

## View xForm - Project Application v6

**This form is for new projects that have not been previously approved by CPHS.**

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**Data entry**

**New Submission Study Personnel**

## NEW CONTACT INSTRUCTIONS

April 2025 cycle.

\_\_\_\_\_HSC\_\_\_\_\_SME: Dr.  
Ventura.

- • • Non-English Documents should be reviewed and approved by Dr. Ruiz before releasing the final CPHS approval letter for this project.

- No request for State data
- A DSL from the NORC at the University of Chicago is attached.
- This application is only requesting approval for the first survey. Researchers will submit an amendment for this project after its approval to request approval for the second survey.

03/19/2025 • Sussan Atifeh • Internal

### Summary:

Researchers from NORC at the University of Chicago, have submitted this application to request approval for a project that is aimed to understand concerns (e.g., physical health, mental health, finances) related to retirement and plans related to long-term care planning and financing of middle-age and older adults in California. The aim is to get perspectives from those who likely will not be eligible for Medi-Cal.

This project involves two surveys targeting Californians aged 50 and older, conducted six months apart through a research panel.

- The first survey in Spring 2025 will ask about retirement concerns, like health, finances, and long-term care planning— This application is requesting approval only for the 1st survey.
- The second survey in Winter 2025/26 will focus on how people in a similar group prioritize aging-support programs— will be submitted to CPHS through an amendment for this

project.

- Funding:

State funded by the California Department of Aging (CDA)

- No state data will be used to filter or identify participants—all will be existing members of the NORC AmeriSpeak Panel.

- Non-English Translations

Yes—Translator Certificate is attached.

- Main site of the study:

NORC at the University of Chicago—A DSL from NORC at the University of Chicago is attached.

- 1st Survey: In this application, researchers only requested approval for the first survey, and they will submit an amendment for this project (after its approval) to request a review and approval of the second survey.

Final Product:

The responses of the surveys will be analyzed descriptively to identify trends, and the findings will be shared with the California Department of Aging (CDA) and included in a legislative report by June 2026.

Linkage:

Yes. Linkage between study code numbers and direct identifiers are needed to maintain complete history of panel member activities, incentives, and to support any inquiries from panel members.

Population Description

The study will include up to 1,250 AmeriSpeak panelists who are California adults age 50+ with household income  $\geq$  139% FPL.

Informed Consent Procedures

AmeriSpeak panelists gave informed consent to participate in the panel and receive survey invitations during the Registration Recruitment Core Adult Profile (RRCAP) survey. The AmeriSpeak team provides minimum key information on

subject matter at the introduction of every survey. This functions as the consent.

03/20/2025 • Sussan Atifeh • Internal

Dear Researchers: Please address the 2 minor comments and resubmit the application. Thank you.

03/21/2025 • Sussan Atifeh • Not Internal • Resolved

*If personnel are not found by their email address while trying to complete the following questions, you can add them in the system with the link below. Click on the "New Contact Form" and complete it. Within a few minutes of completing the form, you will receive an email notifying you of the availability of the new contact. You should then be able to add them in the subsequent questions.*

New Contact Form

## PRINCIPAL INVESTIGATOR (PI)

**Enter the Principal Investigator's email address.**

Lisa Shugarman, PhD

**Email:** Shugarman-  
Lisa@norc.org

**Business:** (714) 348-0189

**Choose the institution with which the PI is affiliated (not the location at which the research is being conducted).**

NORC at the University of Chicago

**Enter the city in which the PI's institution is located.**

Chicago

**Enter the state in which the PI's institution is located.**

*Start typing in the state name to select the name from the list.*

Illinois

**Attach a copy of the PI's Curriculum Vitae.**

Shugarman\_Lisa\_CV.docx PI Curriculum Vitae

Deleted Attachments: 1 (Most Recent: 2\_Shugarman\_Lisa\_CV.docx on 03/07/2025 2:54 PM ET)

## CO-PRINCIPAL INVESTIGATOR (CO-PI)

**Enter the Co-PI's email address by clicking on the "Add Contact" button.**

*If there are multiple co-principal investigators, repeat this action for all Co-PIs. If there are no Co-PIs for this project, skip this question.*

*No answer provided.*

## ADMINISTRATIVE CONTACT

*Enter the email address(es) for the administrative contact(s). If you are the administrative contact, enter your email address, and enter anyone else you want listed as an administrative contact.*

Nora Marino, MPH

**Email:** marino-nora@norc.org

**Business:** (847) 915-1360

Lisa Shugarman, PhD

**Email:** Shugarman-  
Lisa@norc.org

**Business:** (714) 348-0189

Xueyin Yang, MA

**Email:** Yang-Xueyin@norc.org

**Business:** (312) 759-5084

## RESPONSIBLE OFFICIAL (RO)

**Enter the RO's email address.**

*The RO **cannot** be the same person as the PI or Co-PI. The RO must have supervisory authority, in the administrative structure of the institution, over the PI.*

Michelle Strollo, Dr.Ph

**Email:** strollo-michelle@norc.org

**Business:** (301) 775-9180

## OTHER RESEARCH STAFF

Enter the email address for any other research staff by clicking the "Add Contact" button.

