve to detect changes in the long-term care industry over time.

What other residential care communities are being contacted to participate in this survey?

The survey includes about 2,090 residential care communities. To protect the privacy of individual residential care communities, their staff, and the residents they serve, we do not release the names of these residential care communities to anyone.

Why can't some other community take our place?

You represent other communities like yours. If you do not participate in NSLTCP, there is no guarantee that residential care communities like yours will be represented adequately and the representation of your community's unique qualities may be lost.

Where did you get my name?

Individual state licensing agencies provided the names of all licensed, certified, or otherwise regulated residential care communities in their respective states.

Will the results be made public?

Yes. NCHS intends to publish reports using 2018 NSLTCP survey data starting in late 2019. Reports will be published at <http://www.cdc.gov/nchs/nsltcp.htm>. If you would like to be notified when new NSLTCP products are available, please subscribe to the NCHS long-term care listserv by going to http://www.cdc.gov/nchs/nsltcp/longterm_listserv.htm and completing the steps. While results from this survey will be made publicly available, all data will be kept strictly confidential and aggregated, so that the names of the communities, staff, residents, and respondents will not be identifiable.

Who will see my information?

We take your privacy very seriously. The information you give us is used for statistical research only. This means that your information will be combined with other people's information in a way that protects everyone's identity. As required by federal law, only those NCHS employees, our specially designated agents, and our full research partners who must use your personal information for a specific reason can see your information. Anyone else is allowed to use your data only after all information that could identify you has been removed.

Strict laws prevent us from releasing information that could identify your information to anyone else without your consent. A number of federal laws require that all information we collect be held in strict confidence: Section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)), the Confidential Information Protection and Statistical Efficiency Act (CIPSEA, Title 5 of Public Law 107-347), and the Privacy Act of 1974 (5 U.S.C. § 552a). Every NCHS employee, contractor, research partner, and agent has taken an oath to keep your information private. Anyone who willfully discloses ANY identifiable information could get a jail term of up to five years, a fine of up to \$250,000, or both. In addition, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 & 151 note). This law requires the federal government to protect federal computer networks by using computer security programs to identify cybersecurity risks like hacking, internet attacks, and other security weaknesses. If information sent through government networks triggers a cyber threat indicator, the information may be intercepted and reviewed for cyber threats by computer network experts working for, or on behalf, of the government.

What does my information have to do with cybersecurity?

The Federal Cybersecurity Enhancement Act of 2015 allows software programs to scan information that is sent, stored on, or processed by government networks in order to protect the networks from hacking, denial of service attacks, and other security threats. If any information is suspicious, it may be reviewed for specific threats by computer network experts working for the government (or contractors or agents who have governmental authority to do so). Only information directly related to government network security is monitored. The Act further specifies that such information may only be used for the purpose of protecting information and information systems from cybersecurity risks.

For more FAQs see [RCC participant webpage]

National Study of Long-Term Care Providers (NSLTCP) Adult Day Services Center Frequently Asked Questions (FAQs)

Why should I participate in this survey?

CDC's National Center for Health Statistics (NCHS) recognizes that adult day services centers are an important component of the long-term care spectrum in the United States. NCHS' National Study of Long-Term Care Providers (NSLTCP) tracks changes, every two years, in the supply and use of five major sectors of long-term care services—adult day, assisted living and similar residential care, home health, nursing home, and hospice. When you participate in NSLTCP, you help ensure that the survey data for adult day services centers and enrolled participants are up-to-date and accurately portray your industry to health care planners and policymakers.

Should I participate if I participated in NSLTCP a couple of years ago?

Yes. Your participation in this 2018 survey is important. NSLTCP is conducted every two years to obtain accurate, up-to-date information about adult day services centers, other long-term care providers, and the people they serve to detect changes in the long-term care industry over time.

What other adult day services centers are being contacted to participate in this survey?

The survey includes about 1,650 adult day services centers operating in the United States. To protect the privacy of individual centers, their staff, and the participants they serve, we do not release the names of these centers to anyone.

Why can't some other center take our place?

You represent other centers like yours. If you do not participate in NSLTCP, there is no guarantee that adult day services centers like yours will be represented adequately and the representation of your center's unique qualities will be lost.

Where did you get my name?

A nonprofit association of adult day services centers, under contract to NCHS, compiled a list of all adult day services centers in the U.S.

Will the results be made public?

Yes. NCHS intends to publish reports using 2018 NSLTCP survey data starting in late 2019. Reports will be published at <http://www.cdc.gov/nchs/nsltcp.htm>. If you would like to be notified when new NSLTCP products are available, please subscribe to the NCHS long-term care listserv by going to http://www.cdc.gov/nchs/nsltcp/longterm_listserv.htm and completing the steps. While results from this survey will be made publicly available, all data will be kept strictly confidential and aggregated, so that the names of the centers, staff, participants, and respondents will not be identifiable.

Who will see my information?

We take your privacy very seriously. The information you give us is used for statistical research only. This means that your information will be combined with other people's information in a way that protects everyone's identity. As required by federal law, only those NCHS employees, our specially designated agents, and our full research partners who must use your personal information for a specific reason can see your information. Anyone else is allowed to use your data only after all information that could identify you has been removed.

Strict laws prevent us from releasing information that could identify your information to anyone else without your consent. A number of federal laws require that all information we collect be held in strict confidence: Section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)), the Confidential Information Protection and Statistical Efficiency Act (CIPSEA, Title 5 of Public Law 107-347), and the Privacy Act of 1974 (5 U.S.C. § 552a). Every NCHS employee, contractor, research partner, and agent has taken an oath to keep your information private. Anyone who willfully discloses ANY identifiable information could get a jail term of up to five years, a fine of up to \$250,000, or both. In addition, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 & 151 note). This law requires the federal government to protect federal computer networks by using computer security programs to identify cybersecurity risks like hacking, internet attacks, and other security weaknesses. If information sent through government networks triggers a cyber threat indicator, the information may be intercepted and reviewed for cyber threats by computer network experts working for, or on behalf, of the government.

What does my information have to do with cybersecurity?

The Federal Cybersecurity Enhancement Act of 2015 allows software programs to scan information that is sent, stored on, or processed by government networks in order to protect the networks from hacking, denial of service attacks, and other security threats. If any information is suspicious, it may be reviewed for specific threats by computer network experts working for the government (or contractors or agents who have governmental authority to do so). Only information directly related to government network security is monitored. The Act further specifies that such information may only be used for the purpose of protecting information and information systems from cybersecurity risks.

For more FAQs see [ADSC participant webpage]