

NPALS Residential Care Community FAQs

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Overview

What is the National Post-Acute and Long-Term Care Study (NPALS)?

NPALS (formerly known as National Study of Long-Term Care Providers or NSLTCP) is a groundbreaking initiative sponsored by the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC). NPALS 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, hospice agencies, long-term care hospitals, and inpatient rehabilitation centers.

NCHS conducts NPALS every two years in order 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, 2016, and 2018 waves are available online at <https://www.cdc.gov/nchs/npals/studyresults.htm>.

Why is NPALS 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. NPALS 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 the older population and younger disabled adults, and will also help to shape long-term care policies.

How will NPALS data be collected?

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

Starting in November 2020, invited residential care communities will be sent information on how to complete the questionnaire. Residential care communities have the option to complete and submit the survey either by web using a secure network, or by mailing back the completed hard copy questionnaire using the enclosed return envelope.

To view a copy of the questionnaire, go to:

- 2020 RCC Questionnaire: <https://www.cdc.gov/nchs/data/npals/2020-NPALS-RCC-Questionnaire-Community.pdf>

Does NPALS include data for other long-term care providers, like nursing homes?

Yes. NPALS obtains administrative data (i.e. claims, assessment, and regulatory survey and certification data) collected by the Centers for Medicare & Medicaid Services (CMS) for home health, hospice, nursing home, long-term care hospital and inpatient rehabilitation sectors. NCHS obtains these administrative data under data use agreements with CMS.

What type of information does the NPALS questionnaire collect? What are the types of questions asked?

NPALS 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 questionnaire, go to:

<https://www.cdc.gov/nchs/data/npals/2020-NPALS-RCC-Questionnaire-Community.pdf>

For what time period do I complete the questionnaire?

The questionnaire 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 questionnaire?

The beginning of July 2021. However, we urge all respondents to complete their questionnaire 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 (2020, 2022, 2024, etc.).

Should I complete the questionnaire if I participated a couple of years ago?

Yes. Your participation in this 2020 survey is important. NPALS (formerly known as the National Study of Long-Term Care Providers or 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 NPALS?

You can call our toll-free number, (877) 256-8171, to talk with a study representative about the National Post-Acute and Long-Term Care Study.

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

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Legitimacy

How do I know NPALS 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, NPALS has received support from national organizations representing residential care communities. The Center for Excellence in Assisted Living (CEAL) and its collaborating organizations, as well as American Seniors Housing Association (ASHA), Argentum, LeadingAge, and the National Center for Assisted Living/American Health Care Association (NCAL/AHCA) support NPALS and encourage your participation in NPALS. You can see their letter of support at:

<https://www.cdc.gov/nchs/data/npals/rcc-letter-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 working on the project, our specially designated agents, and our full research partners can see your personal information. Anyone else is allowed to use your data only after all information that could identify you has been removed.

NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and Title III of the Foundations for Evidence-Based Policymaking Act of 2018 (Pub. L. No. 115-435, 132 Stat. 5529, § 302). In accordance with CIPSEA, every NCHS employee, contractor, and 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.

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 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 or staff.

If you have any questions about confidentiality, call NCHS' Confidentiality Officer at (888) 642-4159.

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

Yes. Since NPALS does not collect any protected health information (e.g., personal identifiers such as name, social security number, or birth date of residential care community residents, the study is not subject to the Privacy Rule mandated by the Health Insurance Portability and Accountability Act (HIPAA). In other words, your community can participate in NPALS, as the Privacy Rule mandated by HIPAA does not apply to NPALS.

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 NPALS, 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 11,600 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 11,600 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

My community has changed the way we provide services/the services we offer due to the COVID-19 pandemic. Can we still participate?

Yes. The survey provides instructions for residential care communities that have been impacted by the COVID-19 pandemic. We understand some questions may be difficult to answer. Please answer to the best of your ability.

This community is temporarily closed due to the COVID-19 pandemic, but we hope to reopen. Should we participate?

The NPALS survey will remain open until early July 2021. If you plan to re-open before then, you can wait to take the survey until you re-open. If you don't plan to re-open by July 2021, we would still like to receive your completed survey. The survey provides instructions for residential care communities that are temporarily closed due to COVID-19. We understand some questions may be difficult to answer. Please answer to the best of your ability.

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 Post-Acute and Long-Term Care Study (NPALS) 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, hospice, long-term care hospital, and inpatient rehabilitation. When you participate in NPALS, 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 questionnaire is 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 questionnaire can also be completed by someone whom the administrator/director designates as qualified to complete it, such as an assistant director.

Why can't some other community take our place?

Your community 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 NPALS?

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

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?

There is a web site with information about the NPALS 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.

WEB SITE: <https://www.cdc.gov/nchs/npals/index.htm>

TOLL-FREE NUMBER THAT RINGS TO THE HELP DESK: (877) 256-8171

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 NPALS. We need a questionnaire completed for each sampled residential care community in your organization. It is important that you complete a questionnaire 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 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 RCC site will receive its own questionnaire and the responses to the questions should be only about the

community whose name and address appear in the label. 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 NPALS questionnaire?

The questionnaire takes, on average, about 30 minutes to complete.

What if I do not have enough time?

The questionnaire takes, on average, about 30 minutes to complete.

Some people find that it is faster or more convenient to complete the questionnaire online or by hardcopy. You can start and stop when you need to and come back to complete it.

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 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 reports and publications at: <https://www.cdc.gov/nchs/npals/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, 2014, and 2016 NSLTCP state tables at the following address: <https://www.cdc.gov/nchs/npals/webtables.htm>

Web Provider Questionnaire

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

Yes. NPALS staff can submit a request to have a hardcopy questionnaire sent to you. The 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 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 questionnaire again from the beginning.

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

Yes.

Hardcopy Questionnaire

Where should I mail my completed hardcopy questionnaire?

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

Use of Data

Will the results be made public?

Yes. NCHS intends to publish reports using 2020 NPALS survey data starting in late 2021. Reports will be published at <https://www.cdc.gov/nchs/npals/reports.htm>. If you would like to be notified when new NPALS products are available, please subscribe to the NCHS long-term care listserv by going to https://www.cdc.gov/nchs/npals/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.

How will NPALS data be used?

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