*Repeat this action for all other research staff not previously provided on this screen that should receive notifications about this project. If there are no additional research staff, skip this question.*

Xueyin Yang, MA

**Email:** Yang-Xueyin@norc.org

**Business:** (312) 759-5084

LeeAnn McCabe, BA

**Email:** McCabe-LeeAnn@norc.org

**Business:** (312) 758-0195

**Check for PI same as RO (internal only question)** *(Internal)*

False

## Project Information

### SUBMITTER

**Application completed by:**

Nora Marino, MPH

**Email:** marino-nora@norc.org

**Business:** (847) 915-1360

### PREVIOUSLY APPROVED EXEMPTION

**Is there a previously-approved exemption from CPHS for this project?**

No

### PROJECT TITLE

*Enter the project title (please capitalize each word in your title).*

California Long Term Services and Supports (LTSS) Financing Initiative

## PROJECT SITE

Indicate the primary site at which the research will be conducted.

NORC at the University of Chicago

## STUDY PROCEDURES

Indicate the study procedures involved in this research. Check all that apply.

Surveys

## TYPE OF RESEARCH REQUEST

Indicate which of the following applies to this research. Check all that apply.

*Death Data Only refers to health-related studies requesting existing mortality data from **within** the California Human Health Services Agency (CHHSA)*

*SB-13 (Information Practices Act) refers to health-related studies requesting existing data from **outside** the CHHSA (e.g. California Department of Corrections and Rehabilitation [CDCR], California Department of Education [CDE], etc.) **OR** studies requesting data **within** the CHHSA that are not state funded or involving state staff.*

*Common Rule/Human Subjects refers to health-related studies that involve direct or indirect interaction with human subjects (e.g. recruitment, interviews, etc.)*

*Common Rule Only refers to health-related studies requesting existing data from **within** the CHHSA (e.g. Office of Statewide Health Planning and Development [OSHPD], California Department of Public Health [CDPH], etc)*

Common rule/Human subjects

## PROJECT TYPE DETAILS

Indicate which, if any, apply to this research. Check all that apply.

*If the research does not involve any of following, choose "None of the above."*

Minimal Risk

Non-English translation required

## **VULNERABLE POPULATIONS**

**Indicate which vulnerable populations, if any, will be involved with this research. Check all that apply.**

*If vulnerable populations are not part of the research, choose "Not applicable."*

*Note regarding minors: in the United States, a minor is under 18 years of age. If research is conducted outside the United States, a minor is under the age of majority in the countries where research is to be conducted.*

Not applicable

## **FUNDING**

**Is this research funded?**

Yes

**Indicate the funding source for this project.**

State funded

**Enter name of state-funded source.**

California Department of Aging



## EXPEDITED REVIEW CONSIDERATION

**Please check the criteria below that you think your project meets to qualify for an expedited review. If none of these expedited criteria are appropriate for your project, choose 'not applicable'; your protocol will be reviewed by the full committee. Note that CPHS will make the final determination of whether the project meets the criteria for expedited review.**

*Protected Health Information/Personally Identifiable Data (PHI/PID) is defined as information in any format that identifies the individual, including demographic information collected from an individual that can reasonably be used to identify the individual. Additionally, PHI is information created or received by a healthcare provider, health plan, employer, or health care clearinghouse; and relates to the past, present, or future physical or mental health or condition of an individual, including any of the 18 HIPAA identifiers.*

*Note: Please be aware that individual participants may be identifiable by combining other items in the data even when none of the 18 HIPAA identifiers are present. Thus, a study may still contain PID even after removing or never acquiring the identifiers, and the investigator may still need to provide complete answers for the data security questions in the protocol.*

*\*\*The Departments within the California Health and Human Services Agency (CHHSA) are: Aging, Alcohol and Drug Programs, Child Support Services, Community Services and Development, Developmental Services, Emergency Medical Services Authority, Health Care Services, Mental Health, Public Health, Rehabilitation, Social Services and Statewide Health Planning and Development.*

Not applicable

## ANTICIPATED PROJECT START DATE

**Projects cannot begin before they have been reviewed. The earliest possible start date is always the date of the next public meeting at which the project will be heard.**

Since the April meeting will be held on 4/25/25, would you please change this date to 4/25/2025?

Thanks.

03/20/2025 • Sussan Atifeh • Not Internal • Resolved

*For a list of public meeting dates, see the CPHS website*

04/25/2025

**ANTICIPATED PROJECT END DATE**

06/30/2026

**Project Details**

## PURPOSE

**Include a brief statement, less than 500 words, describing the research project. Be sure to address the background for the project, including relevant literature, the major research questions to be addressed, and the expected end product (e.g., article, report or other publications). Include the location(s) where the project will take place. The summary should be understandable to the general public.**

Please confirm in this section that this application serves as a request for the approval of the first survey only, and for the second survey, a request for review and approval will be submitted as an amendment to this project following its approval (of the first survey) by CPHS.

Thank you.

03/20/2025 • Sussan Atifeh • *Not Internal* • Resolved

This project involves two surveys conducted approximately six months apart using NORC at the University of Chicago's (NORC) AmeriSpeak Panel. This application serves as a request for approval for the first survey only. We will contact California residents over 50 years of age who are members of the panel. The first survey will be fielded as soon as approval is obtained (Spring 2025) and will focus on respondent concerns (e.g., physical health, mental health, finances) related to retirement and plans related to long-term care planning and financing. The second survey will be fielded in Winter 2025/26 and survey questions will focus on how a similar population would prioritize programs to support them as they age. No state data will be used to filter or identify participants. All participants are existing members of the AmeriSpeak Panel.

