

Residential Care Community NSLTCP FAQs

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Overview

What is the National Study of Long-Term Care Providers (NSLTCP)?

NSLTCP is a groundbreaking initiative sponsored by the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC). NSLTCP produces reliable national and state statistical estimates, where possible, on the supply, use, and characteristics of assisted living and similar residential care communities (RCCs), adult day services centers (ADSCs), nursing homes, home health agencies, and hospice agencies.

NCHS conducts NSLTCP every two years to provide accurate, up-to-date information about residential care communities, adult day services centers and other long-term care providers and the people they serve, and to detect changes that are occurring in the long-term care industry over time. Results and publications from the 2012, 2014, and 2016 NSLTCP waves are available from https://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm

Why is NSLTCP being conducted?

The number of people in the United States needing long-term care services is increasing and residential care communities are an important part of the long-term care services and supports spectrum. NSLTCP aims to provide an accurate picture of residential care communities and other types of long-term care providers, the range of services they provide, and key characteristics of the people they serve. With these data, we will gain greater insight into how residential care communities meet the needs of older persons and younger adults with disabilities. These data will also help policy makers shape long-term care policies.

How will NSLTCP data be collected?

NSLTCP is composed of two types of data: survey questionnaire data for the residential care and adult day services sectors and administrative data (i.e., claims, assessment, and regulatory survey and certification data) for the home health, hospice and nursing home sectors.

NSLTCP survey data are collected from residential care community administrators/directors/owners/operators or their designated staff through provider and services user questionnaires. RTI International is an independent, nonprofit research organization that is under contract with NCHS to collect the NSLTCP survey data. RTI International is a designated agent of NCHS.

Starting in July 2018, all residential care communities that have been sampled will be sent information on how to complete the provider and services user questionnaires. Residential care communities have the option to complete and submit the provider

questionnaire either by web using a secure network, or by mailing back the completed hard copy questionnaire using the enclosed return envelope. The services user questionnaire where directors will provide information about two residents will be completed over the telephone. Directors, with the help of a telephone interviewer, will select two residents/participants using random sampling procedures.

How do you obtain administrative data?

For data about the nursing home, home health, and hospice sectors, NCHS uses administrative data (i.e. claims, assessment, and regulatory survey and certification data) collected by the Centers for Medicare & Medicaid Services (CMS) NCHS obtains these administrative data under data use agreements with CMS.

What type of information do the NSLTCP questionnaires collect? What are the types of questions asked?

NSLTCP collects information about the characteristics of the community and its users, such as size, ownership, computerized capabilities, services provided, resident demographics and health and physical functioning, and numbers and types of staff among other things.

To view a copy of the Questionnaires, go to:

- 2018 RCC Provider Questionnaire:
https://www.cdc.gov/nchs/nsltcp/rcc_participants.htm
- 2018 RCC Services User Questionnaire:
https://www.cdc.gov/nchs/nsltcp/rcc_participants.htm

For what time period do I complete the provider and services user questionnaires?

The questionnaires should be completed using the most current information available unless question text specifies the reference period (such as during the last 30 days, in the last 90 days, in the last 12 months).

What is the closing date to complete the questionnaires?

The middle of January 2019. However, we urge all respondents to complete their questionnaires as soon as possible to avoid receiving follow-up mailings or calls inviting them to participate in the survey.

How often will this survey take place?

We plan to conduct this survey every other year, occurring in even years (2018, 2020, 2022, etc.).

Should I complete questionnaires 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 services providers, and the people they serve, to provide you and other valued stakeholders with current information and to detect changes in the long-term care industry over time.

Whom can I contact if I have additional questions about NSLTCP?

You can call our toll-free number, (877) 256-8029, to talk with a study representative about the National Study of Long-Term Care Providers.

If you have any further questions or comments related to participating in this study, please contact:

Lauren Harris-Kojetin
National Center for Health Statistics
Chief, Long-Term Care Statistics Branch
3311 Toledo Road
Hyattsville, Maryland 20782
Phone: 301-458-4369
Fax: 301-458-4693
Email: LHarrisKojetin@cdc.gov

Legitimacy

How do I know NSLTCP is a legitimate study? Who sponsors this study? Who supports this study?

NCHS is the federal government's principal health statistics agency. The initial authority for NCHS surveys is the National Health Survey Act (Public Law 84-652), which was enacted by Congress on July 3, 1956.

