

USER'S GUIDE TO THE NLTCS QUESTIONNAIRES

I. Overview

The U.S. Census typically uses four core questionnaires to obtain information for the NLTCS: the SCREENER, CONTROL CARD, COMMUNITY, and INSTITUTIONAL questionnaires. Occasionally, these core instruments are supplemented with questionnaires that gather additional information about CAREGIVERS (1989, 1999) or NEXT-OF-KIN (1984, 1999). In 1999, a genetics component was added to the NLTCS with the gathering of blood and buccal samples; the genetics data is not covered by questionnaire documentation.

The SCREENER is administered to all sampled persons, but persons who received a detailed interview in previous survey years are given an abbreviated SCREENER. Based upon responses to SCREENER questions, an individual is determined to be: "automatic in" (i.e., has received a detailed survey in previous years and is automatically scheduled to receive another detailed survey), institutionalized, disabled, or "screened out" (i.e., since none of the above conditions apply, the individual is non-disabled and living in the community). Persons who have screened out are not interviewed further; all other persons are scheduled to receive a detailed interview.

The CONTROL CARD is administered to all candidates for a detailed interview and gathers information about the individual's residence (community versus institutional) as well as information on his/her family and household. Institutional residence, which was initially evaluated on the SCREENER, is evaluated more thoroughly here. A person is considered institutionalized if they reside in an Assisted Living Center and receive substantial nursing care, or if they are living in a nursing, convalescent, or rest home, a mental / long-stay hospital, or some other institution where three or more unrelated individuals live and a registered nurse, licensed practical nurse, physician, or other health care professional is on duty daily.

The COMMUNITY detailed instrument is administered to persons living within the community, and collects information about medical conditions, ADL and IADL disability, equipment use, helpers, income, education, medical providers, cognitive function, and other measures of interest.

The INSTITUTIONAL detailed instrument collects information about people residing in institutions. This instrument gathers information about cognitive functioning, ADL disability, equipment use, institutionalization history, income, and other measures.

The CAREGIVERS survey was administered in 1989 and 1999, with an extensive revision and expansion of the 1999 instrument. It is administered to the primary informal caregiver for persons living in the community, and collects information about help provided to the sample person by the caregiver, help that the caregiver receives from others, the caregiver's experiences, living situation, work situation, and income.

The NEXT-OF-KIN survey was first administered in 1984 as the Deceased Interview, which was conducted for persons in the 1982 NTLCS who died between 1982 and 1984. In 1999, a different instrument and design was used. Mortality for persons who were part of the 1999 sample is tracked through quarterly updates from CMS, and interviews are conducted with the next-of-kin of the decedents.

II. Organization conventions for the 1999 NLTCS Questionnaires

In addition to documenting the survey questions, the CDS questionnaires provide information about case management, skip patterns, coding, variable names (for the SAS data file), starting column position (for the ASCII file), and the format of the variables. The layout of a typical question followed by a check item is presented in Table 1.

Table I
Question Layout

c. About how long has ... had someone stay nearby just in case ... might need help with any of those things? ADL_7C Col. 1488 Char 1	1	<input type="checkbox"/>	Less than 3 months
	2	<input type="checkbox"/>	3 months to 6 months
	3	<input type="checkbox"/>	6 months to 1 year
	4	<input type="checkbox"/>	1 year to 5 years
	5	<input type="checkbox"/>	5 years or over
ADL_CK4 Refer to ADL_EAT, ADL_BED, ADL_INS, ADL_DRS, ADL_BTH, and ADL_TOI. Are all six ADL variables = 1? ADL_CK4 Col. 1489 Char 1	1	<input type="checkbox"/>	Yes - SKIP to ADL_CK5
	2	<input type="checkbox"/>	No

The question box is split into a left and right segment. Questions asked of the respondent by the Census Field Representative, CAPI interview instructions, and/or inquiry order (i.e., ‘check item’ or ‘goto’) labels appear first on the left side of the question box. Beneath these items, a variable description line gives the SAS variable name, followed by the variable column position in the ASCII data, data type, and variable length.

In the right segment of the question box, permissible response values, descriptive labels of the response values, and skip instructions are documented. A response of D (“don’t know”) or R (“refused”) is permissible for most questions, although it is not explicitly documented unless it affects the skip patterns.

Occasionally, the question box records and describes an item, such as a skip pattern label or an instruction to the Field Representative, for which no data was stored. In these cases, the item has no associated variable and, consequently, no variable description line is recorded.

Variables Not Documented in the Questionnaires

In addition to the variables referenced on the questionnaires, documentation is provided for a group of variables common to all observations which are created outside of the interview process and included in the NLTCS SAS and ASCII data files. These variables include the CENSUS SCREENER CROSS-SECTIONAL WEIGHT, as well as a description of the variables used to create that weight. The SURVEY variable that documents whether the individual was a non-interview, screened out, an institutional interview, or a community interview with or without an associated caregiver, is also in this file (*99_NonSurveyVariables.pdf*). This file is available from the “Data Dictionaries” section of the NLTCS website.

Lists of Variables

An alphabetic list of the NLTCs variables giving the SAS variable name, start position in the ASCII data file, the data type, the variable length, and the name of questionnaire where the variable first appears is contained in *1999_NLTCs_Alphabetic_Variable_List.pdf*. An ASCII position ordered list is contained in *1999_NLTCs_ASCII_Position_Variable_List.pdf*. These files are available from the “Data Dictionaries” section of the NLTCs website.