Older adults today are expected to live another 20 years compared to previous generations. However, 80% of households with older adults are financially insecure or are at risk of economic insecurity as they age (National Council on Aging, 2024). This project seeks to examine the financial health and concerns related to finances in retirement of older adults in California. Participants will be asked to complete the 12-minute survey online or over the phone depending on their preferred mode. Survey participants will be consented prior to starting the survey and will receive a \$4 incentive for completing the survey. Participants may refuse to answer any question. The survey is included with this submission and includes questions about financial health, financial concerns related to retirement, and sociodemographic information. Several months after this first survey, a second survey will be fielded to this same population to understand their opinions regarding long term care financing policies. The first survey will be fielded in Spring 2025 and the second survey in Winter 2025/2026. At the

appropriate time, we will submit a request an approval of the second survey and submit as an amendment to this project for its approval by CPHS.

The research team will perform descriptive analysis of survey responses including univariate and bivariate analysis and these results will be presented to CDA and incorporated into a legislative report in June 2026.

### **MAJOR RESEARCH QUESTION**

#### **What is the major research question to be addressed in this project?**

Survey 1: How prepared are California residents for potential long-term care needs as they age?

Survey 2: What do California residents prioritize for programs that will support them as they age?

## STUDY PROCEDURES

**Describe in detail all procedures for this research. Do not attach grant applications or similar documents. Information in this application must be sufficient to fully explain the procedures without such documents**

Sussan, I will need a Spanish-speaking reviewer to review all Spanish material submitted in this IRB. I can only review the English versions. Thank you.

04/01/2025 • Maria Ventura, PhD • Internal

1. Participants will be asked to complete the 12-minute survey online or over the phone depending on their preferred mode.
2. Survey participants will be consented prior to starting the survey.
3. Participants may refuse to answer any question.
4. Survey participants will receive a \$4 incentive for completing the survey.
5. A second survey will be conducted online or over the phone derived from the same AmeriSpeak panel although respondents to the second survey may not be identical to the respondents of the first survey. That survey will be conducted in Winter 2025/2026.

**Please upload here any tables or charts related to your study procedures and any materials (such as surveys or interview questions) that will be presented to participants.**

California Long Term Services and Supports (LTSS) Financing Instruments  
Initiative\_SURVEY.docx

Deleted Attachments: 1 (Most Recent: CA\_Middle Market Survey (English and Spanish) on 03/07/2025 4:07 PM ET)

## RECORDING

**Will audio or video recording occur?**

Yes

**Describe how the recordings will be maintained during and upon completion of the project. Describe what will become of the recordings after use (e.g., shown at scientific meetings, erased, etc.).**

Participants who complete the survey over the phone will be asked their consent to have the phone call audio recorded for quality assurance purposes. They may refuse to have the call recorded and still complete the survey. The audio recordings will only be accessed by the NORC research team (for quality assurance purposes) and will be erased after use.

## DECEPTION

**Will deception be used in this study?**

No

## CALIFORNIA HEALTH AND HUMAN SERVICES AGENCY (CHHSA) DEPARTMENTS LIST

**Indicate any of the following CHHSA department(s)' involvement in providing research staff, funding and/or patients from State mental hospitals for this project.**

CDA: Department of Aging

## Study Population

### POPULATION DESCRIPTION

**Provide a full description of how human subjects will be involved in the research. Address characteristics of subjects such as: age; sex; ethnicity; and number of participants. Include requested participant number.**

The study will include up to 1,250 AmeriSpeak panelists who are California adults age 50+ with household income  $\geq$  139% FPL.

### RATIONALE

**What is the rationale for studying the requested group(s) of participants?**

This study seeks to understand concerns (e.g., physical health, mental health, finances) related to retirement and plans related to long-term care planning and financing of middle-age and older adults in California. The aim is to get perspectives from those who likely will not be eligible for Medi-Cal.

## RECRUITMENT DETAILS

**Describe how potential subjects will be identified for recruitment. Examples include: class rosters; group membership; individuals answering an advertisement; organization position titles (e.g., presidents, web designers, etc.). How will potential participants learn about the research and how will they be recruited (e.g., flyer, email, web posting, telephone, etc.)?**

Should there a Spanish translation for the email?

04/01/2025 • Maria Ventura, PhD • *Not Internal*

Sussan, I again need a Spanish-speaking reviewer to review the phone script. Thank you.

04/01/2025 • Maria Ventura, PhD • Internal

*Important to remember: subjects cannot be contacted before IRB approval.*

Participants recruited for this study are all members of NORC's AmeriSpeak Panel. These panel members have already been recruited and consented for participation in the Panel.

Participants will be contacted through email or phone, depending on their preferred mode to participate in this specific survey. The recruitment materials are attached in both English and Spanish.

### **Attach copies of all recruitment materials.**

California Long Term Services and Supports (LTSS) Financing Initiative_RECRUITMENT MATERIALS_EMAIL.docx	Recruitment Materials
California Long Term Services and Supports (LTSS) Financing Initiative_RECRUITMENT MATERIALS_PHONE SCRIPTS.docx	Recruitment Materials
California Middle Market LTC AmeriSpeak Survey_ES Survey Invite.docx	Recruitment Materials

Deleted Attachments: 2 (Most Recent: California Middle Market LTC AmeriSpeak Survey\_ES Survey Invite.docx on 04/05/2025 2:44 PM ET)

## SCREENING

**Will subjects be screened prior to entry into the research?**

Yes

**Please address the criteria for exclusion and inclusion in the research during the screening process. Provide reasons for not including women or minorities. Provide justification for including vulnerable populations such as children or prisoners. Please also provide a statement regarding what will happen to the information collected about the individual should they not enter into the study.**

Participants will be screened to ensure they 1) live in California, 2) are 50 years of age or older, 3) have household incomes  $\geq$  139% Federal Poverty Level.

Information collected about individuals who do not pass the screening questions will be destroyed from project folders.