Because of its importance, NSLTCP has received support from national organizations representing residential care communities. The Center for Excellence in Assisted Living (CEAL) and its collaborating organizations, such as American Seniors Housing Association (ASHA), Argentum, LeadingAge, and the National Center for Assisted Living/American Health Care Association (NCAL/AHCA) support NSLTCP and encourage your participation in NSLTCP. You can see their letter of support at: https://www.cdc.gov/nchs/data/nsltcp/residential_care_communities_letter_of_support.pdf

Confidentiality

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 data. 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.

Will my name and information be held confidential?

Yes. All information collected will be the property of NCHS and kept strictly confidential. The identity of specific residential care communities, residents and staff will not be released in any manner, except to NCHS staff, contractors, and designated agents when required and with necessary controls. Results of the study will be published using only aggregated data that will not allow identification of any individual residential care community, resident or staff.

Does the HIPAA Privacy Rule allow my residential care community to participate in NSLTCP?

Yes. This study conforms to the Privacy Rule as mandated by HIPAA, where disclosure of resident data is permitted for public health purposes.

Voluntary Nature

Is participation voluntary? Is this survey mandatory?

Your participation in this survey is voluntary, but will assist greatly in helping to further our nation's understanding of the long-term care needs of the older population and younger disabled adults.

You represent not just your own residential care community, but also others that are of the same size as yours and in the same part of the country as yours. If your community does not participate, its unique qualities will not be represented in NSLTCP, thus making the results less accurate.

Selection

How was my residential care community selected?

Your residential care community was scientifically and randomly selected to represent not only your residential care community, but also other comparably sized residential care communities like yours across the United States. Residential care communities licensed to exclusively serve persons with intellectual or developmental disabilities or severe mental illness are excluded. Nursing homes are excluded as well.

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

The survey includes a scientifically selected, nationally representative sample of 2,090 residential care communities operating in the United States. We do not release the names of sampled communities to anyone. This is to protect the privacy of individual places and the residents they serve.

Why was my residential care community not selected?

The survey includes a scientifically selected, nationally representative sample of 2,090 residential care communities operating in the United States. Your residential care community may have been on our master list, but was not sampled for this wave.

Participation

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, policymakers, consumers, researchers, the media, and the public.

Why am I being asked to complete the questionnaires? Am I the only one who can complete the questionnaires?

The provider and services user questionnaires are intended to be completed by someone who is knowledgeable about the day-to-day operations and the residents served. Typically, this person is an administrator or director. The provider and services user questionnaires can also be completed by someone whom the administrator/director designates as qualified to complete them, such as an assistant director.

Why can't some other community take our place?

Your facility was scientifically and randomly selected to represent both your residential care community and others like yours. You cannot be replaced. Your participation is important to ensure an accurate picture of your industry to health care planners, policymakers, consumers, researchers, the media, and the public.

I received a questionnaire packet with a hardcopy questionnaire and information to complete the survey via Web. Does it matter which way I complete the questionnaire?

It doesn't matter which way you complete the questionnaire. You can complete it however is most convenient for you, but you do not need to complete it more than once for the same place.

Eligibility

Are residential care communities for the developmentally disabled included in NSLTCP?

Yes. However, if residential care communities are licensed to exclusively serve developmentally disabled residents, these communities are excluded from NSLTCP.

What is the minimum length of time that a residential care community should be operating to be eligible to complete the survey?

There is no set minimum length of time.

Approval

What if I am part of a corporate chain? What if I need chain approval? What if I need supervisor approval?

NSLTCP has a web site with information about the study and a toll-free number to call with questions. You can share this information with the person who can give approval for your residential care community to participate.

<https://www.cdc.gov/nchs/nsltcp.htm>

(877) 256-8029

Multiple Residential Care Communities

What if my organization operates multiple residential care communities?

If your organization operates multiple residential care communities, more than one of your residential care communities may be sampled for NSLTCP. We need a provider and two services user questionnaires completed for each sampled residential care community in your organization. It is important that you complete provider and services user questionnaires for each residential care community separately so that the government can make accurate estimates of residential care communities in the United States. Please do not provide answers for multiple communities on one provider questionnaire.

What if I received a survey for two or more residential care communities in my organization?

These communities were invited to participate in the study. Each sampled site will receive its own provider questionnaire and the responses to the questions should be only about the community whose name and address appear in the label. Each sampled site will be asked to complete two services user questionnaires. It is important that you

complete the survey for each community separately so the government can make accurate estimates of residential care communities in the United States.

Time-related

How long will it take to complete the NSLTCP provider and services user questionnaires?

The provider and services user questionnaires each take, on average, about 30 minutes to complete.

What if I do not have enough time?