## COMPENSATION

**Will subjects be compensated for participating in the study?**

Yes

**Compensation type**

Gift card

**Explain the amount and schedule of compensation that will be paid for participation in the study. Include provisions for prorating payment. The amount should not be coercive.**

Participants will be compensated with AmeriSpeak Virtual Incentives (see below for details).

Participants will receive (4,000 / \$4) AmeriPoints after completing this survey. They will have the option to redeem points for Mastercard® Reward Cards, a variety of virtual gift cards for retailers such as Amazon.com, Apple, movie theaters, restaurants, and many more.



## STUDY DURATION

**Estimate the probable duration of the entire study. This estimate should include the total time each subject is to be involved and the duration of each data collection about the subject.**

*E.G., This is a two-year study. Participants will be interviewed three times per year; each interview will last approximately two hours. Total approximate time commitment for participants is 12 hours.*

This is a one-year study. Participants will be asked to complete a 12-minute survey once in Spring 2025 and in Winter 2025/26. However, since the participants are members of the AmeriSpeak Panel, some participants may not be asked to participate in both surveys. The AmeriSpeak panel is continuously updated to address attrition and remain a representative sample; as a result AmeriSpeak Panel members may change from year to year.

## Risks and Benefits

### RISK DESCRIPTION

**Provide a description of possible risks to participants: physical, psychological, social, economic, loss of data security, and/or loss of confidentiality. Describe and justify whether the research is minimal risk or greater than minimal risk.**

There is a risk that participants may feel stressed when answering questions related to their concerns about retirement and long-term care. However, the magnitude for potential harm is small.

### AUDIO/VIDEO RECORDING RISKS

**State if audio/video taking could increase potential risk to subject's confidentiality.**

Participants who complete the survey over the phone will be asked their consent to have the phone call audio recorded for quality assurance purposes. They may refuse to have the call recorded and still complete the survey. The audio recordings will only be accessed by the NORC research team (for quality assurance purposes) and will be erased after use.

### **MEDICAL SERVICE RISKS**

**Describe how medical services will be provided if subjects suffer adverse mental or physical effects as result of research activity. If no services provided, state that clearly.**

No services will be provided.

### **INTERNATIONAL RESEARCH**

**Will this research occur outside of the United States or U.S. territories?**

*Check with client to see if they consider territories to be outside the U.S. or not, as this can vary between institutions.*

No

### **LESS RISKY METHODS**

**Describe any less risky methods and why they are not being used.**

There are no less risky methods to conduct this survey.

### **BENEFITS**

**Describe the benefits, if any, to the subjects or to society that will be realized as a result of this project. Discuss the benefits that may accrue directly to the subjects as well as to society. If there is no direct benefit anticipated for the subjects, state that clearly.**

Potential direct benefits to subjects include encouraging them to think about their concerns related to retirement and long-term care. Benefits to society include increased knowledge about concerns related to retirement and long-term care for older adults, which may lead to policy and programmatic solutions to address these concerns.

## JUSTIFICATION OF RISKS

**Explain why study risks are reasonable in relation to the potential benefits to subjects and to society.**

While there is a risk that participants may feel stressed when answering questions related to their concerns about retirement and long-term care, the magnitude for potential harm is small. The potential benefits to participants and society are much greater in relation to the potential risks. Increased knowledge about concerns related to retirement and long-term care for older adults may lead to policy and programmatic solutions to address these concerns.

## Administrative Safeguards

### PERSONALLY IDENTIFIABLE DATA (PID) INSTRUCTIONS

***Protected Health Information/Personally Identifiable Data (PHI/PID) is defined as information in any format that identifies the individual, including demographic information collected from an individual that can reasonably be used to identify the individual. Additionally, PHI is information created or received by a healthcare provider, health plan, employer, or health care clearinghouse; and relates to the past, present, or future physical or mental health or condition of an individual, including any of the 18 HIPAA identifiers.***

***Note: Please be aware that individual participants may be identifiable by combining other items in the data even when none of the 18 HIPAA identifiers are present. Thus, a study may still contain PID even after removing or never acquiring the identifiers, and the investigator may still need to provide complete answers for the data security questions in the protocol.***

*If the researcher demonstrates that he or she is unable to comply with any of the requirements below, he or she may request an exception from these requirements. The researcher should indicate any measures that will be taken to address this requirement. The exception request should be made in the text box of the corresponding requirement. An exception will only be granted if the researcher can demonstrate that adequate alternative measures have been taken to minimize risks so as to justify the exception.*

### HIPAA IDENTIFIERS

*Please identify which HIPAA Identifiers you plan to request as part of your submission.*

No identifiable materials

## **TRAINING PROCEDURES**

**Describe the procedures for training all research staff who have access to PID on privacy and security. Indicate if staff are required to sign a confidentiality statement related to general use, security, and privacy.**

All NORC staff involved with the conduct of the survey are required to read, sign, and commit to a confidentiality statement, which addresses upholding subject confidentiality as defined by 28 CFR Part 22 and the Federal Privacy Act. Access to data captured for this project is limited to staff who are required to perform necessary tasks for the project and who agree in writing to comply with regulations under 28 CFR Part 22. All NORC staff complete annual training on security awareness, data governance, and privacy

## **STAFF VETTING PROCEDURES**

**Describe procedures, either background check or thorough reference check, for vetting staff who will have access to PID.**

All NORC staff who will have access to PID completed a thorough background check.

## **SUPPORT LETTER**

### **Obtain and submit a department support/data release letter.**

*This is a statement from the state agency or department you are receiving data from. It must be on that agency's/department's letterhead and should include both*

- 1)** *that the release of the desired data is legal and*
- 2)** *that the entity is willing to release the desired data to you, the researcher. If you are not receiving data, this letter should indicate that you are supported.*

*\*\*For VSAC requests, if you do not have a Departmental Letter of Support (LOS)/Data Release, you may upload a copy of the Data Request Form (application) from the department to secure a review for the upcoming cycle. The protocol will not be approved until the LOS is uploaded to the protocol.*

*Please also review the CPHS Statement for Birth and Death Data.*

California Middle Market LTC AmeriSpeak Survey\_NO SUPPORT LETTER NEEDED\_SIGNED.pdf      Department Letter of Support

Deleted Attachments: 1 (Most Recent: California Middle Market LTC AmeriSpeak Survey\_NO SUPPORT LETTER NEEDED.pdf on 03/07/2025 5:04 PM ET)

## PREVENTING RE-USE AND UNAUTHORIZED ACCESS

**Explain how you will ensure that data will not be reused or provided to any unauthorized person or entity.**

*Unauthorized means that the person or entity does not have a need to access the data for purposes of the research project approved by CPHS.*

Data are secured via NORC data security policies and procedures. The project will follow all AmeriSpeak procedures for data security (see below), including routine non-disclosure analysis to prevent risk of reidentification.

- NORC Secure Network. NORC IT maintains a highly secure internal network storage system. Partitioned network storage is provided for each project to mitigate the potential for data loss due to accidents, computer equipment malfunction, corruption, unauthorized security breaches, or human error, and to administer access rights regarding privacy issues related to both legal and contractual obligations. A wide array of network security precautions are undertaken by NORC to ensure the proper storage of all project data. All electronic data collected for this project will be stored on a secured network in a project-specific data folder.

- Encryption. All of NORC's systems run on computers with automatic full disk FIPS compliant encryption system software to protect against loss of sensitive data. NORC secures data transfer via the Internet by means of FIPS 140-2 compliant VPN. Data at rest are encrypted by means of using FIPS 140-2 compliant whole full disk encryption technology.

- Storage. NORC production block data is stored on self-encrypting storage drives utilizing AES-256 bit encryption, and FIPS 140-2 compliant.

- Access Controls. NORC follows the least privilege data access model, meaning that users have visibility only to the data for which they have been approved. All unique user credentials and associated permissions are subject to the controls and standards maintained by the Information Technology department. Passwords must be changed on a regular basis, in addition to meeting stringent requirements for length and complexity.

- Remote Access Procedures. In order to access the secure network, authorized users must log into a virtual private network (VPN) with multi-factor authentication.

- Firewalls and Perimeter Protection Controls. For protection against unauthorized access, NORC maintains a solid tracking system of internal and external attempts of the network. Our internal tracking allows for a limited number of attempts, after which the account is temporarily locked. It can only be unlocked by an authorized individual from the technical support team, who will review each situation prior to unlocking the account. To protect against unauthorized access from outside the NORC network, there is a firewall that prevents anyone from getting to a network login. The only method of getting through the firewall would be through the virtual private

network (VPN) or a secure externally facing server, which would require an active User ID, password and multi-factor authentication. This applies to both the VPN and the SFTP.

- Data Access. All NORC staff will be required to read, sign, and commit to a confidentiality statement, which addresses upholding subject confidentiality as defined by 28 CFR Part 22 and the Federal Privacy Act. Access to data captured for this project will be limited to staff who are required to perform necessary tasks for the project and who agree in writing to comply with regulations under 28 CFR Part 22. Computer security systems will be implemented to prevent access by unauthorized individuals.

- Security controls, including anti-spam, anti-malware, and anti-intrusion tools. NORC has taken several measures to prevent viruses and other malware from entering our systems. All NORC computer systems are protected from viruses by centrally managed anti-malware software and distribution of the latest security patches. NORC's network is further protected by tightly controlled firewalls and email-filtering technology.

### **CONFIDENTIALITY OF PUBLISHED DATA**

**Indicate whether information will be published that could possibly be used to identify an individual subject.**

No information will be published that could possibly be used to identify an individual subject. All data will be aggregated to the population level or aggregated based on select characteristics of the respondents (e.g., age group) but no cell sizes smaller than 11 will be presented in public data presentations.

### **DATA REQUEST JUSTIFICATION**

**Provide adequate justifications for the quantity of the data, the years and the variables being requested. Have you requested no more than the minimum necessary data to perform the research?**

The data source for the sampling frame related to this project comes from NORC's AmeriSpeak panel. The California Department of Aging (or any other State entity) has not provided nor facilitated any access to any data sources for this project.

## **LIMITATIONS TO DATA ACCESS**

**Indicate if access to data is limited only to those with a need to know for purposes of implementing or evaluating the research.**

NORC follows the least privilege data access model, meaning that users have visibility only to the data for which they have been approved.

## **PROTECTION AGAINST SMALL CELL SIZES AND ASSOCIATED PROBLEMS**

**Describe appropriate and sufficient methods to protect the identity of individual subjects when small cells or small numbers and/or data linkage to another data set are involved in the research project.**

No cell sizes smaller than 11 will be presented in public data presentations.