The provider questionnaire takes, on average, about 30 minutes to complete. Some people find that it is faster or more convenient to complete the provider questionnaire online than by hardcopy. You can start and stop when you need to, and come back to complete it.

The services user questionnaire takes, on average, about 30 minutes to complete. You will be asked to provide a limited amount of information about just two residents over the telephone. You can make an appointment for the telephone interview that is convenient for you.

Will I be compensated for my time?

Since NCHS is a federal government agency, we are not allowed to compensate our respondents. However, we release reports using NSLTCP data where you are able to compare your residential care community with the residential care industry on key characteristics. To see the free products available for your use, please see the data brief in your advance packet or other NSLTCP reports and publications at:
https://www.cdc.gov/nchs/nsltcp/nsltcp_reports.htm

You can also use our state tables to compare your residential care community with other communities in your state. You can access the 2012 and 2014 NSLTCP state tables at the following address: https://www.cdc.gov/nchs/nsltcp/nsltcp_webtables.htm

Contact Confirmation Call

Why are you calling?

We are calling to confirm that we have the correct information to mail information about the National Study of Long-Term Care Providers, an initiative sponsored by the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC).

What will you be mailing me?

We would like to mail you some information about an opportunity to participate in the National Study of Long-Term Care Providers, an initiative sponsored by the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC).

Advance Packet

I received a packet of information about the study. What will I be asked to do if I choose to participate?

The first step is to complete a short questionnaire over the telephone to see if your residential care community is eligible to participate in the study.

If eligible, participating in this study will involve you completing a provider questionnaire by web or mail. This questionnaire takes, on average, 30 minutes to complete.

Once you complete and submit that questionnaire, we will call you back and ask you to select two residents using random sampling procedures and complete a questionnaire for each of the two residents over the telephone. This will take about 30 minutes to complete.

Screening

If my residential care community is eligible, what will I be asked to do?

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 using random sampling procedures and completing a questionnaire for each of the two residents. We ask that you complete the provider questionnaire first. We will schedule a time to complete the sampling and questionnaires for two residents.

Web Provider Questionnaire

Can I complete a hardcopy questionnaire instead of completing it online?

Yes. You can request to have a hardcopy provider questionnaire sent to you by calling (877) 256-8029. The provider questionnaire and a pre-addressed, postage-paid envelope for returning it will be sent to you.

If I choose to complete the Web questionnaire, can I stop partway through and start again where I left off at a later time?

Yes. If you are unable to complete the Web provider questionnaire in one sitting, the answers you entered will be saved, and you can pick up where you left off at a later time. You will not need to start the Web provider questionnaire again from the beginning.

Will I be able to print a copy of the completed Web provider questionnaire for my records?

Yes.

Hardcopy Provider Questionnaire

Where should I mail my completed hardcopy provider questionnaire?

Please return your completed hardcopy provider questionnaire in the enclosed pre-addressed, postage-paid envelope. The address is: NSLTCP, RTI International, attn.: Data Capture, 5265 Capital Boulevard, Raleigh, NC 27690-1653.

Telephone Services User Questionnaire

When should I complete the services user telephone questionnaire?

We would like to schedule an appointment 4 – 10 weeks out to give you time to complete and submit the provider questionnaire before you complete the services user telephone questionnaire.

What do I need to do to prepare for the services user telephone questionnaire appointment?

We ask that you print out a list of the residents currently living in your residential care community as of midnight the night before the services user telephone questionnaire appointment. You will also need the show cards that we either sent to you or asked you to print from the Web.

- To print another copy of the show cards, go here:
<https://www.cdc.gov/nchs/nsltcp/2018-NSLTCP-RCC-Showcards.pdf>

If I need to reschedule my services user telephone questionnaire appointment, who should I call?

You can call our toll-free number, (877) 256-8029, and a study representative will assist with rescheduling your appointment.

Use of Data

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 <https://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 https://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/centers, staff, participants), and respondents will not be identifiable.

How will NSLTCP data be used?

NSLTCP data will be used by the U.S. Congress and other public health policy makers, government agencies, the long-term care industry, academic institutions, professional associations, consumers, and health services researchers, as well as the media and the public, to describe and understand the changes that occur in the delivery of long-term care services.

The NSLTCP Study Results and Publications page at https://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm contains a variety of free reports and other products that have been published using data from previous NSLTCP waves. If you would like to be notified when new NSLTCP products are available, we invite you to subscribe to the NCHS long-term care listserv at https://www.cdc.gov/nchs/nsltcp/longterm_listserv.htm.