## LINKAGES

**Will the data set be linked with any other data sets?**

Yes

**Identify all data sets and each of the variables to be linked, with a brief description of each variable and justification for each linkage. If there is an extensive list, you may attach that list in the next question and indicate such here.**

Linkage between study code numbers and direct identifiers are needed to maintain complete history of panel member activities, incentives, and to support any inquiries from panel members. These linkages include first and last name, phone number, email address, and home address. Such linkage will be kept for as long as a panelist is participating in the panel and after a panelist stops participating in the panel as required by law (currently operationalized as seven years). A panelist can request a deletion of their data at any time by contacting the NORC Privacy Compliance Office. NORC will honor such requests within 7 days of receipt of the request. No personally identifiable information will be shared with anyone other than internally among the NORC research team. No personally identifiable information is shared with anyone other than the NORC research team, including with the University of Massachusetts and the California Department of Aging.

**Attach a copy of the document detailing all data sets and each of the variables to be linked. If you provided this information in the answer to the above question, skip this question.**

*No answer provided.*

**Will a third party be used for data linkage?**

No

## DESTRUCTION OF PID VERIFICATION

**Indicate that you will provide CPHS with a letter certifying that PID has been destroyed and/or returned to the data source once research is concluded.**

Yes

## DATA SECURITY LETTER

Upload a certification/statement from the Chief Information Officer, Privacy Officer, Security Officer or equivalent position of the researcher's institution that CPHS Data Security Standards are met.

- Data security letters cannot be signed by the Principal Investigator or Responsible Official.
- The data security letter must be on your institution's letterhead.
- Example of data security letter

California Middle Market LTC AmeriSpeak Survey\_CPHS  
Data Security Requirements\_NORC Letterhead\_signed.pdf

Data  
Security  
Letter

## Physical Safeguards

### DATA PROTECTION

**Indicate that research records and physical samples will be protected through the use of locked cabinets and locked rooms; PID in paper form will not be left unattended unless locked in a file cabinet, file room, desk, or office.**

Yes

### DATA DESTRUCTION

**Will data/samples will be destroyed or returned as soon as it is no longer needed for the research project.**

Yes

### RETAINED DATA

**Will the retained data/samples have personal identifiers or be de-identified?**

data will contain personal identifiers

## **DESTRUCTION METHODS**

**Describe how you will ensure the PID in paper form is disposed of through confidential means, such as cross cut shredding or pulverizing.**

There will be no PID in paper form for this project.

## **FAXING**

**Describe how you will ensure that faxes with PID are not left unattended and fax machines are in secure areas.**

The team will not fax any PID for this project.

## **MAILING**

**Indicate whether mailings of PID are sealed and secured from inappropriate viewing; and whether mailings of 500 or more individually identifiable records of PID in a single package, and all mailings of PID to vendors/contractors/co-researchers, are sent using a tracked mailing method, which includes verification of delivery and receipt, such as UPS, U.S. Express Mail, or Federal Express, or by bonded courier.**

The team will not mail any PID for this project.

## **ELECTRONIC STORAGE**

**State whether PID in paper or electronic form, e.g., stored on laptop computers and portable electronic storage media (e.g., USB drives and CDs), will ever be left unattended in cars or other unsecured locations.**

PID in electronic form will never be left unattended in cars or other unsecured locations.

## PHYSICAL STORAGE

**Describe whether facilities, which store PID in paper or electronic form, have controlled access procedures, and 24 hour guard or monitored alarm service.**

Data are secured via NORC data security policies and procedures. The project will follow all AmeriSpeak procedures for data security (see below), including routine non-disclosure analysis to prevent risk of reidentification.

- NORC IT maintains a highly secure internal network storage system. Partitioned network storage is provided for each project to mitigate the potential for data loss due to accidents, computer equipment malfunction, corruption, unauthorized security breaches, or human error, and to administer access rights regarding privacy issues related to both legal and contractual obligations. A wide array of network security precautions are undertaken by NORC to ensure the proper storage of all project data. All electronic data collected for this project will be stored on a secured network in a project-specific data folder.

- Storage. NORC production block data is stored on self-encrypting storage drives utilizing AES-256 bit encryption, and FIPS 140-2 compliant.

- Access Controls. NORC follows the least privilege data access model, meaning that users have visibility only to the data for which they have been approved. All unique user credentials and associated permissions are subject to the controls and standards maintained by the Information Technology department. Passwords must be changed on a regular basis, in addition to meeting stringent requirements for length and complexity.

- Remote Access Procedures. In order to access the secure network, authorized users must log into a virtual private network (VPN) with multi-factor authentication.

- Firewalls and Perimeter Protection Controls. For protection against unauthorized access, NORC maintains a solid tracking system of internal and external attempts of the network. Our internal tracking allows for a limited number of attempts, after which the account is temporarily locked. It can only be unlocked by an authorized individual from the technical support team, who will review each situation prior to unlocking the account. To protect against unauthorized access from outside the NORC network, there is a firewall that prevents anyone from getting to a network login. The only method of getting through the firewall would be through the virtual private network (VPN) or a secure externally facing server, which would require an active User ID, password and multi-factor authentication. This applies to both the VPN and the SFTP.

- All NORC offices are located in buildings with 24 hour monitored alarm services. Staff must use a key card to enter NORC offices and wear their staff badge at all times.

## **SERVER SECURITY**

**Provide a description of whether all servers containing unencrypted PID are housed in a secure room with controlled access procedures.**

All servers only contain encrypted PID. All of NORC's systems run on computers with automatic full disk FIPS compliant encryption system software to protect against loss of sensitive data. NORC secures data transfer via the Internet by means of FIPS 140-2 compliant VPN. Data at rest are encrypted by means of using FIPS 140-2 compliant whole full disk encryption technology.

## **STORING IDENTIFIERS**

**Indicate whether identifiers will be stored separately from analysis data.**

Yes, identifiers will be stored separately from analysis data, and only de-identified data will be sent to University of Massachusetts. County information will be sent to University of Massachusetts and it'll be protected by a Data Transfer Agreement.

## **DISK STORAGE**

**State whether all disks with PID will be destroyed.**

Data will be kept the duration of the panelist's participation and up to 7 years after it concludes. A panelist can request a deletion of their data at any time by contacting the NORC Privacy Compliance Office by mail or emailing [privacy@amerispeak.org](mailto:privacy@amerispeak.org). NORC will honor such request within 7 days of receipt of the request. As part of contract closeout and at expiration of the contract, NORC shall provide all required documentation to the client (University of Massachusetts) to certify that, at the client's direction, all electronic records are appropriately disposed of and all devices and media are sanitized in accordance with NIST SP 800-88, Guidelines for Media Sanitization.

## **Electronic Safeguard**

### **COMPUTER ACCESS OVERVIEW**

**State whether all computer access will be protected through the use of encryption, passwords, and other protections.**

All computer access will be protected through the use of encryption, passwords, and other protections. All of NORC's systems run on computers with automatic full disk FIPS compliant encryption system software to protect against loss of sensitive data. NORC secures data transfer via the Internet by means of FIPS 140-2 compliant VPN. Data at rest are encrypted by means of using FIPS 140-2 compliant whole full disk encryption technology.

### **FIPS 140-2 COMPLIANCE: WORKSTATIONS**

**Indicate whether all workstations that contain PID have full disc encryption that uses FIPS 140-2 compliant software. If not, explain why not and what encryption will be used.**

All workstations that contain PID have full disc encryption that uses FIPS 140-2 compliant software. All of NORC's systems run on computers with automatic full disk FIPS compliant encryption system software to protect against loss of sensitive data. NORC secures data transfer via the Internet by means of FIPS 140-2 compliant VPN. Data at rest are encrypted by means of using FIPS 140-2 compliant whole full disk encryption technology.

### **FIPS 140-2 COMPLIANCE: LAPTOPS**

**Indicate if all laptops that contain PID have full disc encryption that uses FIPS 140-2 compliant software. If not, explain why not and what encryption will be used.**

All laptops that contain PID have full disc encryption that uses FIPS 140-2 compliant software. All of NORC's systems run on computers with automatic full disk FIPS compliant encryption system software to protect against loss of sensitive data. NORC secures data transfer via the Internet by means of FIPS 140-2 compliant VPN. Data at rest are encrypted by means of using FIPS 140-2 compliant whole full disk encryption technology.

## **FIPS 140-2 COMPLIANCE: REMOVABLE MEDIA DEVICES**

**Indicate if PID on removable media devices (e.g. USB thumb drives, CD/DVD, smartphones, backup recordings) are encrypted with software that is FIPS 140-2 compliant.**

This project will not store PID on removable media devices

## **SECURITY PATCHES**

**Indicate if all workstations, laptops and other systems that process and/or store PID have security patches applied in a reasonable time frame.**

All workstations, laptops and other systems that process and/or store PID have security patches applied in a reasonable time frame. All NORC computer systems are protected by centrally managed anti-malware software and distribution of the latest security patches. NORC's network is further protected by tightly controlled firewalls and email-filtering technology.

## **PASSWORD CONTROLS**

**Indicate if sufficiently strong password controls are in place to protect PID stored on workstations, laptops, servers, and removable media.**

Sufficiently strong password controls are in place to protect PID stored on workstations, laptops, and servers. Passwords must be changed on a regular basis, in addition to meeting stringent requirements for length and complexity.

## **ELECTRONIC SECURITY CONTROLS**

**Indicate if sufficient system security controls are in place for automatic screen timeout, automated audit trails, intrusion detection, anti-virus, and periodic system security/log reviews.**

Sufficient system security controls are in place for automatic screen timeout, automated audit trails, intrusion detection, anti-virus, and periodic system security/log reviews. NORC has taken several measures to prevent viruses and other malware from entering our systems. All NORC computer systems are protected from viruses by centrally managed anti-malware software and distribution of the latest security patches. NORC's network is further protected by tightly controlled firewalls and email-filtering technology.

## **FIPS 140-2 COMPLIANCE: ELECTRONIC TRANSMISSION**

**Explain whether all transmissions of electronic PID outside the secure internal network (e.g., emails, website access, and file transfer) are encrypted using software which is compliant with FIPS 140-2.**

All transmissions of electronic PID outside of the secure internal network are encrypted using software which is compliant with FIPS140-2.

## **INTERNET ACCESSIBILITY**

**Note if PID in an electronic form will be accessible to the internet.**

PID is stored in an electronic form and can be accessed by internet. Only the NORC team are able to access with a special permission to access this information. NORC follows the least privilege data access model, meaning that users have visibility only to the data for which they have been approved. All unique user credentials and associated permissions are subject to the controls and standards maintained by the Information Technology department. Passwords must be changed on a regular basis, in addition to meeting stringent requirements for length and complexity. All NORC staff are required to read, sign, and commit to a confidentiality statement, which addresses upholding subject confidentiality as defined by 28 CFR Part 22 and the Federal Privacy Act. Access to data captured for this project are limited to staff who are required to perform necessary tasks for the project and who agree in writing to comply with regulations under 28 CFR Part 22. Computer security systems are implemented to prevent access by unauthorized individuals. Request for access needs to be approved by Project Director and IT Project Director. All NORC personnel must pass through security training every year.



## **DISPOSING OF PID**

**When disposing of electronic PID, indicate whether sufficiently secure wiping, degaussing, or physical destruction will be used.**

Data will be kept the duration of the panelist's participation and up to 7 years after it concludes. A panelist can request a deletion of their data at any time by contacting the NORC Privacy Compliance Office by mail or emailing [privacy@amerispeak.org](mailto:privacy@amerispeak.org). NORC will honor such request within 7 days of receipt of the request. As part of contract closeout and at expiration of the contract, NORC shall provide all required documentation to the CO and/or COR to certify that, at the client/agency's direction, all electronic and paper records are appropriately disposed of and all devices and media are sanitized in accordance with NIST SP 800-88, Guidelines for Media Sanitization.

## **Conflict of Interest Information**

### **CONFLICT OF INTEREST (COI) INSTRUCTIONS**

**A COI is defined as any financial or other relationships of the researcher(s) or the institution that could be perceived as affecting the objective conduct of the research, including the interpretation and publication of the findings. Researchers must disclose any COI, including perceived COI.**

**Financial relationships to be disclosed include but are not limited to the following:**

- **Present or anticipated ownership of stock, stock options, or other financial obligations of the source of funding.**
- **Receipt or expectation of payment of any sort in connection with papers, symposia, consulting, editing, etc. from the source of funding.**
- **The sale or licensing or anticipated sale or licensing of medical or other products or intellectual property, such as patents, copyrights, or trade secrets to the source of funding or other entities.**
- **Any past, present or anticipated receipt of money or other valuable consideration from the source of research funding by the researcher(s), the family of the researcher(s), the research institution, or by an institution in which the researcher(s) or the family of the researcher(s) has an interest as owner, creditor, or officer.**

## DISCLOSURES

**Does any member of the study team, members' spouses, or members' dependent children have any significant financial interests related to the work to be conducted as part of the above-referenced project?**

No

## Informed Consent Procedures

### INFORMED CONSENT PROCEDURES

**Provide a description of procedures to be used in obtaining and documenting informed consent from participants.**

*See instructions and examples on CPHS website.*

AmeriSpeak panelists gave informed consent to participate in the panel and receive survey invitations during the Registration Recruitment Core Adult Profile (RRCAP) survey. The AmeriSpeak team provides minimum key information on subject matter at the introduction of every survey. This functions as the consent.

### CONSENT FORMS

**Attach copies of consent forms and any other documents or oral scripts used to inform potential research subjects about the study. See examples of consent and assent forms on the CPHS website.**

The English consent form reading level is too high (app. 12th grade). Please rewrite at 8th grade reading level.

04/01/2025 • Maria Ventura, PhD • *Not Internal*

*Be sure to include a concise explanation of key information for participants at the beginning of your consent form, as shown in the examples on the website. Also attach the Participant's Bill of Rights (download the revised version from the same CPHS website). CPHS may approve the use of a consent procedure which does not include, or which alters, some or all of the elements of informed consent. If a waiver or alteration of informed consent is being requested, attach a document that explains how all of the criteria below will be satisfied.*

California Middle Market LTC AmeriSpeak Survey\_ENGLISH      Consent  
CONSENT.docx      Form

Deleted Attachments: 1 (Most Recent: California Middle Market LTC AmeriSpeak Survey\_Waiver of Documentation of Consent.docx on 03/07/2025 5:48 PM ET)

## TRANSLATED DOCUMENTS

**Provide copies of the non-English version of consent/assent forms and/or scripts to be used in this research.**

ATTN: Sussan - need a Spanish-speaking reviewer to review Spanish consent form. Thank you.

04/01/2025 • Maria Ventura, PhD • Internal

California Middle Market LTC AmeriSpeak Survey\_SPANISH CONSENT.docx      Consent Form

## TRANSLATOR

**Provide a copy of the curriculum vitae of the translators(s) and/or proof of certification of the translation firm.**

*CPHS may reject poorly written documents or documents from translators lacking adequate proof of training or expertise. For studies using documents translated into Spanish, the translation should use formal language.*

Global Lingo Certificate\_CA LTSS Financing Initiative\_FOR CPHS.pdf      Translator Curriculum Vitae

Deleted Attachments: 1 (Most Recent: California Middle Market LTC AmeriSpeak Survey\_GLOBAL LINGO.pdf on 03/19/2025 2:28 PM ET)

## HIPAA Determination

### HIPAA INSTRUCTIONS

**To determine if this project is covered by HIPAA, answer the following questions.**

### COVERED ENTITY

**Will health information be obtained from a covered entity, known as a clearinghouse, such as Blue Cross, that processes or facilitates processing health data from another entity, including but not limited to state databases?**

No

**HEALTHCARE PROVISIONS**

**Will the study involve the provision of healthcare by a covered entity, such as the UCD Medical Center?**

No

**OTHER HIPAA CRITERIA**

**Will the study involve other HIPAA criteria not listed above?**

No

**Cover Letter and PI Signature for PI Submission**

**BUDGET**

**Does this project have a budget?**

Yes

**Attach a copy of your project budget here**

California Middle Market LTC AmeriSpeak Survey\_BUDGET.pdf

Project Budget

**COVER LETTER**

**Attach a copy of your project cover letter.**

*Cover letter must have the requesting institution's letterhead.*

California Middle Market LTC AmeriSpeak Survey\_COVER LETTER SIGNED.pdf

Cover Letter

Deleted Attachments: 1 (Most Recent: California Middle Market LTC AmeriSpeak Survey\_BUDGET.pdf on 03/07/2025 5:37 PM ET)

**In order for the PI to review and sign this form, you will need to click "Next" and on the next page, click "Submit." At that point the PI will receive notification that will need to review the application and if they request changes, they will return the form to you and you will receive an email notification.**

